

# Chapter

The context for decision  
making in fetal and  
neonatal care

# 3



# The context for decision making in fetal and neonatal care

- 3.1 In fetal and neonatal medicine, there are several stages at which decisions have to be made that may determine whether a baby lives or dies. How such decisions are made, and the way in which ethical principles guide decision making are the focus of this Report. Yet ethical principles cannot be considered in isolation if they are to make a difference to practice. For example, we concluded in Chapter 2 that a baby's best interests are central to decision making. However, his or her interests are bound up with those of his or her family and can be difficult to determine in isolation. It is therefore essential that the medical, social and legal frameworks for critical care decisions before and after birth are well understood. That is the purpose of this chapter.
- 3.2 We begin by considering how rates of infant survival and low birthweight have changed over the past 50 years. We then set out the clinical context for pregnancy, birth, babies born at the borderline of viability,<sup>1</sup> and for babies where complications or abnormalities are present after birth. Following this, we consider how social and cultural factors may influence families and healthcare professionals in decision making. Some of the possible consequences of critical care decisions for a child and his or her family, including practical issues upon leaving hospital, coming to terms with possible disability, and the impact on his or her quality of life, are described. Finally, we present a brief outline of the economic and legal context.

## Infant survival and prevalence of low birthweight

- 3.3 In developed countries the number of babies who die in their first year has declined in the past 40 years (see Figure 3.1 for data from England and Wales). Increased survival is likely to have arisen as a result both of general improvements in healthcare and increased standards of living, and from targeted improvements in obstetrics, midwifery and neonatal intensive care.<sup>2</sup> In England and Wales, there have been improvements in the survival rates for babies of all birthweights, particularly those classed as low birthweight (see Box 3.1 and Figure 3.2). The mortality rate for these babies decreased markedly between the 1960s and the late 1980s, and is continuing to fall. Despite these improvements, prematurity is still a major cause of neonatal death in the UK (Appendix 3).<sup>3</sup>

<sup>1</sup> In this Report we use the term 'borderline of viability' to refer to babies born up to 25 weeks, six days of gestation. By convention, the number of weeks of gestation refers to the period from the first to the last day of that week. For example 'at 23 weeks' means from 23 weeks to 23 weeks, six days of gestation (161–167 days of gestation).

<sup>2</sup> However, we note that it is difficult to link reductions in mortality with recorded changes in health provision. See Appleby J and Harrison A (2006) *Spending on Health Care: How much is enough?* (London: King's Fund), pp 11–13. In one study that has been carried out in the USA, two-thirds of the decrease in neonatal mortality seen in two major hospitals in Boston in 1989–90 and 1994–5 could be attributed to improvements in neonatal intensive care, see Richardson DK, Gray JE, Gortmaker SL, Goldmann DA, Pursley DM and McCormick MC (1998) Declining severity adjusted mortality: evidence of improving neonatal intensive care *Pediatrics* **102**: 893–9. This study was based on comparisons of neonatal outcomes in the two time periods taking into account birthweight and severity of illness on admission.

<sup>3</sup> Confidential Enquiry into Stillbirth and Deaths in Infancy (2001) *8<sup>th</sup> Annual Report* (London: Maternal and Child Health Research Consortium).

**Box 3.1: Birthweight and prematurity: definitions**

**Length of pregnancy**

Full term	birth between 38 and 42 weeks of gestation
Premature (or preterm)	birth before 38 weeks, 0 days of gestation
Moderately premature	birth between 35 and 37 weeks of gestation
Very premature	birth between 27 and 34 weeks of gestation
Extremely premature	birth before 27 weeks of gestation

**Weight**

Low birthweight	less than 2,500 g (5.5 lb)
Very low birthweight	less than 1,500 g (3.3 lb)
Extremely low birthweight	less than 1,000 g (2.2 lb)

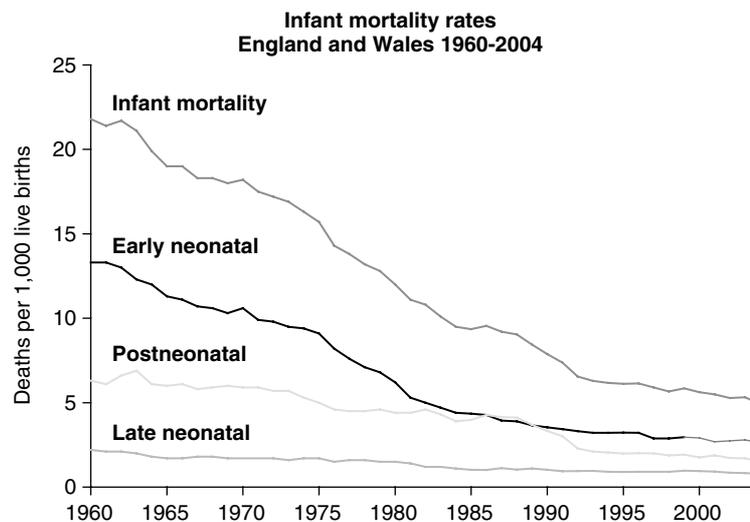
**Gestational age:** In the UK, the duration of gestation is measured from the first day of the pregnant woman's last menstrual period. Dates are then confirmed using ultrasound imaging in 95% of cases.

**Figure 3.1: Infant mortality rates within one year after birth in England and Wales 1960–2004<sup>4</sup>**

With kind permission from Professor Alison Macfarlane

Mortality rates are shown as deaths per 1,000 live births in the following periods after birth:

- Early neonatal: up to six completed days
- Late neonatal: between seven and 28 days
- Post neonatal: between 29 days and under one year
- Infant: under one year (total)



Source: Office for National Statistics, Mortality statistics, Series DH3  
Graph by Alison Macfarlane, City University

3.4 In England and Wales, the percentage of babies born with a low birthweight has gradually increased in recent years, particularly since the mid-1980s (see Figure 3.3). This change has been attributed to several factors, including a trend towards registering a live birth for babies born at the limits of viability whose deaths might previously been classified as miscarriages or stillbirths, and a rise in multiple births.<sup>5</sup> Health outcomes are poorer in multiple pregnancies, irrespective of their cause.<sup>6</sup> The increase in multiple birth rates is often attributed to the

<sup>4</sup> Comparable recent data are available for Scotland and Northern Ireland but definitions used differ.

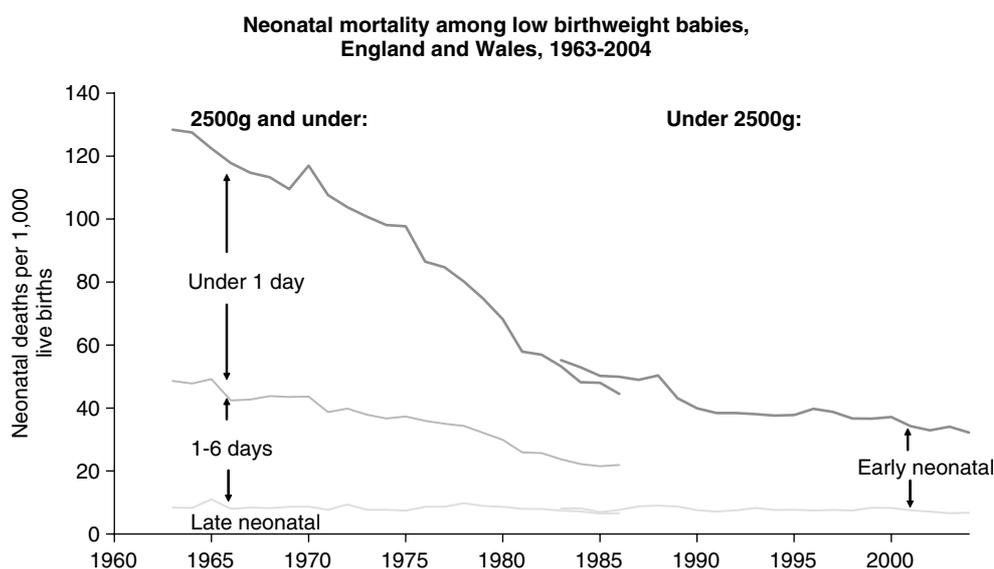
<sup>5</sup> Macfarlane A and Mugford M (2000) *Birth counts: Statistics of pregnancy and childbirth*, 2nd Edition (London: The Stationery Office), Volume 1, p 55. From 1992 the gestation at which a stillbirth was registered rather than a miscarriage was lowered from 28 weeks to 24 weeks.

<sup>6</sup> Marlow N (2006) Does neurodevelopment of twins and singletons differ? in *Multiple Pregnancy*, Kilby M, Baker P, Critchley H and Field D (Editors) (London: RCOG Press), pp 235–44.

### Figure 3.2: Neonatal mortality among low birthweight babies within 28 days after birth in England and Wales 1963–2004

With kind permission from Professor Alison Macfarlane

The uppermost line shows the total rate of deaths of low birthweight babies within 28 days of birth. The section between this upper line and the middle line shows the proportion of this rate that is accounted for by babies under one day old; the section immediately below shows the proportion of this rate that is accounted for by babies who died at between one and six days old; and the lowermost section is the rate for babies who died between seven and 28 days after birth (the late neonatal period). Data collection changed in the mid-1980s when data on the rates of deaths under one day and between one and six days were combined. After this time, the section between the upper and lower lines represents the 'early neonatal' period. Additionally, there was also a minor change to the classification of 'low birthweight' babies to exclude babies of 2,500 g (previously the definition was 2,500 g and under). Data for the years 1989 to 1994 are unreliable because of missing birthweights.



Source: DHSS, LHS 27/1 low birthweight returns and ONS, mortality statistics, Series DH3 Birth counts, Tables A3.5.1 and A3.5.2. Graph by Alison Macfarlane

concomitant rise in *in vitro* fertility treatment since the 1980s, as there has been a tendency to implant two or more embryos.<sup>7</sup> Although the prevalence of triplets has declined greatly over the past five years, the birth rate of twin pregnancies has stabilised.<sup>8</sup> However, evidence that similar success rates for *in vitro* fertilisation may be achieved by implanting only single embryos is now available and in countries where this limit has been adopted, the rate of twinning has declined markedly.<sup>9</sup> There have also been suggestions that the increasing tendency to delay motherhood has contributed to increases in multiple births in many developed countries, as older women are more likely to conceive multiple pregnancies than younger women.<sup>10</sup> In addition, the UK has the highest rate of teenage pregnancy in Europe and

<sup>7</sup> Macfarlane A and Mugford M (2000) *Birth Counts: Statistics of pregnancy and childbirth*, 2nd Edition (London: The Stationery Office). We note that in early 2007 the Human Fertilisation and Embryology Authority (HFEA) will hold a public consultation on ways to reduce multiple births, including the transfer of single embryos.

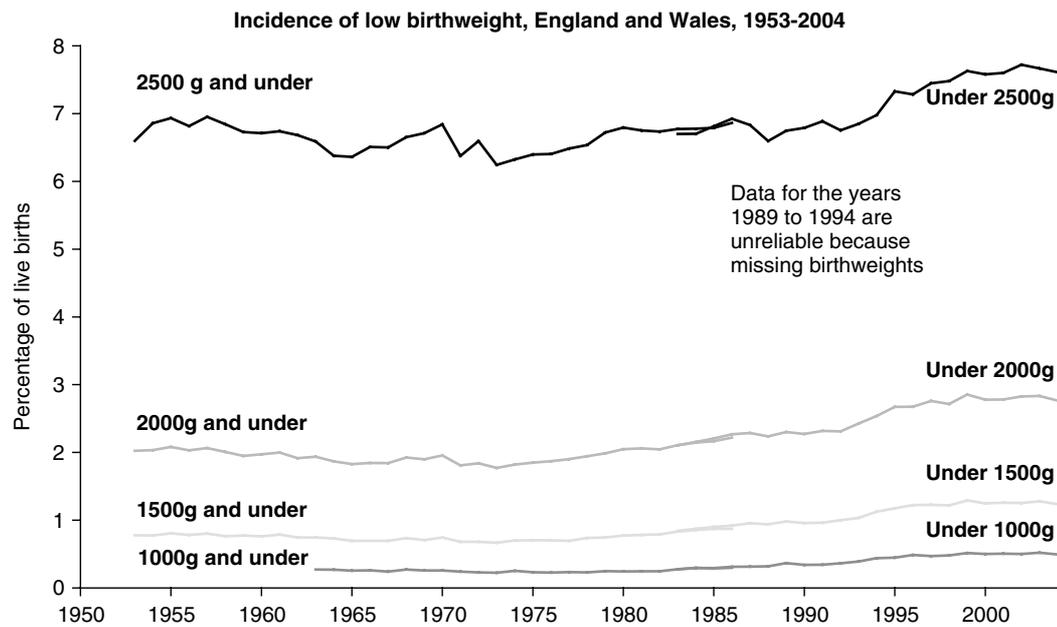
<sup>8</sup> National Statistics *Birth Statistics* (London: Office for National Statistics), Series FM1 Numbers 29–33 (2000–2004).

<sup>9</sup> Saldeen P and Sundström P (2005) Would legislation imposing single embryo transfer to a feasible way to reduce the rate of multiple pregnancies after IVF treatment? *Hum Reprod* 20: 4–8.

<sup>10</sup> A biological basis for this phenomenon has recently been proposed, see Beemsterboer SN, Homburg R, Gorter NA, Schats R, Hompes PGA and Lambalk CB (2006) The paradox of declining fertility but increasing twinning rates with advancing maternal age *Hum Reprod* 21: 1531–2.

**Figure 3.3: Incidence of low birthweight in England and Wales 1953–2004**

With kind permission from Professor Alison Macfarlane



Source: LHS 27/1 low birthweight returns and ONS mortality statistics  
Birth counts, Tables A3.4.1 and A3.4.2

teenagers are more likely to have a premature or low birthweight baby.<sup>11</sup> Increasing rates of premature birth have been recorded in other developed countries, including the USA, where a recent major study identifies prematurity as “a public health problem”.<sup>12</sup>

### The clinical context

- 3.5 An understanding of what fetal and neonatal medicine can and cannot achieve is crucial to addressing the difficult choices that families, professionals and policy makers may have to make. The medical advances that have prompted the dilemmas discussed in this Report have occurred in three main areas. First, in fetal medicine there have been major improvements in the diagnosis of fetal abnormalities and illness. A great deal can now be discovered about the health of the fetus through the use of new technologies. Secondly, some babies born at low gestational ages respond to resuscitation and can be helped to survive. Thirdly, much more is known and continuing to be discovered about what causes babies to suffer pain or develop disabilities. Doctors are therefore better placed to make predictions about how a baby may be affected by a particular disability later in life, although usually it will be difficult to give parents precise information when asking for their consent to any treatment (see Appendix 5).
- 3.6 One feature common to these developments in fetal and neonatal medicine is that the improved ability to diagnose problems is not yet matched by the prospect of effective treatment with medicine or surgery. Another is the uncertainty of the initial prognosis for a particular baby. We shall see that in some cases doctors can give parents a reasonably certain account of whether their child is likely to survive, for how long and if he or she will have any disabilities. In many others, however, doctors may have to base their advice on statistical

<sup>11</sup> Department for Education and Skills (2005) *Teenage Pregnancy*, available at: <http://www.dfes.gov.uk/highlights/article01.shtml>, accessed on: 27 July 2006; Macfarlane A and Mugford M (2000) *Birth counts: Statistics of pregnancy and childbirth*, 2nd Edition (London: The Stationery Office), Volume 1, p 142.

<sup>12</sup> Institute of Medicine Committee on Understanding Premature Birth and Assuring Healthy Outcomes (2006) *Preterm Birth: Causes, consequences and prevention* (Washington, DC: IOM).

probabilities derived from studies such as EPICure (see paragraphs 5.7–5.11) and will be unable to tell parents how their baby will fare, nor predict the extent of any disability that he or she may develop.

### ***The impact of antenatal screening on neonatal survival and disability***

3.7 While routine antenatal screening is accepted by the majority of pregnant women and provides reassurance for many, it may also give the first indication that the health of a fetus or the future baby may be compromised. Screening is a public health service through which members of a defined population are offered a test. The purpose is to identify individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications.<sup>13</sup> Improved antenatal diagnosis of problems with fetal health has provided new challenges for pregnant women, their families, health professionals and for society as a whole. Routine screening has meant that more pregnant women now experience moral dilemmas because of the diagnosis of fetal problems which would, in the past, have been apparent only after birth.<sup>14</sup> In the UK, the numbers of fetal abnormalities identified by the screening processes are not systematically recorded. Most are not life threatening and are dealt with after birth. The options for fetal surgery or treatment in the womb are still very limited, so when a fetus is in poor condition, the choice is often between continuing a pregnancy in the knowledge of an increased risk of the fetus or baby dying or having childhood disability, delivering the baby early or terminating the pregnancy (paragraph 4.2). A baby may be delivered early if problems have been identified. A decision is made after considering the risks for the woman and for the fetus. The immediate risks for the woman are generally resolved by delivery. When a fetus is at risk, the crucial question is whether the delivery of an extremely premature baby with consequent risks to the baby's health is justified by the seriousness of the problems (see paragraphs 4.3–4.6). Doctors have had to balance the risks of premature birth against continuation of a pregnancy since neonatal intensive care practices were first developed in the 1960s. Consequently data on outcomes are available to inform current practice (see paragraphs 5.7–5.11 and Table 5.1). Parents confronted with difficult decisions may find non-directive counselling<sup>15</sup> helpful when facilities in National Health Service (NHS) units are available. They can also seek advice from patient support groups such as Antenatal Results and Choices (ARC).<sup>16</sup>

### ***The borderline of viability***

3.8 Birth at the borderline of viability (up to and including 25 weeks and six days of gestation) usually occurs through natural causes. More rarely, it can result from clinical intervention (see paragraph 3.7). Approximately 0.3% of all deliveries (including both live and stillbirths) in England (1,620 in 2004–5)<sup>17</sup> occur at the borderline of viability. For babies born alive at these gestational ages, the prospects for survival are generally much less than 50% and if a baby survives, he or she is at risk of some level of disability, although as we have said, predicting the outcome for a particular baby at the time of birth is difficult (see Chapter 5). In such cases a widely used approach is for full neonatal intensive care to be instituted until the prognosis

<sup>13</sup> Defined by the UK National Screening Committee.

<sup>14</sup> Williams C, Sandall J, Lewando-Hundt G *et al.* (2005) Women as moral pioneers? Experiences of first trimester antenatal screening *Soc Sci Med* **61**: 1983–92.

<sup>15</sup> Nuffield Council on Bioethics (1998) *Mental Disorders and Genetics: The ethical context* (London: NCOB), paragraphs 8.31–8.38.

<sup>16</sup> See the Antenatal Results and Choices website, available at: <http://www.arc-uk.org>.

<sup>17</sup> National Statistics (2006) *NHS Maternity Statistics, England: 2004–05*, Table 21. Data for the other countries in the UK are collected in a different way from those in England and so cannot be combined. Figures for England are included as an example. The EPICure study, however, covers the UK and the Republic of Ireland.

becomes clearer.<sup>18</sup> This may be when the results of investigations are known or after a period when the clinical picture changes.

### **Neonatal resuscitation and intensive care**

3.9 During the mid-1960s it became possible to save the life of a newborn baby who had stopped breathing by using mechanical ventilation. At the same time progressively more complex surgery was developed to correct life-threatening abnormalities in the newborn baby. Currently, approximately one in eight babies in the UK needs some level of special care after birth, and approximately one in 40 needs the highest level of intensive care.<sup>19</sup> These babies need special care for a variety of reasons. They may have been born at the borderline of viability or at or near term. Most babies born before 32 weeks of gestation and/or those with a very low birth-weight will need to spend at least some time in high-dependency care.<sup>20</sup> National data on the reasons for which babies are admitted to neonatal units are not currently available.<sup>21</sup> However, some insight can be gained from a report published by a neonatal intensive care unit (NICU) in the UK where babies born up to and including 32 weeks of gestation make up around a quarter of all the NICU admissions.<sup>22</sup> Approximately one fifth of the intensive care cots in 2004–5 were occupied by babies born at 23–24 weeks of gestation, who stayed for an average of eight weeks.<sup>23</sup> The remaining patients were babies born at or near term who were ill because of breathing problems, congenital abnormalities, infection, brain injury, feeding difficulties or jaundice.

3.10 We concluded in Chapter 2 that certain circumstances merit discussion of whether all possible means of preserving the life of a baby should be tried. Critical care dilemmas arise in several situations. For extremely premature babies born at the borderline of viability or other babies who are unable to breathe unassisted, whether premature or born at term, decisions might have to be made about whether to begin resuscitation (see Box 3.2). When babies are dependent on artificial ventilation, the parents and doctors may have to decide whether to

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<sup>18</sup> “The greater the immaturity, the more needs to be done to support a baby’s breathing (often with mechanical ventilation), and to protect them from infection and to achieve growth equivalent to that which occurs in the womb. Thus even ‘well’ very premature babies require intensive care simply to support their organ systems until they have matured. This includes sophisticated mechanical ventilation with oxygen, intravenous feeding, and the use of incubators to control body temperature and protect from infection. It also involves treatment of illnesses which are more common in such vulnerable babies. Several weeks of intensive care may be needed for babies born prematurely, as for babies who are ill or who have congenital disorders. After that, some babies may need further weeks of high dependency or special care provided in neonatal units. Neonatal intensive care is also required for a small number of larger, more mature, babies who become ill from complications of delivery, from infection or metabolic disorders or when surgical or other treatment is required for congenital abnormalities such as congenital heart disease, disorders of the lung or gut, or of other organs.” See Department of Health (2003) Report of the Neonatal Intensive Care Services Review Group, available at: <http://www.dh.gov.uk/assetRoot/04/01/87/44/04018744.pdf>, accessed on: 15 June 2006.

<sup>19</sup> BLISS—The premature baby charity (2005) *Special Care for Sick Babies – Choice or chance?* (London: BLISS), available at: [http://www.bliss.org.uk/pdfs/Special\\_care.pdf](http://www.bliss.org.uk/pdfs/Special_care.pdf), accessed on: 27 June 2006. In the UK there are 230 hospitals that provided some form of neonatal care. Approximately 20% of the neonatal units in these hospitals can be defined as level 1 units, i.e. they provide special care but do not aim to provide any continuing high dependency or intensive care. Approximately 35% of the units can be defined as level 2 units, i.e. they provide high-dependency care and some short-term intensive care; while 45% were defined as level 3 units, i.e. they provide the full range of medical neonatal care. See Redshaw M and Hamilton K (2005) *A Survey of Current Neonatal Unit Organisation and Policy* (Oxford: National Perinatal Epidemiology Unit).

<sup>20</sup> High-dependency care is a form of intensive care provided by level 2 and level 3 intensive care units and entails breathing support and intravenous nutrition, along with other care needs, depending on the individual baby. See Teamwork Management Services Limited (2005) *Neonatal Medicine: Review of intensive and high dependency care for Greater Manchester, East Cheshire and High Peak Children and Young People’s Network – Final report* (Bolton: Teamwork Management Services Limited).

<sup>21</sup> However, the RCPCH and BAPM are coordinating the collection of a national dataset.

<sup>22</sup> University of Bristol and North Bristol NHS Trust *Southmead Hospital Neonatal Medicine Annual Report 2003*, available at: <http://www.nbt.nhs.uk/services/wch/nicu/documents/Southmead%20NICU%20Annual%20Report%202003.pdf>, accessed on: 27 June 2006; University of Bristol and North Bristol NHS Trust *Southmead Hospital Neonatal Medicine Annual Report 2004*, available at: <http://www.nbt.nhs.uk/services/wch/nicu/documents/Southmead%20NICU%20Annual%20Report%202004.pdf>, accessed on: 27 June 2006.

<sup>23</sup> Personal communication from Professor Andrew Whitelaw, consultant neonatologist, Bristol Southmead Hospital.

continue this and other interventions that constitute treatment (see Box 3.2). For some babies, life-saving therapies will mean lifelong severe disabilities or only prolong inevitable death.<sup>24</sup> For babies with brain injuries, information from scans may be sufficient for a prognosis on which to base a discussion with parents about the withdrawal of treatment and substitution with palliative care if further intensive treatment is believed to be futile. However, for babies born with serious lung or other injuries, it can be very difficult for doctors to predict the extent of the chronic illness from which they will suffer in the future (see paragraph 3.28), and consequently decisions to withdraw treatment in such cases are rare.

### Box 3.2: Medical procedures in neonatal medicine

#### Resuscitation

Most babies require only gentle stabilisation after birth, allowing them to start breathing while ensuring that body temperature is maintained. However, very premature babies or babies born in a poor condition may need more invasive treatment to facilitate breathing. Resuscitation will be considered for a baby born at the limits of viability and any baby who does not start breathing unaided. The procedures below may be carried out.

After birth, the baby is taken to a warm resuscitation platform or 'resuscitaire' and placed in a plastic bag to minimise evaporation and drying which make the baby cold. The baby's lungs are inflated with air (and possibly additional oxygen) using a face mask connected to a bag which is rhythmically squeezed. If the heart rate is below 60 beats per minute, inflation of the lungs is combined with rhythmic compression of the chest to improve oxygen delivery to the heart muscle and thus assist the baby's heart to pump. If he or she does not start breathing after a few breaths, or if chest inflation is ineffective using a face mask, a tube is inserted into the trachea (windpipe). Intubation is a skilled procedure carried out using a laryngoscope to visualise the trachea and the vocal cords, and may require several attempts. Once the baby has been successfully intubated, the tube is secured onto his or her face to deliver ventilation more effectively by hand or so that the tube can be connected to a mechanical ventilator. If the heart rate does not increase despite effective inflation of the lungs, chest compression is continued and adrenaline or other drugs are injected through a catheter inserted into the umbilical vein to speed up the pumping of the heart. This is also a skilled procedure that must be carried out using a sterile technique.

In some cases, the baby does not achieve a normal heart rate of 120–160 beats per minute, a pink colour, spontaneous breathing or responsiveness after carrying out these procedures. The clinician may then decide to administer injections of salt water (saline), glucose or sodium bicarbonate depending on the results of analysis of blood samples. In some cases, a blood transfusion is urgently required. Very premature babies born at under 30 weeks of gestation usually have surfactant injected into their lungs, which facilitates lung expansion.

After a baby has been resuscitated, a catheter is inserted at the earliest opportunity through the umbilical artery so that the tip lies in the aorta, the main artery of the body. Once the catheter is fixed in place it can be used to measure blood pressure, heart rate, and the composition of gases in the blood and pH levels without causing pain. Clinicians are able to use this information to guide their decisions on ventilation and further resuscitation as necessary. Although the procedures described above are very invasive and stressful for a baby, resuscitation saves lives.\*

#### Withdrawal of life support

The most common situation where withdrawal of life support may be contemplated is when a baby is dependent on a respirator because his or her breathing has failed. Withdrawal of life support will involve removing the tube from the baby's windpipe so the ventilator is no longer inflating the lungs. Many parents will want to hold their baby when this procedure is carried out. Morphine is frequently used to provide pain relief and sedation when a baby is ventilated and this would normally be continued after ceasing ventilation to relieve any distress from difficulty in breathing. Alternatively, a decision might be made to continue ventilation but to withdraw or withhold medication being used to support the heart and blood pressure. When this is done, the reduced circulation of blood results in the baby gradually becoming unconscious. Another decision might be to not give cardiac massage or an injection of adrenaline (to try and restart the heart) if a cardiac arrest occurs. In other situations, withdrawal of life support might take the form of a decision not to treat an infection, especially pneumonia, with antibiotics. The parents and doctors might also make a decision to withhold surgery for a life-threatening condition, such as a severe heart defect (see paragraph 6.12).

In all of these examples, if the baby dies, the primary cause of death is the disease or abnormality. When life support is withdrawn, a dying baby will still receive other forms of treatment aimed at comfort and relief of symptoms, commonly termed 'palliative care' (see paragraphs 6.18–6.21).

\*For further information, see Resuscitation Council (UK) (2005) *Newborn Life Support*.

<sup>24</sup> This type of case will sometimes reach the courts when parents and doctors have disagreed over the appropriateness of continuing treatment when no benefits are perceived by one of the parties (see Chapter 8).

### **Clinical trials and neonatal care**

3.11 The care of the newborn is often integrally linked with clinical research that seeks to develop, refine and assess the impact of new technologies and methods of treatment. We recognise that clinical trials are important to identify the best forms of clinical care for these babies and to ensure that the benefits outweigh the risks of adverse effects. A description of how trials are conducted is provided in Appendix 6.

### **The family and the role of professionals**

3.12 In this section we give an overview of the emotional and practical adjustments that families make as they reconcile their expectations with reality. When a woman or a couple embarks on a pregnancy it is generally a time of great anticipation. Parents are often very distressed to discover before or after birth that their baby has a major problem that may severely limit his or her potential for the future. Widely publicised improvements in neonatal care may lead them to have mistaken or unrealistic expectations of the likelihood of their child surviving without disability (see paragraph 3.26). Many of the parents of babies in neonatal care or intensive care will have experienced a complicated pregnancy, labour or birth. In other cases, early delivery may have occurred spontaneously with little or no warning and patients may have had little time to consider a prognosis or to prepare themselves. The baby they had imagined and had looked forward to holding may not resemble the baby whom they see in the intensive care cot or the incubator. They may be beset by uncertainty and fear for the future. There have been numerous studies identifying parental stress in the neonatal unit that have shown that parents can feel helpless, confused, frightened, angry, isolated and guilty. Their feelings are sometimes heightened by grief for the loss of the expected healthy child or anticipatory grief at the thought of their baby dying.<sup>25</sup> These are very difficult circumstances in which to ask parents, as well as for doctors and nurses, to make decisions about critical care. The consequences of decisions about the critical care of a baby may extend far beyond the hospital, especially if he or she has a severe condition which leads to disability (see Chapter 7). Often the implications will be lifelong for the child and their families, raising issues of healthcare, education and social welfare. Sensitivity and understanding are therefore crucial professional requirements.

3.13 Nurses play a crucial role within the neonatal intensive care setting, and in the decision-making process. They are the healthcare professionals who spend the most time with babies and their parents, helping them to feel and act as normal parents as much as possible in the difficult environment of the neonatal unit. They deliver treatment and closely monitor a baby's responses and are the primary source of information and support for parents. Through their close, frequent contact with parents, nurses learn about their values, beliefs, attitudes and customs and will actively encourage parents to participate as much as possible in a baby's daily care. Neonatal nurses can serve as advocates, helping parents to articulate what is important to them or helping other members of the healthcare team to appreciate the parents' perspective. Additionally, nurses assess parents' physical and psychosocial needs and can refer parents to the appropriate resources within the healthcare system, liaising with other members of the team and facilitating communication. Their special knowledge of a baby and his or her family is essential for making critical care decisions and they may be directly involved in the discussions, although this practice varies between neonatal units.<sup>26</sup> They have a professional responsibility to ensure that the rights and interests of a baby and his or her family are respected and that parents are given the information and support necessary to

<sup>25</sup> O'Shea J and Timmins F (2002) An overview of parents' experiences of neonatal intensive care *J Neonat Nurs* 8: 178–83.

<sup>26</sup> Hurst I (2005) The legal landscape at the threshold of viability for extremely premature infants: A nursing perspective, part II *J Perinat Neonat Nurs* 19: 253–62.

participate fully in decisions about their baby.<sup>27</sup> Neonatal nurses implement many of the decisions that are made to provide or withdraw life-sustaining treatments and are experts in the prevention and management of pain (see paragraphs 6.14–6.16).

- 3.14 Understanding the family's perspective is critical for the professional not only to be able to offer support and guidance when it is required but also to reconcile their own emotions should the family come to a different decision about the critical care of their baby than the one that a healthcare professional would have made. The professionals may or may not have received special training about how to deal with this situation. Some units have multidisciplinary meetings where differing views on a baby's care can be discussed, others provide access to individuals with special expertise, whereas some do not provide any formal processes for family or staff support. This variability contrasts sharply with other areas of neonatal practice, where monitoring and discussion occur regularly between neonatal units to ensure continuing improvements in quality, for example in infection control or resuscitation skills. **The Working Party noted that healthcare professionals are likely to need specific training to help them understand the perspectives of parents faced with critical care decisions and to communicate effectively with them.** This training could also help doctors and nurses reconcile decisions that are different from the choices they would have made for themselves.

### ***Making decisions: the perspective of parents***

- 3.15 The question of parental involvement in decision making about the care of the fetus or the newborn baby who has, or is likely to develop, serious health problems and disabilities is extremely important. In suggesting that there are several factors which influence parental decision making, we recognise that detailed sociological research would be required to assess their relative impact on the process. Some of these factors concern the parents' reproductive history, which may involve experience of a previous premature birth or the loss of one or more of the fetuses in a multiple pregnancy. If the mother has previously had a termination of a pregnancy, the grounds on which she did so may have a bearing on decisions about her new child. The father or the mother may have children with a previous partner, and hence have divided parenting responsibilities. A couple who had difficulties with conceiving or had experienced miscarriage, stillbirth or loss of a child or children may be initially much more concerned about a baby's survival than his or her prognosis.
- 3.16 Decision making may also be affected by expectations of family life. If both the mother and the father are new to parenthood, they are likely to have no prior experience of 'normal' childbirth and parental responsibilities. They may therefore have quite idealised views of what to expect. The parents may already have been planning to have further children or may now decide that this is what they intend. If they have older children, parents might worry about the impact of having a new child who has disabilities. They may feel obliged to take the welfare of their other children into account in decision making. In the short term at least, parental attention may be displaced towards the new child. Parents may wonder if they should involve their other children in care giving which in some cases may entail a lifelong commitment.
- 3.17 The attitudes and experiences of parents and their wider families towards pain, suffering, vulnerability, disability and death, and the influence of spirituality,<sup>28</sup> including any religious

<sup>27</sup> National Association for Neonatal Nurses (1999) *Position Statement #3015: NICU Nurse Involvement in Ethical Decisions (Treatment of Critically Ill Newborns)* (Glenview, IL: National Association of Neonatal Nurses); Nursing and Midwifery Council (2002) *Code of Professional Conduct* (London: NMC).

<sup>28</sup> Spirituality has been defined as a concern with matters of the spirit (or essence) of a person, involving a sense of connection to a much greater whole. It is a belief system that may be experienced as an alternative to religion or as an expression of personal faith within religion.

beliefs, will also have a bearing on decision making (see also paragraphs 3.23–3.24). The birth of a severely ill newborn baby in a family may undermine, strengthen, confuse or clarify preconceived notions about family ties. The actual effects in a particular family are unpredictable. Individual family members may be influenced, for example, if they have relatives or friends with disabling conditions; they may react in different ways at different points in their lives. Disagreement may occur within the family, for example, between parents, between parents and their immediate family, and between other family members. Broader social attitudes and expectations often come into play when family members find themselves directly involved in decisions about withholding or withdrawing medical treatment for another family member.

- 3.18 Over the past five years, the Internet has contributed to a significant change in the way that people communicate and make decisions about healthcare. There are far more opportunities to seek other views and opinions on a child's condition, and families who have never met each other and who are geographically many miles apart, can communicate readily. Parents sometimes form support networks or pressure groups through which they may receive help and/or channel their experiences to assist others.<sup>29</sup>

### ***Making decisions: the relationship with healthcare professionals***

- 3.19 We agree with professional guidelines which advise that parents and the team of healthcare professionals should, wherever possible, jointly decide on the most appropriate treatment for a baby (see paragraphs 2.16 and 2.45 and Appendix 9). Achieving truly collaborative decision making depends greatly on the nature of the relationship between these parties. A number of sociological studies have explored what is meant by 'lay' knowledge, beliefs and experiences, and examined health and illness as it is experienced by the individual and the family.<sup>30</sup> However, there remains a need to gain a deeper understanding of the process of shared decision making in the medical context.<sup>31</sup> The perspective of the family contrasts with that of the health professional, for whom the illness is the focus of their knowledge of the patient. Both are influenced by their own health status, as well as their knowledge, experience and expectations.<sup>32</sup> Research has shown that families are generally more positive about a baby's health problems than the neonatal doctors and nurses who provide his or her care. Furthermore, as they grow up, children who develop disabilities report a more positive outlook than their carers (see paragraphs 5.37 and 7.9). It is therefore particularly important that stereotypes or prejudices against states of disability are not fostered during the decision-making process.

- 3.20 Interactions between professionals and parents take place within a broader social context that includes the nature of medical knowledge,<sup>33</sup> the notion of expertise,<sup>34</sup> relationships between healthcare professionals, and between them and other groups.<sup>35</sup> In the UK, the medical profession is aware that its image has changed in the public's mind in recent years. Patients are now more likely to question the judgement of healthcare professionals than they

<sup>29</sup> In a study in the USA, 56% of users of the Internet said that it had helped their relationships with family members, and 38% of users said that it had helped the way they obtained health information. See Pew Internet & American Life Project (2005) *Trends 2005: Internet: the mainstreaming of online life*, available at: [http://www.pewinternet.org/pdfs/Internet\\_Status\\_2005.pdf](http://www.pewinternet.org/pdfs/Internet_Status_2005.pdf), accessed on: 25 Jan 2006.

<sup>30</sup> For example, see Nettleton S (1995) *The Sociology of Health and Illness* (Cambridge: Polity Press); Annandale E (1998) *The Sociology of Health and Medicine* (Cambridge: Polity Press).

<sup>31</sup> For further information, see Greenhalgh T and Hurwitz B (1998) *Narrative Based Medicine* (London: BMJ Books), p 259.

<sup>32</sup> Pal DK (1996) Quality of life assessment in children: a review of conceptual and methodological issues in multidimensional health status measures *J Epidemiol Community Health* **50**: 391–6.

<sup>33</sup> Foucault M (1976) *The Birth of the Clinic* (London: Tavistock).

<sup>34</sup> Freidson E (1986) *Professional Powers* (London: University of Chicago Press).

<sup>35</sup> Parsons T (1975) The sick role and the role of the physician reconsidered *Health Soc* **53**: 257–78; Illich I (1976) *Limits to Medicine* (London: Marion Boyars).

were in the past.<sup>36</sup> Although there is a perception that this change in behaviour may have led to an increase in the level of disagreement over critical care decisions, there is a lack of robust evidence to support this view. There is also potential for conflict between different health-care professionals. For example, there may be disagreement between obstetricians and neonatologists, and between neonatologists and paediatricians, as well as between doctors and nursing staff or managers.<sup>37</sup>

3.21 The influence of social factors upon decision making in the particular context of neonatal medicine has been subject to relatively little systematic research. We consider that research in this area has potentially valuable practical applications. It could provide an evidence base to explain the variations in practice and their consequences, assist the identification of good practice, and aid understanding of the issues which arise when clinical teams and parents have different views. It would also provide an evidence base for identifying and applying effective change in practice and for dispute resolution.

### The wider socio-legal context

3.22 We have seen that there are a number of ethical frameworks available to help parents and healthcare professionals come to decisions about the critical care of the fetus or newborn baby. While ethical approaches are crucial to the resolution of dilemmas in neonatal critical care, emotional influences and personal experiences can also be highly pertinent, as we have seen above. For those involved in decision making, certain paradoxes that exist within the wider socio-legal context may add complexity. For example, the legal distinction between a fetus and a newborn baby (see paragraph 8.13) is at odds with the teachings of many faiths based on the scriptures and some people's moral intuitions. In another example, the late termination of pregnancy is permitted in the UK for a 'serious fetal handicap', yet once an affected baby is born, healthcare professionals often strive very hard to keep him or her alive, highlighting the "different moral status we accord to [fetuses and] neonates even of the same gestational age" (response to our consultation from the RCPCH). Another paradox concerns the prohibition of discrimination on grounds of a disabling condition, while there is inadequate social provision for the growing child and his or her family, or for when the child becomes an adult (see Chapter 7). An additional complicating factor for those involved in decision making is that what may have been judged as morally acceptable in the past may be inconsistent with current standards. For example, in certain circumstances doctors with good intentions may actively have hastened death. This occurred in the UK in the 1970s when doctors followed the criteria developed by Dr John Lorber for babies with spina bifida.<sup>38</sup>

<sup>36</sup> Royal College of Physicians (2002) *NHS Day – Commentary on the NHS from the President*, available at: [http://www.rcplondon.ac.uk/news/news.asp?PR\\_id=120](http://www.rcplondon.ac.uk/news/news.asp?PR_id=120), accessed on: 1 Aug 2006. Also, in response to our consultation, the RCPCH noted that "Over the past 20+ years there has been greater public desire for transparency, accountability and responsibility in all spheres of professional activity, perhaps with increasing mistrust of professionals."

<sup>37</sup> Brown SD, Truog RD, Johnson JA and Ecker JL (2006) Do differences in the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists positions on the ethics of maternal-fetal interventions reflect subtly divergent professional sensitivities to pregnant women and fetuses? *Pediatrics* 117: 1382–7; McHaffie HE and Fowlie PW (1996) *Life, Death and Decisions: Doctors and nurses reflect on neonatal practice* (Cheshire: Hochland and Hochland (now Elsevier)). A recent study indicated that different professional groups perceive outcome for extremely premature babies differently and that this may affect their willingness to use interventions at borderline viability. See Chan KL, Kean LH and Marlow N (2006) Staff views on the management of the extremely preterm infant *Eur J Obstet Gynecol Reprod Biol* 128: 142–7.

<sup>38</sup> In the UK in the 1960s, Dr John Lorber developed criteria for the selective non-treatment of infants with severe spina bifida and hydrocephalus. Infants who met two or more of these criteria were not offered an operation but were sedated with chloral hydrate and fed on demand. Infection such as ascending meningitis was not treated with antibiotics. These infants usually died within weeks. The 'Lorber criteria' became well known in the UK and were widely accepted by paediatricians as being a humane way of reducing suffering. Lorber J (1972) Spina bifida cystica Results of treatment of 270 consecutive cases with criteria for selection for the future *Arch Dis Child* 47: 854–73; Lorber J (1971) Results of treatment of myelomeningocele. An analysis of 524 unselected cases, with special reference to possible selection for treatment *Dev Med Child Neurol* 13: 279–303. The practice of active ending life in severely ill newborn infants in the Netherlands is described in Box 8.2.

In general, attitudes today have changed. The use of the Lorber criteria was discontinued when evidence became available that early surgery and physiotherapy could give an affected child a good quality of life. Even today, outside the UK, doctors and midwives may not always consult the family or other professionals before acting to withdraw treatment from newborn babies.<sup>39</sup>

3.23 Historically, much of the original moral argument about decision making for a newborn baby in critical care in the UK was informed by the Judaeo-Christian tradition. Although the population in the UK is often said to be more secular than in the past, spirituality remains an important part of the lives of many people. As the diversity of our society has increased, so has the influence of other religious traditions and cultural beliefs. In addition, each person brings their own set of presuppositions, held consciously or subconsciously, consistently or inconsistently, about the basic constitution of the world.<sup>40</sup> While ethnicity, and other non-religious cultural factors that contribute to diversity, undoubtedly add complexity to decision making in fetal and neonatal medicine, evidence from empirical studies is lacking.<sup>41</sup> However, we do know that orthodox religious beliefs have led to disagreements between families and healthcare professionals that have had to be resolved in the courts (see Chapter 8).

3.24 During the course of its deliberations, the Working Party held a workshop with people representing different faiths (see Appendix 1) to learn about advice that would be given to parents and doctors needing to make decisions in critical care. There was marked commonality between the different religious approaches, especially in relation to making the best interests of the child a fundamental principle. The value that predominated was that of compassion for both the child and the parents. There was also recognition that each situation was different and would require a sensitive interpretation of religious principles.<sup>42</sup> The value of providing access to a religious counsellor or chaplain during periods of critical care decision making for parents with religious faith was acknowledged. While all attendees placed a high value on the sanctity of life (see paragraph 2.9), most faiths counselled that life need not be prolonged at all costs, for example in situations when treatment was futile or the pain and suffering for the child were greater than any benefit potentially gained from continuing medical intervention. Equally, all were agreed that every child had value in the eyes of God, meaning that disability in itself was not a reason for discounting the value of a God-given life.

3.25 Some of the issues discussed in this Report receive regular and widespread media coverage. It seems possible that some reporting, for example in the form of television programmes, could affect public perception of the medical problems. Research on the effects of the media on public perception in other health-related areas has been undertaken by the Glasgow University Mass Media Unit.<sup>43</sup> One particular study examined the press and television treatment of issues arising about mental health. The findings showed how ill-informed public beliefs on, for example, the association of schizophrenia with violence, could be traced directly to accounts in the media. Another study on coverage by the media on a range of scientific issues revealed that people were aware of the main themes but the knowledge that they had assimilated usually reflected those aspects that had received the most persistent coverage.<sup>44</sup>

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<sup>39</sup> Cuttini M, Nadai M, Kaminski M *et al.* (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries *Lancet* **355**: 2112–18.

<sup>40</sup> This is sometimes known as a 'worldview': a particular philosophy or view of life.

<sup>41</sup> Culture has been defined as "a constellation of shared meanings, values, rituals and modes of interacting with others that determines how people view and make sense of the world".

<sup>42</sup> We note that individual members of a faith group may interpret their faith differently from their religious leaders when making decisions.

<sup>43</sup> See the website of the Glasgow University Mass Media Unit, available at: <http://www.gla.ac.uk/departments/sociology/units/media.htm>.

<sup>44</sup> Hargreaves I, Lewis J and Speers T (2003) *Towards a Better Map: Science, the public and the media* (Swindon: ESRC).

3.26 Cases of extreme prematurity tend to receive a great deal of attention in press coverage, especially in newspapers and magazines. Numerous articles feature 'miracle babies' who survive despite being born extremely prematurely, but seldom address the implications for these children's future development, and for the lives of their families. This coverage tends to give a misleading impression that most babies born at the borderline of viability are healthy, whereas in reality, many do not survive and those who do often have disabling conditions ranging from mild to severe (Table 5.1). Reporting by the media of decision-making processes and the reasons for disputes may also be misleading. This is because those cases in which court proceedings are used as a means of resolving disputes between parents and doctors tend to make headline news, whereas those that are resolved privately do not.

### Consequences of decision making

3.27 We now turn to describe the immediate practical issues for parents when they take their baby home from the hospital. We then examine what is meant by disability and quality of life.

#### *Practical issues on leaving hospital*

3.28 If a baby with a severe condition survives and is discharged from hospital, the ability of a family to manage at home is likely to be a major source of concern. We have noted that the interests of a baby are bound up with those of his or her parents and that the availability of resources affect those interests (see paragraph 2.29). Although not universal, many neonatal units now have community liaison teams to give some support to parents and families when their baby is discharged home. The majority of babies who have required intensive care will have a discharge plan which is developed during their stay in the neonatal unit. Many will be discharged with complex medical requirements such as a continuing need for oxygen therapy or special feeding needs. Very premature babies who have been treated on a ventilator are at risk of chronic lung disease. Once they no longer need the ventilator, support to the lungs may still need to be provided by continuous positive airway pressure (CPAP), and oxygen therapy. Recovery sometimes takes several months and if a baby is otherwise well, he or she may be allowed to go home with an oxygen supply. Most babies with chronic lung disease gradually improve and no longer need oxygen by 12 months of age. We consider longer-term issues of health, education and social welfare in Chapter 7.

#### *What is disability?*

3.29 Decision making in the critical care of the fetus and the newborn baby requires an understanding of the possible consequences. This is why deciding how to act in the best interests of a baby with serious medical problems demands some thought on what people perceive as 'disability' and how clinical views on a baby's health relate to the social framework in which families function. Over the past decade there has been a growing interest in the experience and the politics of disability, including studies that challenge the distinctions drawn between impairment and disability (see Glossary).<sup>45</sup> Various definitions of disability are currently in use. The Disability Discrimination Act (DDA) 1995 defines a person as having a disability if:

*"... he has a physical or mental impairment that has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities"* (see also paragraph 7.26).

Attention has been drawn to the issue of how the social organisation of everyday life (for example the design of buildings, transport, social security systems and employment legislation) has 'disabled' those with physical impairments. Estimates using the widest definition suggest that there are approximately 11 million disabled adults in the UK (i.e. one in five

<sup>45</sup> Barnes C, Mercer G and Shakespeare T (1999) *Exploring Disability: A sociological introduction* (Cambridge: Polity Press).

of the total adult population) and 770,000 disabled children.<sup>46</sup> Many of these people would not define themselves as disabled because their impairments have a low impact on their lives. This contemporary understanding of 'disability' means that discussions of disability in the specific context of the long-term future of severely ill babies must pay close attention to the relationships that will be available to that person, and broader social provision.

- 3.30 The social value and meanings attributed to notions of disability and impairment, and therefore to the very term 'disabled', are rooted in broader social, cultural and religious attitudes towards humanity. These meanings and values also derive from philosophical and historical conceptions of what it means to live a 'good life'. Striving for a 'good life' goes beyond the professional obligation upon health practitioners to do no intentional harm to their patient. The DDA 1995 and 2005 aim to protect disabled people from discrimination in every aspect of their lives, including access to health, education and social care as well as community facilities and commercial services. The Disability Rights Commission has actively promoted the rights (and potential) of disabled people to be equal citizens. Attitudes towards disability have changed markedly over the past decade and opportunities have increased. In 2006, the Government appointed a new National Director for Learning Disabilities, or 'tsar' for learning disabilities, who has a learning disability herself.<sup>47</sup> We return to the question of health, educational and social care for those with disabling conditions in Chapter 7.
- 3.31 Modern sociological thinking agrees that disability should no longer be viewed simply as something that resides in the body of a person and which has to be coped with by him or her and their family, in isolation. This concept remains an ideal given the current realities of discrimination and the lack of resources (see Chapter 7). Studies on the ethics of care (see paragraph 2.3) and the sociology of emotions have found that notions of burdens and of dependence are highly relative terms. Most of us are interdependent with other people, regardless of whether or not we or they have impairments.<sup>48</sup> The main findings arising from research on the 'sociology of the body' are that terms such as 'impairment' and 'normal' and 'abnormal' also have to be understood within a wider social context.<sup>49</sup> Disabled people, their families and many researchers tend to refer to this 'social' model of disability rather than the 'medical' model, which is embedded in much of the medical literature describing outcomes after neonatal intensive care.
- 3.32 Many disabled people feel that portrayals by the media do not reflect the reality of their lives. This was demonstrated by a survey which analysed over 1,000 national and local press cuttings covering disability and disabled people over an eight week period in 1999. There were over 800 occurrences of pejorative terms. The terms used most frequently were 'suffer' and 'suffers', but these terms do not reflect accurately the perceptions of disabled people about themselves.<sup>50</sup> It was also observed that the achievements of disabled people often went unreported.
- 3.33 These examples show why it is important that accurate information is provided for pregnant women and for parents of newborn children about the nature and prognosis of the conditions of which their baby is at risk. There have been concerns about the adequacy of arrangements for informing parents about the disabilities that their baby is likely to develop, and his

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<sup>46</sup> Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People*.

<sup>47</sup> Department of Health (2006) Press release: *Government announces appointment of new learning disabled tsar*, available at: <http://www.gnn.gov.uk/environment/fullDetail.asp?ReleaseID=200756&NewsAreaID=2&NavigatedFromDepartment=False>, accessed on: 10 July 2006.

<sup>48</sup> Bendelow G (Editor) (1998) *Emotions in Social Life: Critical themes and contemporary issues* (London: Routledge).

<sup>49</sup> Shilling C (2003) *The Body and Social Theory*, 2nd Edition (London: Sage).

<sup>50</sup> Scope (1999) *Stop Press!*, see *Stop Press! – an overview*, available at: [http://www.scope.org.uk/issues/media\\_stoppress.shtml](http://www.scope.org.uk/issues/media_stoppress.shtml), accessed on: 22 Sept 2006.

or her additional needs.<sup>51</sup> In 2000, the Department of Health and Department for Education and Skills published joint guidance for parents and professionals (*Together from the Start*).<sup>52</sup> This guidance identified several barriers to effective decision making at the time of early diagnosis. These include parents' perceptions of a lack of sensitivity, misunderstandings about the implications of a diagnosis, and the subsequent impact of a disability or health need on a child and his or her family. Some of the existing definitions of disability can be particularly insensitive, especially when it is not clear whether the child will develop disabilities or what the longer-term future might be. A template for good practice in discussing early identification, diagnosis and management of a disability or other special needs developed by the charity SCOPE in 2003 was rapidly adopted, disseminated and further developed in partnership with paediatric and other child health services and partners in health, education and the voluntary sector.<sup>53</sup>

3.34 It was apparent from a number of parents of young disabled children, consulted on behalf of the Working Party, that they dread any suggestion that their child is 'blocking' a bed and may interpret any advice about withdrawal of treatment or changes in regime as a judgement that their child is 'not worth treating'.<sup>54</sup> A crucial question for parents in this situation is what quality of life their child can expect, given individual circumstances. The approach taken by professionals in conveying the prognosis and in particular, paying attention to attitude and language used, can help parents greatly. For example, doctors refer to 'withholding or withdrawing' treatment, but parents might prefer 'changing the treatment', 'reassessing the treatment' or 'reorienting the goals of care'. Honesty, understanding, tact and timing were considered to be crucial considerations. These parents wanted a sense of the future and how their child could reach his or her full potential. They could also feel very isolated and appreciated personal support.<sup>55</sup>

### **Quality of life**

3.35 The concept of 'quality of life' is a fundamental issue which arises when making critical care decisions (see paragraph 2.9). In simple terms, a person's quality of life refers to their emotional, social and physical wellbeing, their intellectual capability, and their ability to perform the ordinary tasks of living within a community. Critical care decisions will often have an impact on quality of life for both a baby and their family. People have different opinions about what constitutes a 'good' quality of life; indeed, disabled children often consider their quality of life to be good (see also paragraph 3.19). However, it is very difficult to judge the quality of life experienced by a very ill, newborn baby for whom a long-term prognosis may be unclear. Evidence of the extent of physical disability may not begin to appear until a baby is a toddler, and the full extent of learning and behavioural problems may not be experienced until he or she is well into school age. Currently it is difficult to assess the quality and variety of support that is available for children and families who need it or the impact on the quality of life of the parents. Parents often experience real difficulties in obtaining information about the social care or support available to them in the community, and how to access it (Chapter 7).<sup>56</sup>

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<sup>51</sup> Scope (2003) *Right from the Start Template: Good practice in sharing the news*.

<sup>52</sup> DiES and DH (2003) *Together from the Start: Practical guidance for professionals working with disabled children (birth to third birthday) and their families*.

<sup>53</sup> Scope (2003) *Right from the Start Template: Good practice in sharing the news*.

<sup>54</sup> Personal communication, Dr Philippa Russell.

<sup>55</sup> Russell P (2005) Information from a consultation group for the Early Support Programme.

<sup>56</sup> Scope (2003) *Right from the Start Template: Good practice in sharing the news*.

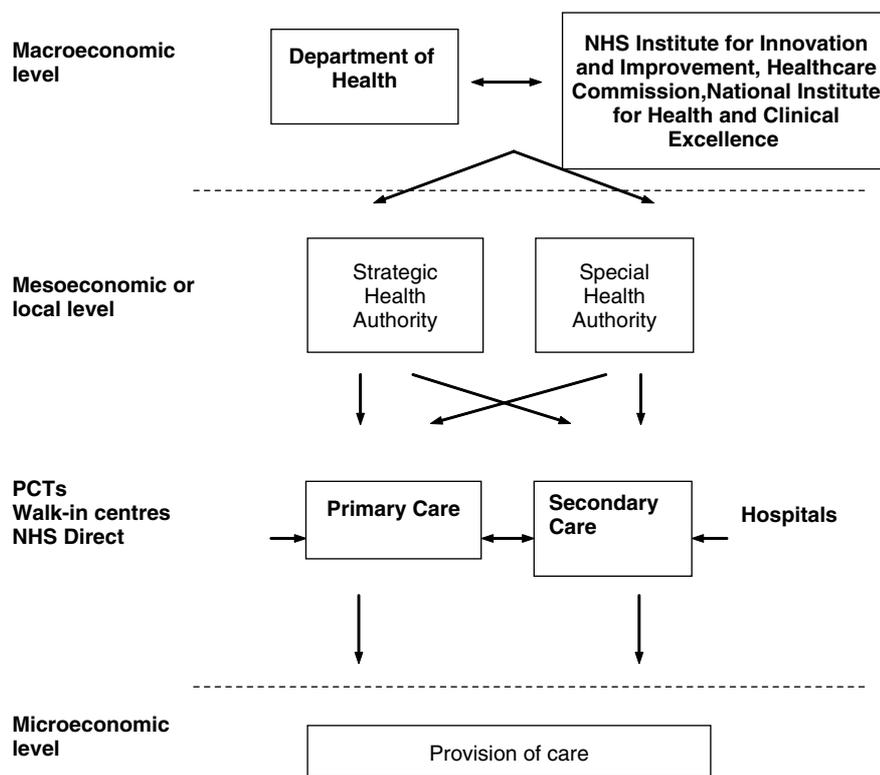
## Economic issues

- 3.36 No healthcare system provides unlimited resources. The resources available for healthcare are limited compared with demand, if not need. All healthcare systems, regardless of their financing and organisation, employ mechanisms to set priorities for finite resources. Increases in funding or the removal of inefficiencies in the healthcare system which improve access to treatment are likely to be counterbalanced by other pressures on resources. Such pressures could, for example, arise from the introduction of new and more costly interventions resulting from medical advances, or from patients expecting healthcare services to do more to alleviate suffering.<sup>57</sup> While some commentators consider that the main economic issues concern improving expenditure on healthcare, or removing inefficiencies from the way in which it is delivered,<sup>58</sup> the need for setting priorities is generally perceived to be self-evident by those who have to allocate resources.
- 3.37 Given that decisions about the prioritisation of healthcare resources are unavoidable, how should we allocate finite healthcare resources in fetal and neonatal medicine? How should the lifetime costs of caring for a seriously ill newborn baby be taken into account when devising policies on whether to institute resuscitation or whether to continue treatment? Is it appropriate to invest heavily in caring for babies with poor prognoses when the resources might be directed to babies with better prognoses or elsewhere within the healthcare system? These questions are difficult to answer because there appears to be no consensus between philosophers, health economists and public health physicians about the moral basis for decisions on resource allocation.<sup>59</sup>
- 3.38 Economic evaluation offers an explicit framework for addressing many of these divisive issues. Health economists attempt to identify the human and material inputs that combine to maximise health benefits or other measures of social welfare. Cost utility analysis is a tool, developed by health economists, that allows all health interventions to be compared in terms of their costs and the health improvements they procure. This permits healthcare resources to be allocated on a 'cost per quality-adjusted life year (QALY) gained' basis (see Appendix 8). However, numerous problems may be encountered when allocating finite resources in fetal and neonatal medicine by this method. Most notably, there is a well-recognised paucity of adequate data on the effects of fetal and neonatal interventions on survival and health-related quality of life for many conditions. In many cases, this information will also prove to be technically difficult and expensive to generate. Thus information on costs and health outcomes may be available for only a few of the range of interventions competing for priority. Moreover, little attempt has been made to test the validity, reliability, responsiveness and interpretability of the health attributes incorporated into the QALY measure in fetal and neonatal medicine. Crucially, however, allocating finite resources in fetal and neonatal medicine on a 'cost per QALY gained' basis raises a number of ethical issues. Important principles of justice may be ignored, for example if a treatment is available in one neonatal unit but not another. In addition, because neither ill health nor the distribution of healthcare resources are distributed randomly, a strategy aimed at maximising health outcomes within a limited budget may perpetuate inequalities or make them worse, and at best ignores them. In principle, this problem could be addressed by weighting the relevant data using agreed criteria for equity.
- 3.39 Broadly speaking, there are three levels at which economic issues could operate to influence decision making in healthcare. These may be described as the macroeconomic, the mesoeconomic

<sup>57</sup> Mooney G (1992) *Economics, Medicine and Healthcare* (London: Harvester Wheatsheaf).

<sup>58</sup> Frankel S (1991) Health needs, health-care requirements, and the myth of infinite demand *Lancet* **337**: 1588–90.

<sup>59</sup> We do not discuss the moral basis of resource allocation in this Report, but see, for example: Harvey I (1996) Philosophical perspectives on priority setting, in *Priority Setting: The health care debate*, Coast J, Donovan J and Frankel S (Editors) (Chichester: Wiley), pp 83–110.

**Figure 3.4: Overview of the organisation of the NHS in England**

and the microeconomic levels (see Figure 3.4; further details are provided in Appendix 7). Government agencies take decisions at the macroeconomic level, for example on the level of resource to be allocated to a particular area of clinical practice or on whether a particular treatment should be available within the NHS. The mesoeconomic level concerns regional and local decision making, such as whether or where a specialist service will be offered and the number of cots to be made available on a neonatal ward. Decisions made by healthcare professionals about a particular patient they are treating are at the microeconomic level. In practice, decision making in healthcare in the UK is affected by economic considerations at the macroeconomic and mesoeconomic levels. In our fact-finding meetings we consistently found that healthcare professionals took account only of ‘the patient in front of them’, although they could be frustrated by the difficulty, for example, of locating an intensive care bed for a very ill child. We reach some conclusions in relation to economic considerations in Chapter 2 and discuss their influence further, including the costs to families, in Chapters 4–7.

## The legal context

3.40 At this point we set out some of the principal features of the law in its application to fetal and neonatal medicine. As we shall see in Chapter 8, English law distinguishes sharply between the legal status of the fetus and the newborn baby. The framework within which the law regulates decision making in fetal and neonatal medicine is equally relevant to both. The professional guidelines that are influential in shaping the law relating to decisions before, after and during birth are provided in Appendix 9.<sup>60</sup>

3.41 On fetuses, the Abortion Act 1967 plays a major role in regulating professional practice. Other Acts of Parliament touch on dilemmas in fetal and neonatal medicine. However, much

<sup>60</sup> It should be noted that professional guidelines do not have a legal basis and that the following of guidelines will not give the doctor immunity from legal proceedings. Courts give some weight to guidelines but they are not treated as conclusive; see *W v Egdel* [1990] 1 All ER 835, CA; *An NHS Trust v B* [2006] EWHC 507.

of the law governing decision making in this area is based on interpretation of recent judgments of the courts, which are made on a case by case basis. In the recent decision in *An NHS Trust v B*, the judge said that his decision was “. . . not a ‘policy based’ judgment at all . . . not designed to have ‘implications’. . . . My sole and intense focus has been on this child alone, in his circumstances as they are today. . . .” This approach allows judges to take into account the circumstances of each case before them and encourages flexibility and pragmatism. That flexibility is often welcome to doctors, but some families may feel that flexible principles have led to their ‘rights’ and those of their children being overlooked. Healthcare professionals may also wish for more certainty and predictability. They may feel especially vulnerable when they could face criminal prosecution or disciplinary proceedings before the General Medical Council (GMC). These fears are not necessarily justified (see paragraph 8.8).

3.42 Legal principles reflect (whether set out in an Act of Parliament, or developed by judges) many of the ethical principles discussed in the previous chapter. One such principle is sanctity of life. However, while English law stresses the reverence for life, it does not adopt a rule that sanctity of life always demands its prolongation. Competing interests can sometimes take precedence<sup>61</sup> and any requirement to preserve life must be balanced against the quality of that life and the burdens of proposed treatment to prolong life.<sup>62</sup> Other influential principles include self-determination, or autonomy. This is crucial in fetal medicine where the English courts have concluded that like every other competent adult, the pregnant woman “. . . has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered”.<sup>63</sup> She decides whether to consent to or refuse any option for fetal surgery, early delivery or delivery by Caesarean section.<sup>64</sup> In law she is the arbitrator of the best interests of the fetus. However, once a baby is born alive (see paragraph 8.13), he or she has an independent legal status. The doctors’ primary duty is now owed to the baby.

3.43 Dignity is central to legal decision making especially in the case of a baby who cannot speak for him- or herself. In discussions of the law, dignity is often discussed as best interests, although it is only one aspect of the principle (see Chapter 2). One of the main legal questions concerns who should decide what is best for a fetus or baby. The law in the UK does not in theory distinguish between a newborn baby a few minutes old and older children or adults. It is a criminal offence to take active measures designed to hasten the death of a baby, however ill that baby may be. However, as in the case of older children or adults, when a baby is suffering, doctors and parents can agree to give him or her doses of pain-relieving drugs to alleviate distress even though a side effect of those drugs could be to shorten life (see paragraph 2.38).<sup>65</sup> The duty to care for the baby is not a duty to prolong life at all costs. Case law clearly establishes that where further treatment is futile and burdensome, the best interests of the baby may be to be allowed to die in as much comfort and dignity as possible. However, deciding when that point has been reached is very difficult. When there is uncertainty, doctors may fear that they are breaking the law in not continuing life support.<sup>66</sup> Where

<sup>61</sup> *Airedale NHS Trust v Bland* [1993] AC 789 at 894.

<sup>62</sup> *Re J (a minor) (wardship: medical treatment)* [1990] 3 All ER 930 at 942.

<sup>63</sup> *St George’s Hospital NHS Trust v S* [1998] 3 All ER 673.

<sup>64</sup> *Ibid.*

<sup>65</sup> *R v Adams* [1957] Crim. L. R. 365. A study of physicians working in neonatal intensive care units found that 70% of those surveyed in the UK reported having previously made a decision to administer sedatives or analgesics to suppress pain even at the risk of respiratory depression and death. It was also found that 4% reported having previously administered drugs to a newborn baby with the purpose of ending life. See Cuttini M, Nadai M, Kaminski M *et al.* (2000) End-of-life decisions in neonatal intensive care: physicians’ self-reported practices in seven European countries *Lancet* **355**: 2112–18.

<sup>66</sup> Personal communication to the Working Party. It has not been possible to obtain systematically collected information on the frequency of such cases reaching the courts.

parents and the professionals disagree and the case is taken to court, the judges have in the past more usually given support to professional judgement over parental views, drawing on the advice of independent professional experts.<sup>67</sup>

3.44 The European Court of Human Rights has ruled that it is illegal for doctors to withhold, withdraw or administer a treatment against parental objection without seeking a ruling from the court except in an emergency.<sup>68</sup> Until recently, judges in the UK were somewhat dismissive of the notion of children's rights.<sup>69</sup> The Human Rights Act 1998, giving effect in domestic law to the European Convention on Human Rights, means that in all cases involving disputes about healthcare, judges must now address the question of the patient's human rights, whether he or she is an adult or a baby.<sup>70</sup> Parents seeking to require continuing intensive care for their baby may invoke his or her right to life reinforced by their claim as parents to the right to family life.<sup>71</sup> Doctors may contend that continuing intrusive, intensive care is inhumane. The European Convention on Human Rights is, however, not "... designed to deal with children's claims".<sup>72</sup> An international treaty, the United Nations Convention on the Rights of the Child (UNCRC) provides much more detail about children's rights.<sup>73</sup> It is not directly enforceable in the UK courts so a legal claim for breach of one of the articles of the UNCRC could not be pursued. The UNCRC articles may be used as guidance about how the law should develop. In the context of the born baby and decisions about his or her medical care,<sup>74</sup> the following Articles of the UNCRC are especially relevant. Article 24(1) requires that States now "recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". Article 6 reiterates the child's "... inherent right to life" and Article 3 requires that in all decision making relating to a child, his or her best interests shall be "a primary consideration".

3.45 In England and Wales, the Children Act 1989 would be used to decide cases of disagreement over treatment for a baby. The Act states that the welfare of the child should be paramount and gives parents certain responsibilities<sup>75</sup> which we describe in more detail in paragraph 8.10. So far, UK courts have not given much consideration to the UNCRC in cases relating to the medical care of babies. The unequivocal recognition in UK law that a newborn baby enjoys the same status as any older child or adult reflects (if unconsciously) the rights approach of the UNCRC. A baby is recognised as having a right to life and to appropriate care determined by his or her best interests. However, the difficult decisions remain of how to interpret and apply the rights of a baby in the context of critical care decision making in fetal and neonatal medicine. In Chapter 8, we examine the constraints that the law imposes on the kinds of decisions that can be made and examine more fully the role of the law in regulation and dispute resolution. Using the models provided by clinical ethics committees, bioethics mediation and dispute resolution, we also explore how other methods of resolving disagreements justly and transparently, could be developed.

<sup>67</sup> *An NHS Trust v B* [2006] EWHC 507.

<sup>68</sup> *Glass v United Kingdom* [2004] ECHR 102.

<sup>69</sup> See, for example, *Re T (a minor) (medical treatment)* [1997] 1 All ER 906 at 916 per Waite L.J.

<sup>70</sup> See Fortin J (2003) *Children's Rights and the Developing Law* (2nd Edition) (Lexis-Nexis), Chapter 10. Article 2 (right to life), Article 3 (prohibiting inhuman (sic) treatment) and Article 8 (right to respect for privacy and family life) of the Human Rights Act are especially important in our context.

<sup>71</sup> See *Glass v UK* (above).

<sup>72</sup> Fortin J (2003) *Children's Rights and the Developing Law* (2nd Edition) (Lexis-Nexis), p 53.

<sup>73</sup> *Ibid.*, pp 31–50.

<sup>74</sup> *Ibid.*, pp 307–41.

<sup>75</sup> The Children Act 1989 applies in England and Wales. It stipulates that when a court determines matters relating to a child, the child's welfare shall be the court's paramount consideration. Similar provisions are contained in the Children (Northern Ireland) Order 1995 and the Children (Scotland) Act 1995.