# Perinatal Intensive Care

**Gezondheidsraad** **President**
Health Council of the Netherlands

To the Minister of Health, Welfare and Sport

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| Subject | : submission of recommendation on perinatal care |
| Your reference | : CSZ/ZT/9811456 |
| Our reference | : 2986/LdO/mr/534-A1 |
| Enclosure(s) | : 1 |
| Date | : 27 April 2000 |

Madam minister,

At your request, I hereby submit a recommendation on perinatal care, which refers to intensive care at the time of childbirth. This recommendation was drawn up by a Health Council committee, which I appointed for the purpose. The Committee requested the views of the Standing Committee on Medicine and the Standing Committee on Medical Ethics and Health Law, which they incorporated in their deliberations.

The field of care addressed in this recommendation is currently in a phase of rapid development. It is increasingly becoming a focus of attention because of the implications that it has for the remainder of an individual's life. In addition, recent demographic developments have resulted in a sharp increase in the need for intensive care at the time of childbirth. IC units are currently experiencing severe shortfalls in available capacity. The direct relationship with tertiary obstetric care and the high care of new-born babies is of critical importance.

The concentration of intensive care at the time of childbirth still leaves much to be desired. The Committee also advocates more extensive regional collaboration in the area of perinatal care, and a sound evaluation of the consequences of such care for the remainder of an individual's life. That evaluation requires a long-term follow-up of the children receiving such treatment. An appropriate infrastructure will also be needed, to implement the findings of this evaluation and to incorporate them into treatment policy.

Yours sincerely,
(signed)
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To:

The Minister of Health, Welfare and Sports

No. 2000/08E, The Hague, 27 April 2000

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Preferred citation
Health Council of the Netherlands: Perinatal Intensive Care. The Hague: Health Council of the Netherlands, 2000; publication no. 2000/08E.



ISBN: 90-5549-389-9

# Contents

# Executive summary

Since the end of the 1970s, neonatal intensive care [IC] has developed from a young and highly technical specialism into a broad, multidisciplinary form of treatment — known as perinatology — which frequently begins antenatally and also concerns the long-term consequences. The chances of premature or severely ill neonates surviving have increased markedly since the advent of perinatology and the majority of these children are not left with any severe handicap. However, many children have minor disabilities, which have a lifelong impact and adversely affect their chances of leading an independent life. The expectation that the rapid advances in the field of medical technology and the centralization of perinatal care would also lead to a reduction in these impairments has not yet been fulfilled. A key reason for this is the fact that, precisely because of these advances, ever-increasing numbers of neonates are being considered for IC, for whom treatment would previously have been regarded as futile because they were either too premature or too sick.

The increasing percentage of neonates requiring IC is due not only to advances in medical technology, but above all to population changes: women are having children at an increasingly late stage in their lives and the proportion of non-Dutch women is growing. As problems during pregnancy occur rather more frequently in older and in non-Dutch women, the percentage of neonates requiring IC is also increasing. According to the trend witnessed in recent years, this percentage will grow from 1.45% in 1986 to 2.4% in 2005. However, due to the expected decrease in the birth rate, the

number of neonates requiring IC will not increase beyond the current annual figure of 4,500 during the coming decade.

In recent years the demand for IC cots has also grown on account of longer IC stays, which, in turn, are a consequence of increased survival rates. If a child does die, this generally occurs shortly after delivery, whereas a child that survives requires prolonged care. For a child born after 25 weeks of gestation, the period spent in IC — assuming no complications arise — is six to seven weeks. Over the past five years, the increased chances of survival for children born at less than 32 weeks of gestation have led to a demand for an extra 27 IC cots. The Committee expects this trend to gradually level off, however, since only a relatively small number of children die. Only if a distinct change occurs in the limit at which a neonate is considered viable will there be a further increase in the demand for IC cots.

Outcome in babies that require neonatal IC is better when this care begins before birth as transportation of ill neonates has adverse effects. Also the expecting mother is often ill or in need of tertiary obstetric care. Tertiary obstetric care concerns care for women who deliver before 32 weeks of gestation and women with severe pregnancy hypertension, severe foetal growth retardation or expecting a baby with congenital malformations. Neonatal IC and tertiary obstetric care in the Netherlands are concentrated in ten perinatal centres.

It is often difficult to decide whether or not it is in the interest of the child to commence or continue treatment, especially when dealing with a new treatment of unproven efficacy or a child at the limit of viability. Every effort must be made to minimize this uncertainty. In order to reach a careful considered opinion on whether or not to institute intensive treatment, it is necessary to investigate both the immediate and the long-term consequences of treatment. The committee considers evaluation of immediate and long-term consequences as a prerequisite for the introduction of new treatments in perinatology. Facilities need to be created in order to continue research that has already started, even if the child has been transferred to another hospital or is back at home. Because many patients are needed in order to reach a careful decision about efficacy, the collaboration of the perinatal centres is required. The requirements for the centres should include participation in a research network and standardized follow-up research. Structural funding of overall data management, analysis and reporting of research data must then be guaranteed. It would be advisable for the professional organizations to include, in their quality control policy, a requirement for a uniform nation-wide system with respect to the recording of data concerning the perinatal period and IC treatment as well as the results of follow-up research. Such follow-up research is also necessary in order to evaluate the consequences of the continually extending the limits. Equally

indispensable is research into the effectiveness of programmes designed to stimulate young children and of interventions for developmental disorders. Furthermore, it is necessary to clearly define for each centre those situations in which no treatment will be offered. Parents and referring specialists must be in no doubt as to which considerations regarding medical uncertainties and which value judgements play a role in parent counselling and about the role the parents have in the decision-making process.

IC has in recent years become both increasingly effective and increasingly intensive. Invasive blood-pressure measurement, medication designed to support the circulation and improved ventilation techniques have reduced the incidence of damage caused by cerebral haemorrhage and hypoxia. Prevention of stress can avert cerebral haemorrhages and later developmental problems as well as reduce IC stays. This also applies to obstetric care that has become increasingly intensive and complex. However, this has major implications for nursing care: more personnel is needed and greater demands are made on the training level of staff in a neonatal intensive-care unit. The requisite minimum size of a perinatal centre is, to a significant extent, determined by the need to acquire and maintain medical and nursing skills. The introduction of new techniques appears at the outset to be associated with a high risk of complications. This risk diminishes as experience with the particular treatment increases. For this reason, the Committee advocates that the number of perinatal centres should not be further increased and that the minimum size of each centre should be fixed at 14 IC cots.

The personnel, equipment and infrastructural facilities required in a perinatal centre have been described in detail in two earlier Health Council advisory reports. These stipulations still apply in full. The greater intensity of the care that is provided has increased the need for medical and nursing staff, while at the same time a number of societal changes (working times, the regulation of night-duties, etc) have had the opposite effect of reducing staff availability. The present shortage of nurses and the frequently inadequate quality of medical staffing outside office hours threatens the quality of care.

The demand for neonatal IC has almost doubled since the first Planning Decree was issued in 1987, yet the growth in the allocation of cots has failed to keep pace with this demand. At present, several hundred neonates every year have no access to an IC cot and for more than 800 children there is no cot available within their own region. A total of 311 IC cots are needed in order to meet the present demand for neonatal intensive care, whereas only 157 cots have been allocated.

In addition, sufficient high care [HC] cots must be created, for neonates who require intensive nursing care, but whose vital functions are not (or are no longer)

threatened. These HC units, which can be located both within the perinatal centres and in the general hospitals, must satisfy quality requirements for care that concerns the prevention of developmental disorders and to the continuation of research that has already started. This requires clear agreements regarding collaboration between these units and the perinatal centres. At present, between 211 and 235 such HC cots are needed. A sufficient number of HC cots would improve the flow of patients from IC to HC, thereby both shortening IC stays and reducing the need for IC cots. An extra number of 14 HC cots is needed to reduce IC stay by one day.

Over the next five years, perinatal units are expected to require 250 cots for tertiary obstetric care.

Chapter 1

# Introduction

## 1.1 Background

Nearly two hundred thousand babies are born in the Netherlands each year. Roughly forty thousand of these neonates require hospitalization, most of them in connection with minor problems adapting to life outside the womb. A small number, however, have more serious problems, often resulting from premature birth, serious infection, hypoxia or serious congenital anomalies. A little more than 2 per cent of all neonates (4500) consequently require intensive care (IC). The mortality rate among neonates receiving IC has fallen sharply in recent decades, but remains much higher than the average neonatal mortality rate in the Netherlands. For most of these children, the risk of death is more than 10 per cent. Serious prematurity and serious illness before, at or shortly after birth also have considerable influence on an individual's health and development in later life. It is increasingly clear that, despite the quality of perinatal care, such problems often have lifelong implications.

With a view to promoting the quality of the care and the efficient use of expertise, manpower and resources, IC for neonates has been concentrated in specialist centres since the mid-seventies. Acting on the Health Council's advice (GR82), the minister of the day brought such care within the scope of Section 18 of the Hospital Provision Act. by issuing a Planning Decree. This first Planning Decree (1987) indicated that 138 IC cots were needed for neonates born after less than thirty weeks' gestation or with a birth weight of less than 1000 grams, and for neonates with seriously impaired vital functions. In addition, between 113 and 134 high care (HC) cots were required for

neonates with short-term or less serious vital function impairment. The Planning Decree also set out certain requirements concerning the qualifications and availability of personnel, the size of the units and the infrastructure of the hospitals providing this specialist care. Ten neonatal IC centres were nominated: the eight university hospitals, the Sophia Hospital in Zwolle and the Sint Joseph Hospital in Veldhoven.

In 1991, the Health Council advised the government to continue its policy of concentration (GR91). Following consideration of the Health Council's report, a second Planning Decree was issued in 1993. Under the provisions of this decree, neonatal IC continued to require ministerial recognition, but most HC for neonates was removed from the scope of Section 18 of the Hospital Provision Act. The one exception in this regard was "IC-HC", i.e. HC that follows on from IC, during which the neonate's vital functions remain sufficiently unstable that the child needs to remain in a specialist centre, in case readmission to IC proves necessary. To accommodate this change, which implied longer hospitalization in specialist centres for some neonates, and to allow for forecast growth in the number of neonates needing IC, it was decided that the number of IC and IC-HC cots in the ten existing centres should be increased to 168 in a series of stages, starting in 1993.

## 1.2 Ministerial commission

Details of the policy to be followed after 1996 were to have been published in a new Planning Decree. However, the preparation of a new decree to cover the next five-year period was initially postponed in connection with changes to the statutory context (as a result of which specialised clinical care is now excluded from the provisions of section 18 of the Hospital Provision Act but instead falls within the scope of sections 2 and 5 of the Exceptional Medical Procedures Act), and the need to go ahead at all is now under review (Ano97). Against this background, the Minister of Health, Welfare and Sport wrote to the Health Council on 25 May 1998 commissioning a further report (Annex A). On 14 January 1999, the President of the Health Council accordingly established a committee to look into the relevant issues on the Council's behalf (Annex B).

## 1.3 Scope and structure of this report

The Committee felt that its remit necessitated consideration of recent developments and the present status of perinatal IC, insofar as relevant to any new Planning Decree. Since neonatal care and obstetric care are inseparably linked and both have lifelong implications, the Committee also decided that it would be inappropriate to confine its deliberations to the neonatal period. Accordingly, as its title suggests, this report includes

sections dealing with developments in obstetrics, problems in post-IC care and evaluation of the consequences of care. This general field is referred to as perinatal care. This report does not, however, consider IC provided for neonates who require surgery in a general paediatric or surgical IC unit.

In preparation for formulation of the new Planning Decree, the minister had previously obtained a report from the National Health Insurance Fund Council (Dutch initials: ZFR). The ZFR in turn commissioned the Netherlands Organisation for Applied Scientific Research (TNO) to produce an evaluation report on section-18 neonatal IC. This report was used by the Committee as a basis for determining the existing level of IC capacity and the extent of its utilization (Oud97, ZFR97). Recent data was extracted from the annual report on the demand for IC submitted by the National Neonatology Registry (LNR) to the Ministry of Health, Welfare and Sport (LNR98). The committee also investigated whether and to what extent IC is provided for neonates outside the ten nominated specialist neonatal care centres (NICUs), and whether the provision of any such care was linked to a shortage of cots in the NICUs or associated third-line obstetric units. The Committee's findings are presented in section 2 of this report. Section 3 is devoted to recent developments and the situation within perinatal IC. In section 4, the Committee considers the later-life implications of neonatal IC and the need to take account of such implications in any evaluation of perinatal care. The implications that decisions to withhold or withdraw treatment have for the level of demand for neonatal IC are examined in section 5. The Committee's estimates regarding the level of demand for neonatal IC over the next five years are presented in Section 6, while section 7 deals with IC quality requirements. Finally, the Committee's concluding remarks are presented in section 8. A glossary of terms and abbreviations is appended to the report (Annex F).

Chapter **2**

# Existing capacity and capacity utilization

## 2.1 General information

The 1993 Planning Decree states that IC should be available for neonates with seriously impaired vital functions. This effectively means those who require respiratory support or have a serious disorder affecting their circulation, fluid and electrolytes balance, energy balance, central nervous system or immune system. It was assumed that all neonates born after less than thirty weeks' gestation or with a birth weight of less than 1000 grams would require IC. Subsequent studies have since shown that in practice most neonates (86 per cent) born after thirty to thirty-two weeks' gestation also require IC (WBC98).

In many cases, it is apparent before a baby is born that it is likely to require IC – if, for example, the birth is expected to be seriously premature, or if congenital anomalies have been detected that will require treatment immediately after birth. Studies have shown that in such cases hospitalization of the mother before the birth is beneficial in relation to the outcome of the treatment (Kol92). Many of the mothers concerned are themselves seriously ill and therefore require obstetric HC or even IC. A hospital with an NICU consequently needs an obstetrics unit with sufficient capacity for third-line obstetric care. This unit and the NICU together form a perinatal centre. As indicated in the introduction, there are ten registered perinatal centres in the Netherlands.

A baby that has been weak or ill enough to require IC will still need a great deal of care and diagnostic support in the period after it has been discharged from IC. Respiratory assistance may be needed in the event of apnoea attacks, for example, or

the baby may need parenteral nutrition or special diagnostic tests to check for brain damage or the like. In an earlier report, the Health Council referred to such care as post-IC HC (GR91). However, use of this term has caused some confusion, since it covers various different forms of care. In the period immediately after removal from IC, a baby's vital functions remain very unstable, making it important for the baby to remain in an IC unit in case ventilation or some other kind of IC needs to be resumed. The 1993 Planning Decree regards this period as part of the IC period, and it is therefore included when calculating the length of an infant's stay in IC. As time goes by, it gradually becomes less likely that the baby will need to go back on IC, making transfer to an HC unit possible. Such units deal not only with post-IC neonates, but also with those whose vital functions were never impaired sufficiently to make IC necessary. The care provided for the latter group is referred to as primary HC. Primary HC is not confined to the ten perinatal centres: the paediatric units of most large general hospitals have HC facilities for neonates. The 1993 Planning Decree removed the need for such HC units to be licensed under the Hospital Provision Act. Short-term IC in emergency cases, or pending transfer to an NICU, can be undertaken at any hospital with a paediatric unit.

When a baby no longer needs HC either, it can be transferred to an ordinary paediatric unit or discharged from hospital altogether. Even under such circumstances, however, special care and supervision is needed, since babies who have started their lives in IC do not tend to respond in the same way as other babies. The outpatient care provided for babies that have been in IC should ideally be close to home in local hospitals. On the other hand, periodic consultations for development assessment (perinatal follow-up) ought in the interests of proper care evaluation to take place in specialist perinatal centres. In addition, long-term outpatient care is advisable, so that the effects of the child's perinatal treatment may be monitored.

A perinatal centre is therefore a hospital department which fulfils various functions: it provides diagnostic facilities and treatment for pregnant women who are ill or have serious complications necessitating third-line care and for their unborn children; it is used for the delivery of babies who are expected to need IC immediately following birth; it provides IC as indicated for neonates and their sometimes seriously ill mothers until they can be transferred to other hospitals; and it is where the long-term treatment evaluation takes place.

## 2.2 Number of births and number of neonates requiring IC

According to the National Obstetrics Registry [LVR], there are 200 000 births a year in the Netherlands following a gestation period of sixteen weeks or more. A little over 40 per cent of these births take place under the supervision of first-line carers (GPs or

midwives); half are supervised by second-line gynaecologists and roughly 9 per cent occur in perinatal centres. Admission to an NICU is very unusual following a birth under first or second-line supervision, occurring in only 0.2 and 0.9 per cent of cases, respectively.


*Figure 1* Annual number of neonates for whom IC was indicated in the Netherlands between 1993 and 1998, grouped according to basis for indication. (beademing = ventilation; overig = other; totaal = total) (Sources: LNR93, LNR94, LNR95, LNR96, LNR97, LNR98.)

By contrast, 60 per cent of neonates born under third-line supervision require admission to an NICU. In a large proportion of these cases, the mother is referred to a perinatal centre by a first or second-line carer before the birth.

The number of neonates requiring IC has risen from 3780 in 1993 to 4333 in 1998 (fig 1). In percentage terms, this equates to an increase from 2.0 to 2.3 per cent of all live births in the Netherlands. Over the same period, the number of neonates admitted to IC after less than thirty weeks' gestation or with a birth weight of less than 1000 grams rose by two hundred to more than a thousand (Dor99). However, the rise in the number of babies requiring respiratory support admitted to IC after more than thirty weeks' gestation (from 1108 in 1993 to 1610 in 1998) is more important in relation to development of the demand for IC. Meanwhile, the proportion of neonates for whom IC is indicated for other reasons has been falling. This is attributable partly to the need to admit full-term neonates to pediatric IC units, due to the shortage of specialist neonatal IC cots.

*Table 1* Increase in the number of children surviving after birth at a gestational age of less than thirty-two weeks, and the impact on the demand for IC. (Sources: LNR93, LNR98)

| gestational age | survivors, 1993 | survivors, 1998 | average stay in IC (days) | additional no. of IC days |
|---|---|---|---|---|
| <24 weeks | | 1 | 74 | 74 |
| 24-25 weeks | 31 | 40 | 74 | 666 |
| 26-27 weeks | 155 | 222 | 47 | 3,149 |
| 28-29 weeks | 365 | 469 | 31 | 3,224 |
| 30-31 weeks | 589 | 743 | 17 | 2,618 |
| total | 1,140 | 1,475 | | 9,731 |

Because survival rates have improved, the average length of stay in IC has increased. This trend is particularly evident among seriously premature babies. Since Dutch records began, the number of babies surviving despite a gestation period of less than thirty-two weeks has doubled, from seven hundred in 1983 to 1475 in 1998. As a result, the total annual number of IC days has gone up by 9731 since the last Planning Decree (table 1). This rise corresponds to twenty-seven additional IC cots (9731 / 365).

## 2.3 Obstetric capacity where neonate is expected to require IC

The prognosis for a neonate born in a perinatal centre is considerably better than that for a baby transferred to an IC unit immediately following birth (Kol92). It is therefore advisable for the mother to be referred to a perinatal centre before giving birth whenever there is reason to believe that the baby may require IC. Admission to a perinatal centre is necessary — for assessment purposes — in cases involving neonates at the limit of viability. In 1999, the Netherlands Association for Obstetrics and Gynaecology [NVOG] and the Netherlands Paediatric Association [NVK] issued guidelines on such admissions (NVO99). In addition, it is desirable for the mother of a neonate transferred to a perinatal centre to be admitted as well, so that the mother-child relationship may develop as near normally as possible, and so that the parents may be given appropriate support. In recent years, many pregnant women and mothers who have recently given birth elsewhere have been denied admission to obstetrics units due to lack of capacity.

The demand for third-line obstetric care cannot be gauged simply from the number of neonates admitted to NICUs. On the basis of LNR data and its own survey findings, the Committee estimates that the number of patients admitted for third-line obstetric care is 160 per cent of the number admitted to NICUs (Annex C). In addition, the Committee has calculated that every year roughly three hundred women expecting

babies that are likely to need IC are refused admission to their regional centre. It is not clear, however, how many of these refusals are attributable to lack of capacity in the NICU itself, and how many to capacity problems affecting the perinatal centre's obstetrics unit. At the university centres, few women are denied admission for the latter reason. However, the two non-university centres have insufficient obstetrics capacity and do therefore have turn patients away on a regular basis (Oei00).

Furthermore, it is not possible to determine whether expectant mothers refused admission to one perinatal centre are referred to another. In view of this situation, the Committee would like to see the ten third-line obstetrics units adopt a uniform system for registering cases in which patients are admitted or refused admission to obstetric HC.

## 2.4 IC capacity for neonates

The 1993 Planning Decree indicated that a gradual expansion would be necessary in IC capacity at the ten NICUs, to a total of 168 cots. By 1998, however, only 157 IC cots were theoretically available. Of these, the Committee's investigations suggest no more than 149 were actually in use – the discrepancy being due mainly to staffing problems during holiday periods. According to the LNR, the actual number of IC days in NICUs was 73 458 in 1998. This means that the equivalent of 201 full-time IC places (73 458 / 365) were occupied, implying that in 1998 forty-four HC cots were used to provide IC for neonates at the centres, in addition to the 157 licensed IC cots. Since staffing levels in HC units are not as high as those in IC units, this situation represents a threat to the quality of care provided for neonates.

Until 1997, places were found for almost all neonates requiring NICU care, although in that year 672 children (18 per cent of all cases) could not be cared for in their own region (LNR97). Extra-regional care necessarily involves the long-distance transportation of a seriously ill child or the transfer of a pregnant woman to a hospital some distance from home. In some cases, the children of multiple pregnancies had to be cared for at more than one hospital. The Committee considers this situation unacceptable, since the transportation of a neonate reduces its chances of survival. The Committee's investigations revealed that the number of extra-regional admissions rose to 743 in 1998. That year was also the first in which it was not possible to accommodate all neonates requiring IC at NICUs in the Netherlands (table 2). What is more, NICU places were not even sought for roughly 15 per cent of the neonates for whom NICU care was indicated on the basis of the Planning Decree's criteria (LNR98).

*Table 2* Distribution of extra-regional neonatal IC admissions in 1998 (Source: Health Council survey).

| | admission in local region not possible | alternative NICU | pediatric ICU | IC facility abroad | not admitted to IC |
|---|---|---|---|---|---|
| LNR98 | | 742 | | | |
| Health Council survey 1998 (retrospective) | 881 | 743 | 75 | 61 | 2 |

## 2.5 HC capacity for neonates

The trends that have brought about the increase in demand for IC have also led to a rise in the number of HC places required for neonates. Furthermore, because IC cots are scarce, there is heightened pressure to transfer neonates from IC to HC as soon as possible. Because the last Planning Decree removed HC from the scope of section 18 of the Hospital Provision Act, the growth in the number of HC cots at perinatal centres has not kept pace with the increase in IC places. According to information collected by the Committee, at least nine of the fifty-three HC cots in the perinatal centres were unavailable due to staff shortages in 1998. The shortage of HC capacity is aggravated by the fact that forty-four HC cots are in constant use for IC and post-IC HC. Furthermore, only a modest number of HC places were available in general hospitals with neonatal HC units. It is also important to note that not all hospitals have HC facilities. As a result, a neonate will often remain at a perinatal centre throughout a period of HC, even though this is not a medical necessity. However, the perinatal centres' HC units do not have any spare capacity, so accommodating non-essential cases reduces the capacity available for babies in need of primary HC. Consequently, nearly three hundred expectant mothers who initially registered in a perinatal centre, but whose babies were not expected to need IC, had to be referred to other hospitals before or immediately after giving birth.

## 2.6 NICU-PICU overlap

Between them, the eight university hospitals in the Netherlands have nine paediatric IC units (PICUs). Neonates are sometimes admitted to these units as well, but not to IC units in which adults are cared for, except in cardiac surgery centres, where patients of all ages may be in the same unit. Hospitals with PICUs have their own guidelines for deciding whether a patient should be admitted to the NICU or the PICU. At one of these hospitals, premature neonates requiring IC are admitted to the NICU, while full-term neonates requiring IC go into the PICU. At the others, the PICUs take

neonates mainly where (heart) surgery is indicated or in cases of transmissible infection. Most of these cases do involve full-term neonates.

At the five PICUs that responded to the Committee's questionnaire, 493 neonates aged less than twenty-eight days were admitted in 1998, forty-nine of them because no place was available in the NICU. The Committee did not establish whether babies with primary PICU indications are ever admitted to NICUs, however. The demand for neonatal IC has been calculated to take account of cases involving neonates admitted to PICUs because no NICU cot was available, but not cases involving neonates with primary PICU indications.

The Committee believes that, in the interests of a co-ordinated treatment policy, the allocation of a hospital's NICU and PICU cots to neonates on a flexible basis is preferable to the transference of new-born babies to other centres, which necessarily involves inter-regional and sometimes even international transportation.

## 2.7 Summary

There is presently a distressing shortage of NICU capacity. To compensate for this shortage, HC and PICU capacity is being used for babies who should really be in NICUs, and some cases are being referred to centres abroad. In addition, nearly 20 per cent of babies admitted to NICUs cannot be accommodated in their own region, which is medically undesirable. Furthermore, there are capacity problems in the third-line obstetrics units that 'feed' the neonatal IC facilities, particularly in the two non-university centres. As a result, even more complex inter-regional transfers are necessary. There are also insufficient HC places for post-IC care, and this inhibits the efficient throughput of patients. Finally, the scope for systematic evaluation of perinatal treatment is inadequate.

Chapter **3**

# Recent and anticipated developments

## 3.1 Demographic and social trends

### *3.1.1 Birth rates*

In the period since the 1993 Planning Decree, the annual birth rate in the Netherlands initially fell slightly, then, after 1996, began to rise. In 1998, there were 199 443 live births. Under the CBS's [Statistics Netherlands] median scenario, the annual number of babies born is forecast to fall to 185 000 over the next ten years, only to rise again to 200 000 in the ten years after that (Bee99, CBS99a). In its last report, the Health Council assumed that 2 per cent of all neonates would require IC (GR91). In practice, the figure has recently exceeded 2 per cent (see table 3). The causes of this rise are considered below.

*Table 3* Number of neonates, anticipated neonatal IC demand and recorded neonatal IC demand (Sources: CBS99b, CBS99c, LNR93, LNR96, LNR98).

| year | live births | percentage requiring IC | neonates requiring IC (anticipated) | neonates requiring IC (recorded) | actual percentage |
|---|---|---|---|---|---|
| 1993 | 195.76 | 2 | 3,915 | 3,780 | 1.9 |
| 1996 | 189.52 | 2 | 3,790 | 4,371 | 2.3 |
| 1998 | 199.44 | 2 | 3,989 | 4,333 | 2.2 |

### *3.1.2 Maternal age*

Between 1993 and 1998, the percentage of women giving birth at the age of thirty or above went up from 53 to 61 (Ste98). This trend is expected to continue. The risk of an expectant mother suffering hypertension and pre-eclampsia, which are associated with premature birth and retarded foetal growth, increase with age (Han86, Kat98, Res90). Furthermore, fertility diminishes beyond the age of thirty, increasing the demand for assisted conception (Hui98, Noo91). This in turn means that multiple pregnancies and complications during pregnancy are more common (Bai99, Dui91, Mer99). Spontaneous multiple pregnancies are also more common among older mothers (Ste98), which is significant because birth is then more likely to be premature (Dal99, Jos98; see also 3.2.3). In addition, older mothers run a higher risk of having a baby with a chromosomal anomaly. Needless to say, all these factors tend to increase the demand for perinatal care. The Committee therefore believes that the upward pressure on demand will continue in the years ahead.

### *3.1.3 Demographic trends*

Nearly a million people in the Netherlands belong to an ethnic minority. Roughly 40 per cent of these people live in the country's four largest cities. The birth rate for the ethnic minorities is higher than that for the population as a whole. Consequently, 64 per cent of the babies born in Amsterdam in 1995 had at least one parent of non- indigenous origin. Furthermore, the perinatal mortality rate among the children of ethnic-minority women is between 1.3 times and twice as high as in the indigenous population (Dri99). Premature birth is also more common in the immigrant population. In the Netherlands, birth after less than twenty-seven weeks' gestation is three times as common with black women as with white women (Doo85, Enk98, Wol98a). The presence of large ethnic minority groups therefore tends to increase both the demand for neonatal IC, and the need to adapt the supervision provided during IC. It is the Committee's view that training which draws attention to cultural differences and the availability of interpreters are among the preconditions for high-quality perinatal IC.

## 3.2 Obstetrics

Premature birth, complications during pregnancy and the presence of congenital anomalies are the main reasons for admission to neonatal IC. Babies born before the thirty-second week of gestation almost always require IC (WBC98). More than three-quarters of premature births follow spontaneous contractions or spontaneous

premature membrane rupture. In around 20 per cent of cases, serious hypertension during pregnancy or serious foetal growth retardation make it necessary to deliver the baby by caesarean section or induced labour before the pregnancy has run its full term (Mei98). Future changes in the way that fertility problems are treated or in the prevalence or treatment of complications during pregnancy or delivery could cause the demand for perinatal care to increase or decrease.

### *3.2.1 Multiple pregnancy*

Between 1993 and 1998, the number of multiple births in the Netherlands rose by roughly 1300 (Ste98). The main causal factors underlying this trend were the rise in the average age of mothers and the increasing use of infertility treatments. (The latter being in part a consequence of the former.) In 1996, 11 154 courses of IVF were undertaken, while ovarian hyperstimulation was employed roughly 25 000 times. Some 30 per cent of multiple pregnancies follow fertility treatment. The increasing use of fertility treatment caused the annual number of sets of triplets born in the Netherlands to rise from twenty or twenty-five before 1984 to 121 in 1991. Since 1991, this number has declined somewhat (to 83 in 1997; CBS99) due to the exercise of greater caution in the replacement of embryos fertilized *in vitro* (GR97, GR98). The prevalence of triple births is also influenced by the willingness of parents to accept embryo reduction following the detection of triple higher multiplet pregnancy (Kan97, Wer99). As indicated, multiple pregnancies often end in premature births. Roughly 10 per cent of twins and 35 per cent of triplets require IC, whereas IC is needed by only 2 to 2.5 per cent of babies born following single pregnancy (Vis97). The prevention of multiple pregnancies following IVF is desirable and could reduce the number of IC admissions by around a hundred a year.

Twin transfusion syndrome (TTS) is a relatively rare problem that can occur with monozygotic twins. It results in one foetus receiving an excessive blood supply at the expense of the other, thereby increasing the risk of foetal injury and mortality. In such cases, labour sometimes has to be prematurely induced to prevent brain damage occurring. Recently, however, expectant mothers have regularly been referred to centres abroad to receive a successful new treatment, which involves the use of lasers to separate the foetuses' circulatory systems (Hec99, Zon99).

Finally, in the last few years it has become possible, following the premature birth of the first baby from a multiple pregnancy, to delay the birth of the other baby or babies. This reduces the risk of complications for the second child or subsequent children (Poe92, Vog99).

### 3.2.2 *Spontaneous premature birth*

The best predictor of premature birth is previous occurrence. It is therefore difficult to anticipate premature birth where a woman is pregnant for the first time, and little success has to date been booked in the prevention of premature first births. Infection is suspected of playing a role in the induction of premature contractions and premature membrane rupture. Treatment with metronidazole is known to reduce the risk of premature birth in cases where bacterial vaginosis is confirmed in a woman who has previously given birth prematurely (Gol98, Kin99). Antibiotic prophylaxis in cases where infection has not been confirmed has not been found efficacious among women who have previously given birth prematurely, however, and has the side effect of increasing the risk of neonatal infection (Ver99). Nor is there any evidence that the preventive administration of antibiotics following premature membrane rupture can prevent problems (Ken99, Par98, Sch99). Thus, no reliable method of reducing the risk of spontaneous premature birth has yet been found. The possibility that the incidence of premature birth could be reduced by psychosocial counselling of the expectant mother has not been properly investigated.

Labour can be delayed in various ways, but only for a short period. Nevertheless, the suppression of contractions is important, since it enables the administration of corticosteroids to the mother (see 3.2.5) and her transfer to an appropriate centre before she gives birth. This in turn improves the prognosis for her child (Mur98).

### 3.2.3 *Induced premature birth*

Medical induction of premature birth is initiated mainly in cases of serious maternal hypertension, which may or may not be combined with retarded foetal growth and indications of foetal hypoxia. Such problems are most common in very young and older expectant mothers. Hypertension during pregnancy is regarded as an inadequate immunological adaptation resulting in vascular constriction and impaired placental blood flow.

Hypertension can lead to serious health problems for the mother, including pre-eclampsia, eclampsia or HELLP syndrome. Under such circumstances, the only available course of action is to terminate the pregnancy. However, various new treatments are under investigation. These include the administration of high doses of corticosteroids with a view to suppressing the immunological response, or medications that induce the release of nitrogen monoxide (NO) to control vascular constriction (Eyc99).

Despite these developments, the Committee does not expect to see a decline in the frequency of induced premature birth in the near future. Not only is there little short-term prospect of the medical profession being able to prevent hypertension during pregnancy or to treat it other than by termination, but the rising average age of expectant mothers is also likely to increase the incidence of hypertension problems.

### 3.2.4 *Congenital anomalies*

Primary prevention of congenital anomalies is presently possible only where neural tube defects are concerned. However, the policy of recommending the preventive use of folic acid (GR93) has not yet led to a demonstrable reduction in incidence of such defects among neonates (Pal00).

Under the Population Screening Act, screening for congenital anomalies can be offered on a routine basis in the Netherlands only subject to licence. The Health Council is shortly to report on the desirability of such screening. The expectation is that more screening will lead to earlier and more frequent detection of congenital anomalies during pregnancy. In some cases – depending on how far pregnancy has progressed, the seriousness of anomaly detected and the parents' wishes – the detection of an anomaly will lead to termination of the pregnancy. On the other hand, the use of ultrasound scanning will result in more prenatal detection of treatable anomalies, such as heart defects, abnormalities of the central nervous system (including neural tube defects), renal and intestinal abnormalities, abdominal wall defects and *hernia diafragmatica* (NVO97). The Committee anticipates that this will increase the number of referrals to and births in perinatal centres, so that specialised IC (in connection with, for example, surgery or ECMO) and, in some cases, terminal care can be provided.

### 3.2.5 *The prevention of neonatal problems*

The administration of corticosteroids to expectant mothers when premature birth is imminent reduces the seriousness of pulmonary problems and risk of consequent mortality and can prevent or reduce intracranial haemorrhage in the baby. However, the efficacy of the treatment depends on birth being delayed for at least twenty-four hours (Cro90, HPI96a, Kat92). No other prenatal methods of preventing intracranial haemorrhage have been found to be effective (Vol95).

Ultrasound diagnostics, foetal behaviour monitoring, Doppler-tests and cardiotocography make it possible to determine the best time for birth in cases of serious growth retardation or imminent foetal distress. Then, by inducing labour or performing a caesarean section at the appropriate time, brain damage can be minimized. The consequence is, however, more premature births (WBC98).

Blood group antagonism is a rare but serious condition, whose total eradication is not in prospect, despite extension of the pregnancy immunization prevention programme (LBP97). It can be treated effectively by intra-uterine transfusion, which increases the baby's survival chances considerably. The demand for IC is not greatly influenced by the use of this treatment, however, since only a handful of admissions are required each year (Jan97). It is only in the event of serious hydrops associated with blood group antagonism (irrespective of the antibody type involved) that babies affected by this condition still need IC (Dij99, Kam00, Vri99a).

The incidence of early neonatal sepsis has been reduced by the prevention of beta-haemolytic streptococcal infections. Last year, the NVK and NVOG issued guidelines on procedures for preventing neonatal infection in cases of streptococci colonization (NVK99). Other intra-uterine treatments and prevention methods are under development or investigation, but have yet to prove their value (Fis97).

## 3.3 Neonatology

Admission to IC during the neonatal period can be necessary for a wide variety of reasons, many of which are linked to the length of the pregnancy. The most common reasons for admission are life-threatening respiratory problems and conditions affecting the central nervous system, which are particularly important in relation to a baby's chances of surviving without permanent disability. The lungs of extremely premature babies (those born after twenty-three to twenty-five weeks' gestation) are not sufficiently well developed to support respiration. As pregnancy progresses, the amount of lung tissue increases. Impaired lung function in less extremely premature babies is attributable primarily to IRDS: the lack of pulmonary surfactant (a complex of proteins and fats that keeps the lungs open when exhalation is complete). Full-term and near-full-term neonates can suffer serious respiratory problems caused by raised blood pressure in the vessels of the lungs (pulmonary hypertension) leading to oxygen deficiency. This condition is liable to follow meconium aspiration, serious infections and perinatal asphyxia (serious hypoxia during birth).

Babies born after less than thirty-four weeks' gestation can suffer from conditions of the central nervous system attributable to immaturity of the blood vessels supplying the brain. Vascular immaturity of this kind can often result in haemorrhages and hypoxic-ischaemic brain damage. Full-term and near-full-term neonates can also suffer similar problems, as a result of birth trauma or hypoxia before or during birth (Per99).

### 3.3.1 *Respiratory support*

Neonatal ventilation has been in use since the seventies, with increasing success. The administration of surfactant to mitigate IRDS has further reduced IRDS-related mortality and the incidence of chronic lung conditions (Dek98, Gor98, HPI96b, Sin98). Since 1991, surfactant therapy has been the standard treatment for IRDS in the Netherlands. Trials are presently underway to determine the efficacy of surfactant therapy for the treatment of serious lung conditions causing pulmonary hypertension in full-term neonates (Fet95, Fin96). The expectation is that use of this treatment will reduce the frequency of complications and the duration of IC.

Since the late eighties, high-frequency ventilation (HFV) has been used increasingly in the care of neonates requiring respiratory support. In those born after very short periods of gestation (less than twenty-nine weeks) the combination of HFV and surfactant therapy may be less harmful to the lung tissues and airways than conventional ventilation. There are indications, however, that the risk of brain damage increases. Furthermore, very little is known about the long-term implications for lung development or psychomotor development (Hen99). No research data is yet available concerning the use of HFV in the treatment of other conditions for which ventilation is indicated.

In the treatment of full-term and near-full-term neonates with serious forms of pulmonary hypertension, it has since 1993 been common practice in the Netherlands to add nitrogen monoxide to ventilator air supplies (Bea98). The presence of NO aids dilation of the blood vessels in the lungs, thereby improving oxygen uptake prior to the use of an 'artificial lung', or ECMO (see below). Data collected by the Netherlands' ECMO centres shows that NO inhalation therapy can actually obviate the need for ECMO treatment altogether. Although NO inhalation therapy appears not to be without risk, its benefits for full-term neonates with pulmonary hypertension easily outweigh the potential side effects (Bar99, Bea98, Dor97). It is as yet unclear, however, whether the therapy is on balance beneficial for premature neonates (Che98, Ros98). The Committee believes that more needs to be known about the safety, efficacy and optimum gas concentrations before NO inhalation therapy is introduced for the treatment of pre-term neonates in the Netherlands.

ECMO is an invasive technique used in the treatment of full-term and near-full-term neonates with serious pulmonary hypertension, who do not respond well to conventional treatments. The Health Council published a report on the use of this technique three years ago (GR97b). ECMO substantially increases the chances of survival for children suffering from conditions that would previously in all probability have been fatal. The number of infants referred for ECMO has consequently been

rising sharply. However, the recent advances made in other forms of treatment (surfactant therapy, HFV, NO inhalation therapy) have made ECMO unnecessary in many cases, so that overall demand for ECMO has levelled off. Short-term follow-up studies have revealed high morbidity rates following ECMO (Gev96, Har99, Hei99), and the Committee regards the systematic longer-term follow-up of ECMO patients as essential for critical evaluation of the technique.

The availability of the new techniques described above means that the scope for effective neonatal treatment is increasing, thereby pushing up the demand for IC cots. The number of neonates on ventilation has recently almost doubled in the space of five years: from 1723 in 1993 to 3067 in 1998. Furthermore, with the improving chances of survival for such infants, the total number of ventilator days rose even more sharply in the same period, thereby increasing the amount of time spent in IC (LNR93, LNR98).

### *3.3.2 The diagnosis and treatment of brain damage*

In recent years, a variety of diagnostic techniques have been developed, including magnetic resonance spectroscopy (MRS), near infrared spectrophotometry (NIRS), positron emission tomography (PET) and single photon emission computed tomography (SPECT). These techniques provide more information about the occurrence of neurological damage, but are not suitable for routine clinical diagnostic use. By contrast, "bedside neurophysiological testing" is expected to enter widespread use in the years ahead. Other diagnostic techniques, such as computerized tomography (CT scanning), magnetic resonance imaging (MRI) and electroencephalography (EEG) are used only to determine the seriousness and extent of suspected brain damage. Data collected using such techniques is used to aid decision-making concerning the continuation or withdrawal of treatment (Vri96) and to ascertain whether early intervention is indicated in connection with anticipated developmental problems.

Routine ultrasound brain scans on premature infants have demonstrated the importance of careful blood pressure and blood gas regulation. Invasive blood pressure measurement, the administration of medication to aid circulation and the use of improved ventilation techniques have reduced the incidence of intracranial haemorrhage and ischaemic injury (Dam99). Stress avoidance can also prevent intracranial haemorrhage (see 3.3.3) and is important in relation to the prevention of subsequent developmental problems.

There remains little scope for the treatment of children with serious perinatal asphyxia, despite increased medical understanding of the pathophysiology of hypoxic-ischaemic injury (Luc97). The administration of allopurinol, which inhibits the release of free radicals, appears promising, however (Van97), and is presently the

subject of small-scale trials in the Netherlands. Selective cooling of the head or total body cooling may also prove beneficial, although neither technique has yet been used in the Netherlands (Gun97, Gun98a, Gun98b, Haa97, Tho95, Tho97, Tre97). If it is found that these techniques have a protective effect, they will inevitably be introduced to the Netherlands. For the time being, however, developments in the treatment of hypoxic-ischaemic injury are not expected to influence the demand for IC.

As the medical profession's ability to prevent brain damage increases, it is less often necessary to withdraw treatment on the grounds of poor prognosis. In addition, a child that survives typically spends much longer in IC than one that does not (LNR98), so the demand for IC consequently rises. What is more, these developments have increased the technical complexity and intensity of IC treatment.

### *3.3.3 The prevention of stress*

For the neonate, IC entails numerous stimuli, such as pain, light, noise and frequent physical contact during medical and nursing procedures. These stimuli disturb the physiological rhythm and form a source of stress, which manifests itself through changes in behaviour, in autonomous function (blood pressure, pulse and respiration) and in hormonal regulation (e.g. adrenaline and noradrenaline levels) (Ben78). It is believed that stress of this kind plays an important role in relation to the subsequent occurrence of developmental problems.

Exposure to excessive light and noise increases the risk of blindness and deafness, as well as affecting biorhythms. However, the guidelines on light and noise levels in neonatal IC units are largely ignored in the Netherlands.

Adequate pain relief for premature neonates receiving respiratory support reduces the risk of mortality and the development of serious problems affecting the central nervous system (Ana87, Ana98, Ana99, Bar96). The subject of pain relief for neonates has in recent years received more attention in the Netherlands: a method for determining whether a neonate is in pain is undergoing validation (Lin93) and national guidelines on the provision of pain-relieving treatment have been drawn up (Boe93, Wie98).

In the United States, a method has been developed whereby the behaviour of infants is systematically observed and used as the basis for regulating treatment and care with a view to minimizing stress (Als86a, Als86b, Als92, Als96, Bec91). Use of the NIDCAP method, as it is known, appears to reduce the time spent on ventilation, to decrease the incidence of ventilation-related complications or intracranial haemorrhage, to accelerate growth and to shorten hospitalization periods (Law97). Positive long-term effects on behaviour and development have also been observed (Als94, Bue95, You96).

The possible introduction of the method to Dutch IC units and the implications of doing so are currently being investigated.

The Committee expects developmental care to become established in the Netherlands and to reduce the average length of stay in IC. However, because such care is highly individualized and consequently very labour-intensive, its introduction has serious implications for the training of nursing staff.

### *3.3.4 Other neonatological developments*

Infections represent one of the main risks to IC patients, especially neonates with immature immune systems. There have been several occasions in recent years when an infection involving antibiotic-resistant bacteria has necessitated the temporary closure of an NICU. Because of the increasing prevalence of antibiotic-resistance and the great pressure that nurses are under, the risk of temporary NICU closure can be expected to rise. Preventive measures aimed at the avoidance of closure, such as the preparation of nutritional and medicinal infusions in the hospital pharmacy, are therefore very important for optimal utilization of the available IC capacity.

The last three months of gestation and the first year of life are important periods in relation to the growth and development of the central nervous system. The early provision of parenteral nutrition and a balanced nutrient supply are critical if ill and immature neonates are to progress normally in these periods. Research is in progress to determine the effects of variations in the composition of nutritional infusions and the apparently essential supplements to mother's milk or formula milk. However, it will be some time before definite conclusions may be drawn. Nevertheless, it seems likely that the perinatal nutrient supply is also significant in relation to the risk of developing certain conditions in adulthood, including hypercholesterolaemia, hypertension, cardiovascular disease, diabetes mellitus and cancer (Bar92, Luc94, Pan95).

Various other metabolic factors are important for the proper growth and development of premature infants. Temporarily decreased thyroid function and slightly raised bilirubin levels were for many years regarded as normal adaptation phenomena in premature neonates. Recently, however, a correlation between these phenomena and subsequent developmental problems has been observed (Bor92, Oud96, Was97) and research is now underway to establish whether and to what extent such problems can be prevented (Dam99, Lev99, Yeo98).

Rapid development is taking place in the field of medication for IC patients. However, medicinal products are normally registered on the basis of data on their efficacy and side effects for adults. Fundamental differences between adult and neonatal metabolic processes mean that the results of trials with adults often say very

little about a drug's efficacy or side effects for infants, or about appropriate neonatal dosages. This implies that new medicines should be introduced to neonatal IC with great caution and that their short and long-term effects need to be carefully evaluated (Con00).

The prevention of visual and aural impairment is presently a very topical subject. At all centres, premature infants are examined for retinal damage by ophthalmologists at particular junctures with a view to preventing the blindness that can result from such damage. A specially adapted programme for the early detection of deafness in NICUs has proved capable of identifying 25 to 35 per cent of infants with impaired hearing in the neonatal period (Str99), so that treatment and support can be provided from an early age. Subsidized by the Dutch Organisation for Care Research, this screening programme (ALGO) is now operating in most of the country's NICUs.

Considerable uncertainty still exists regarding many of the matters described above. The Committee believes that forms of intervention – however promising – whose effects have yet to be precisely determined should be used only under carefully regulated conditions, preferably in randomized trials. In this context, it should be recognized that the ultimate effect of an intervention is often not apparent until some time after the relatively brief period of IC treatment. Since reliable conclusions regarding the efficacy of an intervention depend upon having data from numerous cases, a national perinatal network is desirable. The possibility should be investigated of making arrangements whereby follow-up may be continued, even when a patient is transferred to another hospital or discharged.

## 3.4 The organisation of practices

Social changes, such as the gradual standardization of working hours, are making round-the-clock care in small specialist practices an increasingly unattractive career option. Admissions for obstetric and neonatal care cannot be planned. Furthermore, the need is always acute, so the organisation of waiting lists is not possible, even though the heightened demand for care is creating considerable pressure within the system. A shortage of paediatricians is, moreover, making it difficult to staff two and three-person practices in many cases. This shortage also has implications for obstetric care in smaller hospitals, since obstetric procedures undertaken in a hospital always require the presence of a paediatrician.

In view of these social developments and in order to promote quality, the NVK and NVOG favour a policy of practice concentration. The consequent mergers have seen the number of paediatric practices fall from 114 in 1992 to 102 in 1999. Practices with less than three paediatricians are now an exception. The Committee believes that as

practice sizes increase, many neonates requiring HC can and should be admitted to hospitals which do not have perinatal centres. Since it will become easier to transfer infants to a general hospital following an initial period of IC treatment, the throughput of IC patients will be improved, thereby reducing the pressure on IC units.

## 3.5 Summary

The Committee expects the percentage of neonates requiring IC to continue rising as the average age of mothers increases and the Netherlands' demographic profile changes. No significant reduction in the frequency of spontaneous or induced premature births, which would ease the demand for IC, is anticipated in the near future. On the contrary, developments in obstetrics and neonatology may be expected to result in more neonates being considered treatable and therefore referred for IC. However, the numbers of infants concerned are likely to be small. The Committee also considers it desirable that the guidelines on IC referral should be revised so that all neonates born after less than thirty-two weeks' gestation are automatically referred. Since, as explained in subsection 2.1, most of these infants already receive IC, such a revision would not lead to a significant increase in demand for IC places, but would mean that prenatal transfers were more common. If the fall in the annual birth rate seen in 1999 (CBS00) should continue, the number of neonates requiring IC will be much the same in 2005 as it was in 1998. In addition, the Committee believes that the increase in the average time that neonates spend in IC brought about by improved survival rates will not be sustained, since the mortality rate is already very low. Taking all these factors into account, the demand for neonatal IC is expected to remain steady over the next five years, although the demand for third-line obstetric care is likely to increase.

Nevertheless, upward movement in both the number of neonates requiring IC and the average length of stay in IC will result if there is any reduction in the minimum period of gestation considered necessary for the survival of a premature infant. On the other hand, a significant reduction in the demand for IC could be achieved by facilitating the throughput of IC patients to HC units.

Chapter 4

# The prognosis after IC

Now that the first patients to receive postnatal IC have reached adulthood, we have much more scope for monitoring its long-term effects. Serious disabilities can generally be detected within twelve to twenty-four months. However, because development is taking place throughout childhood, more minor problems may not come to light for several years. Since minor disabilities are common, follow-up research is required to determine the consequences of perinatal IC for subsequent health and development and to identify any link between problems in these areas and the treatment received. The findings of follow-up studies enable the profession to answer questions posed by parents concerned about their children's futures, facilitate the early detection of developmental problems and provide information about the longer-term social implications of providing IC for neonates.

## 4.1 Survival

As perinatal IC becomes more sophisticated, its recipients are more likely to survive. At the same time, the minimum period of gestation considered necessary for the survival of a premature infant is becoming shorter and shorter. Figures from Japan, the UK, Canada and the USA point to increasing survival rates among seriously premature babies. In these countries, between a quarter and a half of those born after twenty-four weeks' gestation survived, while less than 5 per cent of those born after twenty-one weeks could be kept alive (Coo96, Gib98, Ois97). It is not clear in some cases,

*Table 4* Live births, mortality and IC admissions of seriously premature neonates in the Netherlands in 1995 (Source: Ant00).

| gestational age | live births | deaths prior to NICU admission | deaths following NICU admission | discharged alive |
|---|---|---|---|---|
| 22-23 weeks | 124 | 122 (98%) | 1 (0.8%) | 1 (0.8%) |
| 24 weeks | 82 | 66 (80%) | 14 (17%) | 2 (2.4%) |
| 25 weeks | 90 | 37 (41%) | 25 (28%) | 28 (31%) |
| 26 weeks | 127 | 22 (17%) | 40 (31%) | 65 (51%) |

however, whether the data relates to all live births or merely to a select group considered to have a good chance of survival.

If one focuses exclusively on infants admitted to IC, the figures for the Netherlands are very similar to those reported from other countries. In 1998, three out of every four babies born after less than twenty-four weeks' gestation died in IC, as did almost half (thirty-nine) of the seventy-nine born after twenty-four or twenty-five weeks (LNR98). However, an as yet unpublished study into perinatal mortality undertaken in 1995 shows that most infants born after such short terms died without ever being admitted to NICUs (table 4).

Survival of premature babies born after terms of more than twenty-six weeks or with a birth weight of more than 1000 grams is more than 90 per cent in the Netherlands (LNR98). The chances of survival for babies admitted to IC for reasons other than prematurity depend on the nature of the condition. Roughly 10 per cent of full-term neonates admitted to IC do not live (LNR98).

## 4.2 Consequences in later life

Follow-up research among children who required neonatal IC is confined to common disabilities, which can vary in seriousness. The Word Health Organisation divides disabilities into three categories on the basis of seriousness (WHO80):

1 mild disability: an anatomical abnormality or functional anomaly which does not affect the sufferer's ability to lead a normal life
2 moderate disability: a disability which precludes the sufferer from participating in one or more normal human activities
3 serious disability: a disability which precludes the sufferer from taking a normal part in society.

A disability may be in any of a number of areas (developmental domains). It may be purely physical, involving, for example, retarded growth, ill-health, or visual or aural impairment, or involving impaired neuromotor development and consequent mobility problems, learning difficulties or socio-emotional immaturity. Many disabilities become more apparent with the passage of time (McC97); it is simply not possible to look at a two-year-old and see exactly what he or she will be like as an adult. Furthermore, many individuals are affected by several minor disabilities, whose significance is greater, because of their combined effect, than might initially have been supposed, given the seriousness of the separate problems.

Recent research into the quality of life experienced by people with chronic conditions has tended to attach more importance to patients' perceptions of their disabilities. Assessed on this basis, someone with a serious disability can sometimes have a higher quality of life than someone with a comparatively mild disability (Rot96). This may be because the expectations of people with mild disabilities, and the expectations that society has of them, are based upon the standards that apply for the population at large. Such individuals are constantly confronted by the fact that they cannot live as those around them live. This is one of the causes of the common behavioural problems observed in mildly disabled children (Sch96).

### *4.2.1 The consequences of prematurity*

Prematurity is associated with a higher incidence of disability (of all levels of seriousness) in later life than that seen in the population at large. Ten to 15 per cent of pre-school children and schoolchildren born between 1960 and 1985 with a birth weight of less than 1500 grams had a serious disability, such as spasticity or mental retardation. Moderate disabilities were found in a quarter of these children (Ayl89, Esc91). It was initially thought that the disabilities (many of which were not particularly serious) would diminish or disappear with increasing maturity, but this has not proved to be the case. Young adults born in the mid-seventies with birth weights of less than 1500 grams are on average smaller than their contemporaries and are more likely to be spastic, to suffer from impaired vision or hearing, to have a low IQ and to attain fewer academic qualifications (Bje95, Eri98, Ste99). More than half of the children born in the eighties with a similarly low birth weight were found to have learning difficulties and behavioural problems that proved seriously problematic at school (Baa94, Sai94).

In the 'POPS study records have been kept, tracking the development up to the age of fourteen of nearly all the children born in 1983 after less than thirty-two weeks' gestation or with a birth weight of less than 1500 grams. A total of 1338 children were monitored. As two-year-olds, fifty-six of the children (6 per cent) were affected by a serious disability (Zeb89). Barely any subsequent change in this figure was recorded

(Oud98, Vee91). The number of children known to have mild or moderate disabilities increased as the children got older, and expectations regarding their abilities increased. By the age of ten, nearly half of the children surveyed were found to have moderate or serious disabilities. This is six times the level of disability seen in other children of that age (Oud98). As fourteen-year-olds, 28 per cent of the children attended special schools, compared with 4.7 per cent of the wider population. Among those who attended ordinary senior schools, disabilities were four times as common as among their full-term contemporaries (Oud99).

The problems experienced by the children at school were attributable not only to lower IQs and learning difficulties, but also to a comparatively high incidence of behavioural problems and concentration disorders, such as ADHD (Bot97, Bot98, Pha94).

On the basis of the POPS data, it may be expected that roughly 40 per cent of the 966 subjects who have survived into adolescence will have difficulty playing an independent part in society as adults. It is reasonable to suppose, however, that the prognosis for similar infants born now is better, since major medical, technical and nursing advances have been made in the interim. On the other hand, those same advances mean that more and more neonates who would previously have been expected to die are surviving neonatal IC. These children are at least as likely as the POPS subjects to exhibit developmental problems later in life (McC97). Research carried out in the Netherlands and other countries has found that children born prematurely in the early nineties still had developmental problems as pre-school children (Jon96, Wol98b). An ongoing study of 250 children born prematurely in 1992 and 1993 and treated in four Dutch NICUs has revealed that 40 per cent of the subjects had developmental problems as five-year-olds. In half of these cases, the problems had not been apparent when the children were younger. The POPS study found that the presence of such disabilities was a good predictor of educational problems later on.

### *4.2.2 Children born at the limit of viability*

The improved survival rate among seriously premature babies since the early nineties (see subsection 4.2.1) is associated with a rise in the incidence of serious disability (Ems98, Ois97, Sau98, Tys95). Researchers in other countries have reported that 20 to 35 per cent of children born after less than twenty-five weeks' gestation or with a birth weight of less than 800 grams suffer serious permanent disability. The lower the birth weight, the greater the likelihood of disability (Bah98, Coo96, Lor98, Ois97, San95, Sau98). The risk of mental retardation, blindness and multiple disability is particularly high compared with slightly less premature children. A comparative study looking at children born after less than twenty-seven weeks' gestation in the United States and the

Netherlands during the first half of the eighties revealed that the much more intensive treatment provided in the US was associated with a better survival rate, but also with four times the incidence of spasticity (Lor99). Little information is available concerning less serious disabilities among children born after very short terms. This is partly because children treated in modern neonatal IC environments are still too young for a clear picture of school age development to have emerged, and partly because systematic follow-up has been lacking in many cases.

The absence of arrangements for systematic follow-up means that no national data is available in the Netherlands regarding the subsequent development of such children. Data from four separate Dutch NICUs shows that four in every ten children born after terms of twenty-four or twenty-five weeks are known to have serious disabilities by the age of two (Hog99, Vri99b). The Committee therefore believes that relaxation of the Netherlands' current conservative policy on the referral to IC of seriously premature neonates (see section 5) is not desirable.

### *4.2.3 Children with specific problems*

With children whose birth weight was abnormally low for their gestational age, the main risk is retarded mental development (Str00, Wol98b). Children who emerge from the neonatal period with permanent lung damage (bronchopulmonary dysplasia, BPD) are often readmitted to hospital subsequently with respiratory problems or inguinal hernias (Gre96). In addition, as toddlers, 21 per cent of these children suffer from developmental anomalies, particularly affecting the motor system (Gre98, Sin97, You99).

Where neonatal examination reveals brain abnormalities, 60 to 90 per cent of children subsequently prove to be spastic (Vri96). Some 30 to 70 per cent of full-term children who experience serious perinatal oxygen problems suffer mental retardation or spasticity, the severity of which depends on the seriousness of the perinatal problems (Pai95, Vol95).

Children with congenital anomalies are primarily likely to suffer physical problems as a result. However, congenital anomalies of the central nervous system or heart defects are frequently accompanied by impaired mental development.

## 4.3 Recommendations regarding follow-up research

Developmental problems and disabilities among children who required neonatal IC are sufficiently common to justify long-term follow-up research. Such research can facilitate the evaluation and improvement of obstetric and neonatal care. It also has the potential to aid the early detection of disabilities, so that treatment or additional support

can be provided in good time, thereby preventing subsequent problems. Research has shown that drop-out from follow-up programmes is selective: those who drop out are more likely to come from a deprived background or to have developmental problems (Oud00). To prevent this, liaison is required with the paediatric health care discipline regarding appropriate forms of after-care. Closer studies of the effects of early childhood stimulation programmes and of interventions made following the detection of developmental problems are necessary in order to minimize the subsequent problems inevitably associated with neonatal IC.

Many perinatal treatments were in the past introduced without evaluation of their long-term implications. Even recently, promising techniques such as ECMO, NO inhalation for premature neonates, the treatments for immature babies and IVF have entered use before extended studies had been conducted. Under such circumstances, proper evaluation is often not possible. The Committee regards evaluation of a new perinatal treatment's short and long-term effects as a precondition for its responsible adoption. Such evaluation requires prolonged studies involving numerous subjects. This in turn implies collaboration, which would have to meet certain conditions (Fie99).

The Netherlands lacks neither the infrastructure nor the professionals willing to undertake collaborative studies. Nevertheless, multicentre trials are unusual because the financial resources needed for data recording, analysis and reporting are not available. Nor are there any arrangements for systematic follow-up studies that conform to national and international standards. A national multidisciplinary working group containing representatives from all the country's NICUs has drawn up a protocol for standardized follow-up research, which has since been accepted by all the interested parties (LNF97). However, the protocol has not been adopted at any of the perinatal centres, because financial resources are not available to cover the cost of implementation: the equivalent of one day's IC per neonate. The Committee regards participation in a perinatal research network and the performance of standardized follow-up research as integral elements of perinatal IC.

Chapter **5**

# Decision-making in cases of doubt and the implications for perinatal IC

Medical and technological advances are continually increasing the scope for supporting the vital functions of seriously ill and premature neonates. As a result, IC is an option in many cases that would previously have been regarded as hopeless. While the chances of surviving in good health have improved, there is also every possibility that a neonate's life will merely be briefly extended, or that the baby will survive with serious permanent disabilities. Sometimes, those responsible must decide whether to treat a neonate, or to continue treating a neonate who is not responding or whose condition is deteriorating, without any clear idea of what the outcome of that decision is likely to be. The legal and moral parameters within which parents, referring practitioners and carers must make their decisions and the applicable conscientiousness criteria are considered closely elsewhere (Cal97, DCE95, Lee94, NVK92). On the following pages, this report seeks to outline the way in which decisions are made in practice and the implications that this has for the demand for neonatal IC. Consideration is also given to the uncertainty associated with new treatments and procedures and to variations in the value judgements involved in the decision-making process.

## 5.1 Developments, uncertainty and value judgements

A decision to withhold or withdraw treatment is influenced not only by expectations regarding the outcome of treatment, but also by value judgements regarding the various possibilities. In the perinatal period, diagnoses and prognoses are often difficult to make. While uncertainty exists, parents may be asked to consent to active treatment until

diagnostic information becomes available or until it becomes clearer what course the baby's condition is taking. Under such circumstances, treatment may be regarded as speculative. Developments in the field of the neonatal neurological diagnostics mean that the diagnosis of brain damage is increasingly possible. However, even when a diagnosis can be made, the prognosis for the individual neonate often remains uncertain. Although the findings of follow-up research (see section 4) enable doctors to predict the risk of disability in many cases, no-one can say whether a given child will be left disabled. Furthermore, little is known about the risk and seriousness of disability associated with newer treatments, such as ECMO, since they have not been in use for long enough to observe how patients fare in the long term.

People respond in different ways to medical uncertainty. Some are inclined to be cautious, whereas others prefer to take a chance. In this context, value judgements about life and about the significance of any anticipated disabilities play a crucial role. While the parents of one child may regard the death of their baby as the worst thing that could possibly happen, for the parents of another the prospect of the child growing up with a serious mental or physical disability is more distressing. Under such circumstances, the fear is that prolonging the child's life will only add to its suffering and that ultimately the child's life will become unbearable. Variations in such value judgements can lead to different decisions being made in medically identical situations (Hil95).

## 5.2 Decision-making in practice

A recent Dutch study found that in more than half the cases of neonatal mortality, death followed a decision to withhold or withdraw treatment (Hei97). In most cases, the decision was motivated primarily by the limited chances of survival. One decision in six, however, was based mainly upon the poor prognosis regarding the child's subsequent health. Where death occurred in a neonatal IC unit, one in three decisions was made mainly because the risk of serious disability was considered too great (Kle93). In all cases, the parents and carers were in agreement that treatment should be withheld or withdrawn.

Research conducted in Utrecht revealed that, in nearly all cases between 1990 and 1995 where neonatal treatment was withdrawn on the grounds of a poor prognosis, the diagnosis was subsequently confirmed by pathological-anatomical examination. Often, post-mortem examinations revealed that the child was suffering from more serious abnormalities than had been supposed prior to death (Bro95). In six cases, treatment was continued at the parents' request, against the advice of the medical team; all the children concerned were subsequently found to have serious multiple disabilities. For fourteen children, the prognosis was so uncertain that repeated discussions were

required before all parties decided that treatment should be continued. Of these fourteen, twelve subsequently proved to be seriously disabled (Bro95).

Perinatal care often involves the treatment of infants born at the limit of viability. Furthermore, many new forms of treatment are available, whose benefits remain unproven. The rapid developments taking place in the field are constantly creating new grey areas, within which decision-making regarding the provision of active treatment is not consistent. In consequence, the circumstances under which IC is indicated are always changing. At present, the treatment of neonates born after twenty-three, twenty-four or twenty-five weeks' gestation forms one such grey area. As indicated in section 4, the survival chances of a baby with a gestational age of twenty-two weeks or less are virtually non-existent. After twenty-six weeks, the odds against surviving in good health have fallen to the point where it is standard practice to treat the infant, and the parents are assumed to consent unless they indicate otherwise. Between twenty-two and twenty-six weeks, the chance of survival increases with the term of the pregnancy, but the risk of survivors suffering serious disability is high.

The NVOG and NVK have drawn up national guidelines on the referral of expectant mothers when premature birth is imminent (NVO99). According to the guidelines, those who are twenty-four weeks pregnant should be referred to a perinatal centre, so that an optimal assessment of the situation can be made and the best course of action decided upon. Furthermore, in response to the NVK's report *Doen of laten* (*To act or not to act*; NVK92), all the centres have formulated protocols setting out conscientiousness criteria to support decision-making in connection with the treatment or non-treatment of neonates. Some of these protocols provide explicit guidance on the treatment of neonates with a gestational age of less than twenty-six weeks. The centres differ somewhat regarding the desirability of providing active obstetric or neonatal treatment for infants born after twenty-four or twenty-five weeks, but active intervention with those born after twenty-three weeks is not normal at any of the centres.

In neighbouring countries, views differ on the wisdom of treating neonates born after very short pregnancy terms, as a European *concerted action* revealed. In contrast to the policy in the Netherlands, infants born after twenty-four weeks are treated as a matter of course in most countries (Lee96, McH99). In several countries, such as France, the UK and Sweden, this is justified on the basis that treatment can be withdrawn if serious complications occur. Elsewhere, however, including Germany and Italy, treatment is continued even if complications occur which entail a significant risk of serious disability, irrespective of the views of the parents. Denmark's Ethics Council (the DCE) takes a rather different view, recommending a conservative approach to the admission of very short-term neonates. The DCE emphasizes the importance of

providing parents with as much information as possible and involving them in the decision-making as far as possible. It is even suggested that differences of opinion within the medical team should be communicated to the parents (DCE95). In the United States, legal liability plays a more important role in doctors' decision-making, but many professionals believe that the parents' views have to be taken into account (San95).

Uncertainty also exists regarding the likely outcome of using experimental techniques to treat neonates with serious congenital anomalies or serious disorders of the vital functions. Again, a decision to withhold or withdraw intensive treatment depends on the nature of the abnormality, the condition of the baby, the medical team's expectations regarding the ultimate outcome and the value judgements of the decision-makers. The continuation of treatment under such circumstances always depends on the avoidance of complications. Referrals to perinatal centres or centres specializing in neonatal surgery or ECMO are consistently motivated by the wish to minimize the medical uncertainty and to arrive at appropriate decisions regarding the provision of treatment.

## 5.3 Influence on the demand for perinatal IC

Uncertainty regarding the outcome of treatment will always play a role in the care provided for seriously ill neonates. The information given to parents should be based on what is known at the time concerning the implications of a condition and of the proposed treatment. Moreover, the uncertain nature of the outcome of new treatment options should be made clear to parents. Research into the grieving processes of parents whose babies died despite more-or-less active treatment has shown that involvement in the opinion-forming and decision-making processes and proper counselling are very important. It is easier for parents to cope with the loss of a child, or to come to terms with a child's disability, if they believe that the decision to continue or withdraw treatment was properly thought through and made with consideration for their views (DCE95, Sch97, Ver98). Since parents' ability to make considered decisions can be affected considerably by their emotional state following the birth of a seriously ill baby, information should where possible be provided before the situation becomes acute. Hence, if a significant risk of extremely premature birth exists or if a serious congenital anomaly is detected, the parents should be given the opportunity to talk to a neonatologist before the birth. The need to provide appropriate information and counselling during the decision-making process implies that the experience, expertise and communicative skills of the medical team must be of a very high order. This is one of the reasons why the Committee believes that the policy of concentrating perinatal IC in specialist centres should be retained and that, where indicated, (expectant) parents should be referred to perinatal centres in good time whenever possible.

Decisions regarding the active treatment of neonates have implications for the demand for perinatal IC, even though the number of infants concerned is relatively small. If the minimum period of gestation considered necessary for survival is reduced or if the treatment of neonates with very serious lung problems becomes more viable, the demand for IC cots will rise, since very short-term babies and those with serious respiratory problems generally have to remain in IC for considerable periods. Such changes would also have consequences for the intensity of care during the IC period and for the level of demand for after care.

The Committee believes that all centres should have clear guidelines on the circumstances under which active treatment is and is not to be provided. Parents and referring specialists need to know what medical uncertainties and value judgements need to be explained to parents, and what role parents play in the decision-making process. In order to make appropriate decisions before birth regarding referral or active obstetric treatment, it is necessary to have consensus and clarity regarding the policy to be pursued after birth. If the minor treatment-policy differences that presently exist between perinatal centres were to increase, or if one centre were to give greater decision-making responsibility to parents than another, this would inevitably generate demand from both referring practitioners and parents for greater freedom to choose which centre to use. Since in practice there can only be choice where capacity is available at more than one site, this would have direct implications for the number of IC cots required.

The fact that children with disabilities are likely to also have learning difficulties and behavioural problems is almost never taken into consideration when decisions are made regarding the provision of active treatment. Yet this fact has far-reaching consequences for a child's ongoing and sometimes lifelong care requirements after IC. There are also important social ramifications, as indicated in section 4.

The Committee would wish to see everything possible done to minimize uncertainty regarding the likely outcome of treatment. To this end, follow-up research should be organised to determine the short and long-term consequences of introducing new techniques and providing treatment for babies born at the limit of viability. Such research is needed to provide information to support decision-making regarding the provision of intensive treatment. Furthermore, without such research, it is not possible to determine what the consequences of constantly pushing back the boundaries of viable life will be for the level of demand for perinatal IC.

Chapter **6**

# Estimated levels of demand for IC and HC

The demand for IC cots is determined by the number of neonates requiring IC and the average length of stay in IC. The average length of stay in IC is itself dependent on the care provided before birth and that available to the baby on release from IC. Improved obstetric care has increased the survival chances of ill neonates considerably (see 3.2.5). Nevertheless, as the threshold for active treatment moves lower, so the average length of stay in IC increases. The demand for appropriate third-line obstetric care is determined by the number of pregnant women whose babies are expected to require IC, by the scope for referral to a perinatal centre before birth and by the length of stay in third-line obstetrics. The timing of a neonate's transfer from an IC unit to an HC unit is influenced by the standard of the facilities in the HC unit. If the standard of the facilities in the receiving general hospital is high, transfers can be made sooner and the average length of stay in IC can be reduced. However, the average length of stay in HC increases as stays in IC decrease. Thus, the demand for neonatal HC depends in part on the survival rate among neonatal IC patients (the higher the survival rate, the greater the number of babies subsequently transferred to HC), and in part on the facilities available in HC units.

## 6.1 Demand for neonatal IC

If the predicted demographic and social changes outlined in subsection 3.1 do indeed take place, the number of neonates requiring IC will not come down, despite the falling annual birth rate, because the percentage of neonates in need of IC will continue to rise.

Nor will developments in obstetrics (see subsection 3.2) lead to any substantial change in the level of demand. No significant decline in the incidence of either spontaneous or induced premature birth is expected in the near future. Technical advances in obstetrics and neonatology (see subsections 3.2 and 3.3) are making it possible to treat many infants who would once have been regarded as hopeless cases. In other words, the range of conditions for which neonatal IC is indicated is widening. However, provided that the conservative policy on the referral to IC of seriously premature neonates is maintained (see section 5), only a small additional number of infants will require IC. If the treatment-policy differences between perinatal centres widen and this trend is considered desirable, it will be necessary to apply an average capacity utilization ceiling of 80 per cent, since 100 per cent occupancy would mean that mothers were regularly denied access to the centre whose policy most closely coincided with the parents' views.

The Committee expects that between 1999 and 2005 the percentage of neonates requiring IC will rise from 2.3 to 2.4 per cent. If the recent downward trend in the birth rate (see subsection 3.1) continues over the next few years, the annual number of neonates in need of IC in 2005 will be around 4560 (2.4 per cent of 190 000). This is roughly the same as the number recorded as receiving IC in 1998 (4443).

Because neonates who survive spend an average of ten days longer in IC than those who die in care (LNR98), the improved survival rate has extended the average length of stay. The increase over the last five years in the number of surviving neonates with gestational ages of less than thirty-two weeks has resulted in nearly twenty-seven additional IC cots being required (see subsection 2.2). Survival rates among infants with serious respiratory problems are also rising, but the Committee sees relatively little scope for continuation of this trend, since mortality in the group is now very low. If the average length of stay in IC stabilizes at roughly twenty days,
(4560 x 20 = 91 200 / 365 =) 249 IC cots will be required. However, in the interests of quality (see subsection 7.2), the Committee would like to see average capacity utilization limited to 80 per cent. On this basis, (1.25 x 249 =) 311 IC cots would be needed.

The admission of infants with ever more complex conditions has meanwhile increased the intensity of IC (see also section 3). Furthermore, additional nursing input and greater nursing expertise is required if the developmental care referred to in subsection 3.3.3 is to be introduced. The provision of such care would necessitate higher staffing levels and the use of better-qualified staff in neonatal IC units (see section 7).

## 6.2 Demand for third-line obstetric care

A clear correlation exists between the number of neonates requiring IC and the number of deliveries in the perinatal centres (see subsection 2.3). The Committee does not foresee any reduction in the frequency with which expectant mothers have to be referred when premature birth is imminent. Indeed, it is likely that in the next few years there will be a slight increase in the number of referrals involving women between twenty-two and twenty-six weeks pregnant. If, as seems probable, the number of third-line obstetric admissions remains roughly 160 per cent of the number of neonatal NICU admissions (see subsection 2.3 and Annex C), some 7296 expectant women per year will need to be admitted. Supposing an average of ten days' stay (including postnatal confinement) and a capacity utilization rate of 100 per cent, the number of third-line obstetric beds required will be (7296 x 10 / 365) = 200. The Committee regards an average capacity utilization rate of 80 per cent as desirable in obstetrics as well, in order to avoid women being refused admission in busy periods. On this basis, 250 third-line obstetric beds would be needed for women whose babies are expected to require neonatal IC.

## 6.3 Demand for neonatal HC

In the context of the first Planning Decree, it was estimated that between 0.44 and 0.74 per cent of all neonates would require primary HC. Primary HC is indicated for infants with less serious or temporary disorders of the vital functions, whose condition does not require IC. No records are kept of neonatal HC provision. The Committee nevertheless assumes that there has not been any major change in the level of demand for primary HC. Hence, in 1998, the number of neonates requiring primary HC would have been between 0.44 and 0.74 per cent of nearly 200 000, i.e. between 880 and 1480. Assuming that the average length of stay in HC remained steady at thirteen days, a total of between thirty-one and fifty primary HC cots (880 to 1406 x 13 = 11 440 to 18 278 care days / 365) would have been needed.

In addition to these primary HC cots, capacity is required to accommodate infants leaving neonatal IC. If 85 per cent of neonatal IC patients survive, 3876 post-IC neonates will require HC in 2005. The average post-IC length of stay in HC is presently also thirteen days, so (3876 x 13 = 50 388 / 365 =) 138 HC cots are required for these infants.

Hence, the total number of HC cots needed would be between 169 and 188, given 100 per cent capacity utilization, or between 211 and 235 if the average occupation level is 80 per cent. Most of these cots could be in general hospitals, thereby allowing more

neonates to be cared for close to home. If the scope for HC admission were increased, the average length of stay in the NICUs could probably be reduced. In the context of increasing regionalization in health care, it is desirable that neonates referred from a small general hospital with limited facilities to an NICU are ultimately discharged via the HC unit of a large general hospital in the same region, which meets the prescribed quality requirements. In order to shorten the average length of stay in an NICU by one day, an additional (3876 x 1 = 3876 / 365 / 0.80 =) 14 HC cots would be needed, but this would of course be offset by a corresponding reduction in the number of IC cots required.

## 6.4 Summary

Assuming that no unexpected changes occur in the demand for perinatal care, by 2005 the overall requirement will be 250 third-line obstetric beds, 311 neonatal IC cots and 211 to 235 neonatal HC cots (given an average capacity utilization rate of 80 per cent). It is important to ensure that adequate HC capacity is available, both at the centres and elsewhere. This could be done by, for example, making special funding arrangements. If HC capacity were increased further, this could be expected to reduce the number of neonatal IC cots needed. To reduce the average length of stay in IC by one day, an additional fourteen HC cots would be needed; a similar reduction could then be made in the number of IC cots.

Chapter **7**

# Quality requirements

## 7.1 Infrastructure

A perinatal centre should form part of a hospital with obstetric, gynaecological and paediatric training facilities. Such an arrangement ensures the permanent availability of experienced doctors and the opportunity to consult subspecialists from particular obstetric and paediatric fields. An integrated set-up of the kind described also facilitates liaison between paediatric intensive care specialists, paediatric cardiologists and paediatric (heart) surgeons concerning the policy to be followed in the care of neonates with particular conditions. The centre should also have a neonatal HC unit so that, at times of peak demand, personnel can be exchanged between IC and HC, thereby enabling the provision of IC in HC cots.

The perinatal centre should function as a regional specialist reference unit, with responsibility for patient care in its region and for the extra-regional referral and (where necessary) transportation of patients where there is insufficient intra-regional capacity or where special treatment is required. Agreements should be made with referring practitioners throughout the region concerning the circumstances under which IC is indicated, the timing of release from IC and the care to be provided thereafter. Since not all hospitals presently have neonatal HC facilities, each regional centre should make arrangements with two or three large paediatric units capable of providing HC for neonates. To assure both medical and nursing standards, such HC units would need to meet certain quality requirements. The arrangements made should cover not only the

diagnosis and treatment of neonates, but also the initial and in-service training of doctors and nurses and the organisation of research.

In order to ensure the general availability of neonatal IC, a balanced distribution of facilities across the country is necessary. With the eight university hospitals and two regional hospitals presently licensed to provide neonatal IC, the Committee believes that this requirement is already met. High-quality perinatal care depends on national co-ordination. To this end, participation in a new network, which would oversee research and standardized follow-up activities, should be made a criterion for recognition as a perinatal centre. A requirement of this kind is the only way to ensure that the efficacy of new treatments is properly tested, as referred to in section 3.

## 7.2 The size of perinatal centres

To be viable, a perinatal centre must be large enough to make practicable the recruitment and retention of personnel with all the requisite medical and nursing skills. It should also have sufficient capacity to meet the regional demand for perinatal IC and to accommodate peaks in the referral pattern. To support a staff with expertise even in relation to less common IC indications (see subsection 3.3.4), a centre needs to have at least two hundred admissions a year (GR91). Given an average stay of twenty days and an average capacity utilization rate of 80 per cent, the minimum number of NICU cots per centre is therefore (200 x 20 = 4000 / 365 = 10.9 / 0.80 =) 13.6, which obviously has to be rounded up to fourteen. As indicated in the Health Council's 1991 report, fourteen is also the minimum number of cots required to ensure sufficient admission flexibility. Given an average occupation level of 80 per cent, two or three cots would normally be vacant in a fourteen-cot unit, so that the risk of a neonate being refused admission would be acceptably low. The Committee wishes to see a fourteen-bed minimum established mainly so that infants from multiple pregnancies do not have be treated in different centres and so that parents are genuinely able to choose between centres.

On a similar basis, a third-line obstetrics unit requires at least 1.6 x 200 admissions a year (see subsection 6.2). Given an average stay of ten days and a capacity utilization rate of 80 per cent, this equates to a minimum of eleven obstetric HC beds.

With the exception of the Leiden-The Hague NICU, which is divided between two sites, the university centres are all large enough to satisfy the requirements set out above. However, under the last Planning Decree, the non-university centres were limited to a maximum of eleven IC cots, which the Committee regards as insufficient for the maintenance of the requisite expertise. Furthermore, given the present levels of demand for IC, all the centres are too small to provide adequate flexibility.

## 7.3 Other requirements and conditions

In two earlier reports, the Health Council set out in detail the requirements that a perinatal centre should meet in relation to staffing and facilities (GR82, GR91). The Committee regards most of these requirements as equally valid today. It is not considered worthwhile re-specifying the technical requirements, since ongoing developments mean that specifications inevitably remain valid for a short time only. However, several important amendments need to be made to the staffing requirements. As indicated in section 3, changes in the patient population and increasing treatment possibilities have made neonatal IC more intensive. As a result, the Committee believes that doctors and nurses working in obstetrics and neonatology, in addition to specialist paediatric or obstetric training now require specialist perinatal training. One of the topics covered by such training should be how to deal with and counsel parents from different cultural backgrounds.

In addition, the constant advances being made in this field are such that qualified staff require regular in-service training. Medical specialists should receive at least ten days' in-service training per year and nursing staff at least four days. Social changes have led to the introduction of revised working hours and changes in the way night shifts are organised. Nursing staff now work thirty-six hours a week, as opposed to the forty hours they used to work. The normalization of junior doctors' working hours has had even more far-reaching consequences: their working week has been cut from an average of sixty to seventy hours, to forty-six hours. The hours worked by medical specialists are now undergoing comparable changes. These developments have implications for the staffing of perinatal centres. The Committee's updated staffing requirement calculations are presented in Annex D.

In conclusion, the Committee believes that neonatal IC capacity should be increased by providing more cots within the ten existing centres. This will ensure adequate distribution across the country while ensuring that the centres are each large enough to support a staff with the necessary expertise. Increasing the number of centres would reduce admission flexibility, so that both onward referrals due to lack of capacity and the separation of infants from multiple pregnancies would continue to be necessary. In order to ensure that the care provided is of an acceptable quality, each of the ten centres must meet a number of conditions, the most important of which are as follows:

- The centre must have a sufficient number of third-line obstetric places to enable treatment to commence in good time.

- The centre must have sufficient medical and nursing staff to provide developmental care, geared not only to maximizing the chances of survival but also to minimizing the risk of subsequent disability.
- There must be sufficient HC capacity, both within the centre and in other hospitals, to admit neonates as soon as their condition warrants discharge from IC. The HC facilities in question must satisfy certain requirements relating to the quality of the medical care available; it must be possible, for example, to give parenteral nutrition, to continue research that is in progress, and to provide individualized developmental care.
- The centre must be able to undertake studies designed to determine the efficacy of new treatments, by working with regional HC units.
- The centre must perform standardized follow-up research to evaluate the longer-term implications of IC and new forms of treatment, and must participate in a national follow-up data registration programme.

Chapter **8**

# Concluding remarks

The Committee has endeavoured to determine the extent to which the conditions set out in the 1993 Planning Decree are actually adhered to in practice, and has identified a number of relevant problems.

Under the 1993 Planning Decree, neonatal IC remained subject to ministerial licence, but HC was removed from the scope of the Hospital Provision Act (which was in force at the time). The policy of centralization has enabled perinatology to develop further, so that almost all serious neonatal conditions can be appropriately treated and the chances of survival have improved substantially. The Planning Decrees have brought about a situation whereby perinatology is more centralized in the Netherlands than in most other European countries. After Poland, the Netherlands has the most centralized system of perinatal care (Pap99). In line with the recommendations of an earlier Health Council report, the 1993 decree specified that the number of centres providing perinatal IC should remain limited to the ten originally nominated in 1987. The Committee's enquiries indicate that, in this respect, the decree has not been adhered to: Leiden-The Hague NICU operates on two sites, so there are in effect eleven centres. Furthermore, the provision of IC outside the licensed centres continues to be tolerated, with roughly 15 per cent of neonates who require IC being cared for in general hospitals (LNR98). The Committee is concerned that the units in which such care is provided are not large enough to have the experience necessary to provide these infants with the care they need. The Health Council's 1991 report indicated that the demand for neonatal IC would rise over the following five years to the point where at least 165 and possibly 202 cots were required. Subsequently, the 1993 Planning Decree made

provision for increasing the number of cots to 168 in a series of stages. However, the Committee has established that the total number of IC cots in licensed centres is still only 157 (see 2.4). One of the main reasons for the failure to further increase the number of cots has been the insistence that any additional facilities must be provided within the intensification allowance available under the Care Budget Principles (FOZ) and in accordance with the University Hospitals Investment Plan (IPAZ), under which neonatal IC is not regarded as a high priority. What is more, not all of the 157 licensed IC cots are actually available for use. Where a cot is taken out of use, one of the reasons is often lack of resources. In practice, insufficient funds are available to maintain the number of IC cots that the authorities have licensed for use.

The shortage of IC cots makes it impossible to reduce the average occupation level as recommended. In practice, most neonates requiring IC do receive treatment, but this is done by making use of HC capacity. The HC facilities used in this way do not have to meet any special quality requirements, despite a Health Council recommendation that they should. Consequently, the units in question lack the staffing levels necessary for IC of the appropriate quality. Moreover, the Committee has established that the number of HC cots available in recent years has itself been insufficient. This situation is attributable to the removal of neonatal HC from the scope of the Hospital Provision Act (since superseded by the Exceptional Medical Procedures Act). The shortage of HC cots is an obstacle to efficient patient throughput, and thus places even greater pressure on the already limited number of IC cots.

In practice, staffing is a problem for all IC units. As a result, both the continuity of care and the availability of sufficient expertise are under threat. Because of the heavy workloads, nursing staff tend to confine themselves to immediately essential tasks. There is currently no scope for developmental care, for individualized behaviour-sensitive care, for reducing stress, or for counselling parents. Furthermore, a working group of the Association of University Hospitals [VAZ] has concluded that high workloads are partly responsible for the shortage of specialised nurses, which is particularly acute in the country's western conurbation. Lack of staff leads in turn to the temporary closure of cots. The shortage can be made good only by increasing the training capacity of the centres. The VAZ also believes that there is a need for nursing research and for improved nursing career prospects (VAZ99). These issues need to be taken into account when allocating and appropriating budgetary resources.

The requirement that a doctor should be in attendance at all times is met at all centres by using the services of junior doctors who are not in training [AGNIOs] and generally have little experience. Moreover, in contrast with traditional practices, doctors nowadays work shifts, as a result of which responsibility is transferred from one individual to another more often than in the past, potentially threatening the continuity of

patient care. Yet obstetricians and neonatologists are still under enormous pressure of work, which many find harder to cope with as they get older.

Now that Rotterdam (1994) and Utrecht (1999) have each moved their obstetrics and neonatology units onto a single site, the requirement that neonatologists and obstetricians should work closely together is met by all the registered centres. However, the obstetrics units at the non-university centres lack sufficient capacity, thereby limiting the number of neonates that can be provided with IC in the regions concerned. Interregional transportation of expectant mothers and neonates is consequently more commonplace (Oei00).

All obstetrics units in the Netherlands submit data on pregnancies and deliveries to the LVR, as co-operation with the LVR is required by the NVOG in the context of its peer review system. By contrast, only half the general hospitals' paediatric units submit data on neonatal admissions to the LNR. All the NICUs do co-operate with the LNR, however, since they are required to do so by the minister. If the NVK's quality policy afforded the LNR similar status to that which the NVOG gives the LVR, it might be possible to move towards a situation whereby data was available on the IC needs of neonates admitted to general hospitals and PICUs or referred to centres abroad. This would remove one basis for the potential underestimation of demand.

Although the 1993 Planning Decree called for the formulation of a national protocol on the provision of IC for neonates, no such protocol has ever been produced. Furthermore, despite the theoretical existence of a national medical and nursing research association, there is in practice no co-operation in the scientific study and evaluation of care. As a result, new treatments are frequently introduced without any evidence of their efficacy or efficiency. The Committee regards this situation as undesirable. Nor is the long-term evaluation of care standardized. Each centre goes about the follow-up of neonates in its own way. It is not even known, for example, how often babies born at the limit of viability are actively treated in the Netherlands, or what the outcome is. While there is a basic protocol on follow-up research (LNF97) that meets international standards, it is rarely adhered to in practice. It appears that the financial resources available for IC are used exclusively in the direct provision of care, with little or nothing expended on flanking policy. This too is undesirable in the Committee's eyes.

The Hague, 27 April 2000,
on behalf of the Committee

(signed)

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| Dr AL den Ouden, | Dr GCML Christiaens, |
| Secretary | Chair |

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# Annexes

Annex **A**

# Request for advice

On 24 July 1998, the President of the Health Council received a letter (reference CSZ/ZT/9811456) from the Minister of Health, Welfare and Sport, requesting that the Council should prepare a report on neonatal intensive care. The text of the minister's letter is reproduced below.

In your letter of 25 May last, you asked me to update and specify the issues I would like addressed in the report on neonatal intensive care, which I originally requested on 13 July 1995 (reference ZZT/TOPAZ/953637). This request was made in anticipation of the implementation of the Exceptional Medical Procedures Act, which supersedes, amongst other things, section 18 of the Hospital Provision Act and the revised Planning Decree policy. In November 1997, you provided me with a report on the present situation with regard to the application of extracorporeal membrane oxygenation (ECMO), in connection with the possible concentration of this form of care. In addition, the National Health Insurance Fund Council has commissioned a policy evaluation study regarding the Neonatal Intensive Care Planning Decree and has recently furnished me with a report on this subject. The report focuses on policy issues connected with application of the Neonatal Intensive Care Planning Decree, such as the structure, cost and organisation of this form of care.

I would accordingly like you to address the following questions in your report.

1 Scientifically speaking, what is the present situation in the field of neonatal intensive care and what significant developments do you expect to see? Do you expect such developments to have further implications for the demand for neonatal intensive care?

2 Has the efficiency of the various forms of neonatal intensive care been the subject of research? If so, what implications do the findings have for neonatal care?

3 Do you consider it necessary to maintain the policy of concentration in neonatal intensive care, as provided for in the present Planning Decree? If so, what preconditions or quality requirements (as provided for in section 2 of the Exceptional Medical Procedures Act) should be attached to the provision of neonatal intensive care, with a view to assuring the quality and efficiency of care provision?

4 Are national guidelines on particular issues necessary in order to assure the quality and efficiency of care provision?

The Minister of Health, Welfare and Sport,

w.g.

Dr E Borst-Eilers

Annex **B**

# The Committee

- Dr GCML Christiaens, *chair*
  gynaecologist; Wilhelmina Children's Hospital, Utrecht University Medical Centre
- Dr AL van Baar
  psychologist; Sint Joseph Hospital Veldhoven; Emma Children's Hospital AMC, Amsterdam
- Dr S Bambang Oetomo
  professor of neonatology; Groningen University Hospital
- Dr M van de Bor
  professor of paediatrics; Nijmegen University Hospital
- Dr HAA Brouwers, *vice-chairman*
  paediatrician-neonatologist; Wilhelmina Children's Hospital, Utrecht University Medical Centre
- Dr F Brus
  paediatrician-neonatologist, Rijnstate Hospital, Arnhem
- Dr HA Büller
  professor of paediatrics; Sophia Children's Hospital, Rotterdam
- IJ Hankes Drielsma,
  lecturer in nursing; Free University Training Centre, Amstelveen
- Dr MT Hilhorst
  ethicist; Erasmus University Rotterdam
- IS Kishna, advisor
  Ministry of Health, Welfare and Sport

- Dr JH Kok
  paediatrician-neonatologist; Emma Children's Hospital AMC, Amsterdam
- RA van Lingen
  paediatrician-neonatologist, Isala Clinics, Sophia site, Zwolle
- Dr JMWM Merkus
  professor of obstetrics and gynaecology; Nijmegen University Hospital
- Dr JG Nijhuis
  professor of obstetrics; Maastricht University Hospital
- IA von Rosenstiel
  paediatrician; Emma Children's Hospital AMC, Amsterdam
- Dr AL den Ouden, *secretary*
  Health Council, The Hague; TNO Leiden

Secretarial assistance: MI Roskam

Annex **C**

# Referral patterns

Using data from its own survey, the Committee has calculated the ratio between the number of neonates requiring IC and the number of associated admissions to the third-line obstetrics units. A comprehensive overview of referral patterns before and after the birth of a baby requiring IC is presented in the diagram below.

*Table* Number of obstetric admissions in cases where IC was indicated for the baby and the number of infants admitted to NICUs in 1998 (Sources: Health Council survey1 and LNR982).

| | not admitted | admitted to obstetrics | admitted to NICU |
|---|---|---|---|
| expectant mother, IC indicated for baby[1] | 983 | | |
| referred back before birth[1] | | 544 (8.8) | |
| maternal indication, IC not required for baby[1] | | 1,642 (26.5) | |
| baby died before or immediately after birth[1] | | 649 (10.5) | |
| baby admitted to PICU[1] | | 75 (1.2) | |
| transferred abroad[1] | | 61 (1.0) | |
| transferred to another NICU[2] | | 198 (3.2) | 232 |
| baby admitted to own NICU[2] | | 1,747 (28.2) | 1,980 |
| following birth, baby to NICU, mother to third line[1] | | 1,280 (20.7) | 1,605 |
| total | | 6,196 | 3,817 |

Overview of perinatal obstetric transfers in the Netherlands

1 to 8: Normal pattern of movement between first, second and third lines, as provided for in the obstetric *vade mecum* in the obstetric indication list (ZFR99).

1 Expectant mother consults first-line carer for help.
2 Uncomplicated pregnancy: birth under first-line supervision.
3 Second line consulted during the pregnancy. Expectant mother either referred back to first line or supervised by second line.
4 During or following birth, transfer to second line for delivery is indicated.
5 Specialist (second-line) supervision of expectant mother is indicated.
6 During the pregnancy, consultation at or transfer of case to regional perinatal centre indicated.
7 Indication superseded (e.g. because, following temporary admission, pregnancy has progressed to point where NICU is no longer indicated); referred back to second line.
8 Birth takes place at regional perinatal centre and mother and baby are referred back to second line before being allowed home.

9 to 13: Pattern of movement during pregnancy between the second line/regional perinatal centre and an extra-regional perinatal centre, due to lack of space.

9 During the pregnancy, consultation at or transfer of case to a perinatal centre is indicated. There is no room at the mother's regional centre, making admission in another region necessary.
10 During stay in extra-regional centre, space becomes available at the mother's regional centre, to which she is moved.
11 If indication remains valid and birth again appears imminent, the mother's regional centre may again be full, making admission in another region necessary.
12 When birth is confirmed as imminent or decision is made to perform a caesarean section, space is available at the mother's regional centre, to which she is moved.
13 When birth is confirmed as imminent or decision is made to perform a caesarean section, the mother's regional centre is full, making admission in another region necessary.

14 to 18: Pattern of movement following birth between the second line/regional perinatal centre and an extra-regional perinatal centre, due to lack of space.

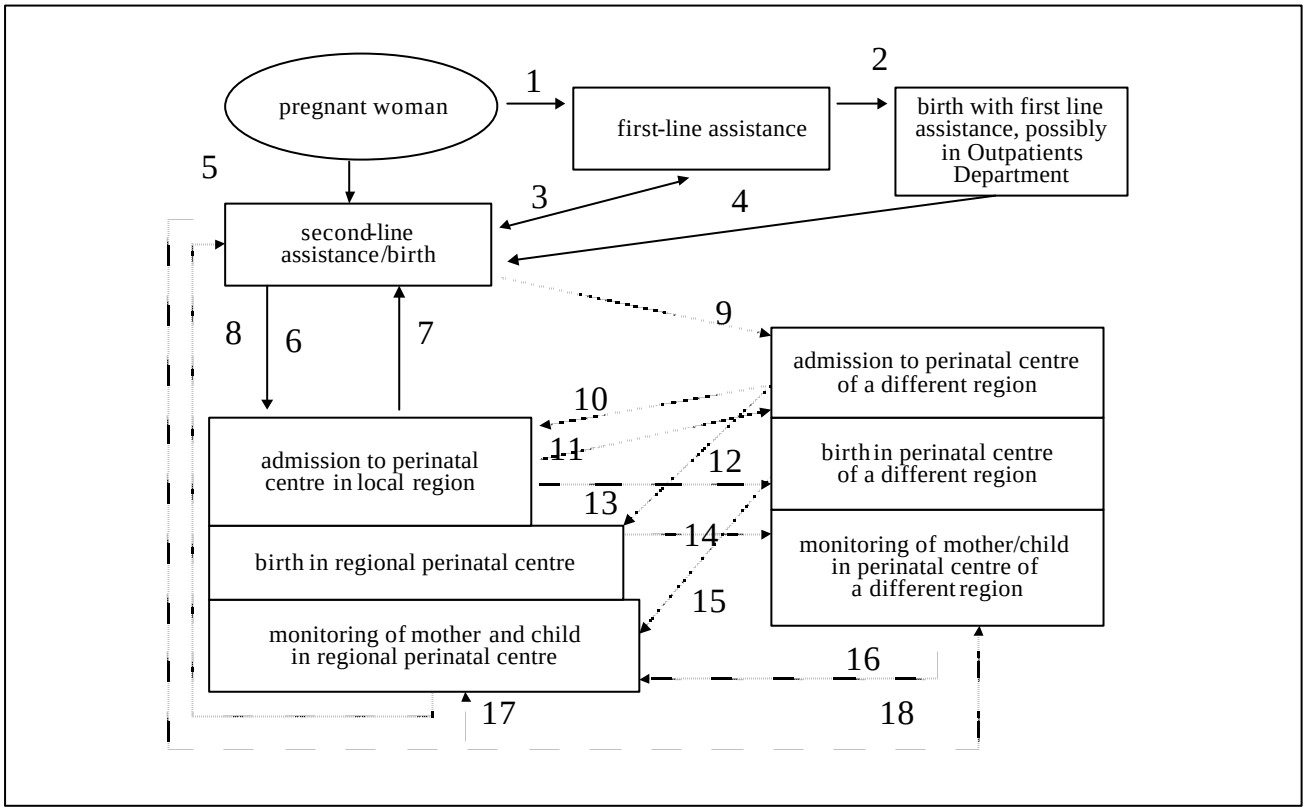
14 Immediately following birth, situation appears to be too problematic for adequate care to be provided locally, or there is no room, but birth happens before transfer can be effected: transfer of mother and baby to an extra-regional perinatal centre.
15 Immediately following birth, situation appears to be too problematic for adequate care to be provided locally, or there is no room, but birth happens before transfer

can be effected: transfer of mother and baby to their regional perinatal centre, where there is now room.

16 Birth takes place at an extra-regional centre, after which space soon becomes available at the mother's regional perinatal centre: transfer back to regional centre.

17 Immediately following birth under second-line supervision, situation appears to be too problematic for adequate care to be provided locally, or birth happens before transfer to the regional perinatal centre can be effected: transfer of mother and baby.

18 Immediately following birth under second-line supervision, situation appears to be too problematic for adequate care to be provided locally, or birth happens before transfer to the regional perinatal centre can be effected; in addition, there is no room at the mother's regional centre: transfer of mother and baby to an extra-regional perinatal centre.



Annex **D**

# Staffing requirement calculations

For the purpose of calculating the staff required to provide round-the-clock care, the Committee has assumed that each employee works a 36-hour week, thereby averaging 1514 hours per year. Junior doctors have a forty-six-hour working week, of which ten hours are allocated to training. Since this training normally involves caring for patients, it is assumed junior doctors normally work 1900 hours per year, giving a full working week.

All calculations have been made for a unit with fourteen or twenty-eight IC cots. For every fourteen neonatal IC cots, there should be eleven beds in third-line obstetrics and ten neonatal HC cots. Some of these HC cots may be located outside the perinatal centre (see subsection 6.4). The associated number of admissions is currently (0.80 x 14 x 365 / 20 =) 204 neonates per year.

The nursing staff requirement for neonatal IC has been calculated on the basis of two nurses to every three IC cots. For round-the-clock care, (2/3 x 365 x 24 hours / 1514 =) 3.85 FTEs per cot are needed. For a fourteen-cot unit, this means 14 x 3.85 = 53.9 FTEs. One FTE is required for outpatient after-care, training and research two FTEs and management three FTEs. A total of sixty nursing FTEs are therefore required in a fourteen-cot neonatal IC unit.

A junior doctor's span of control is seven IC patients by day and fourteen patients in the evening and at night. Thus, a twenty-eight-cot NICU requires four junior doctors for daytime patient care and delivery room admissions, each working a nine-hour day. This equates to (4 x 9 hours per day x 5 days =) 180 hours per week. To provide

continuous cover with two junior doctors during the evening and night, four shifts of 8.5 hours are required; (4 x 8,5 hours per day x 5 days =) 170 hours per week. Continuous manning by two junior doctors at the weekend requires (2 x 52 =) 104 hours per week. A total of 454 hours per week or (52 x 454 + 70=) 23 678 hours per year is therefore required. Since a junior doctor works 1900 hours per year, a twenty-eight-cot IC unit needs (23 678 / 1900 =) 12.5 FTE junior doctors.

In addition, a twenty-eight-cot IC unit requires five FTE medical specialists for direct daytime patient care. A unit of this size also needs two paediatricians on call for consultation purposes at night and in the weekend. To compensate for hours worked at night and in the weekend, an average of 1.5 FTEs are needed. The medical supervision of ill neonates in transit requires an average of 0.5 FTEs, although this figure is subject to variation, depending on journey durations and frequencies, the size of the IC unit and the size of the region served. A further 1.5 FTEs are needed for outpatient after-care, while 2.5 FTEs are required for administration and management. Furthermore, specialists have to devote 15 per cent of their time to training (1.5 FTEs) and 25 per cent to research (2.5 FTEs). Hence, a total of fifteen FTE medical specialists are required, ten to twelve of them neonatologists and three to five paediatricians training to become neonatologists (fellows).

The presence of a developmental psychologist and a paediatric physiotherapist is also considered necessary for research into the prevention of subsequent development problems, for the follow-up evaluation of treatment during the perinatal period and for the supervision of children who during the follow-up are found to have development problems. It is assumed that the developmental psychologist would need to devote an average of two hours per admission, i.e. (408 x 2 =) 816 hours per year. Follow-up in accordance with the national basic protocol requires an average of ten hours per baby, spread over a number of years. Assuming that 15 per cent of neonates requiring IC do not survive, the time required for follow-up is (0.85 x 408 x 10 hours =) 3468 hours per year. For in-patient and outpatient care together, this equates to (4284 / 1514 =) 2.8 FTEs for every twenty-eight IC cots. The paediatric physiotherapist is expected to work an average of 1.5 hours per admission and an average of two hours over the entire follow-up period. This corresponds to just over one FTEs for twenty-eight-cot IC unit.

A twenty-eight bed IC unit will admit an estimated 720 patients per year for third-line obstetric care (see section 6). Roughly 150 of these patients will be women who have recently given birth and 580 will be expectant mothers, of whom roughly 508 will give birth in the perinatal centre, as indicated in Annex C. The nursing staff required for a unit caring for high-risk expectant mothers is 20.3 FTEs. To handle 508 births, two delivery rooms are required, with one nurse in constant attendance, i.e. 5.8 FTEs. The

additional staff requirement for management, training and research is comparable with that for a neonatal IC unit. Hence, a total of 28.6 FTEs are needed.

A twenty-bed third-line obstetric unit handling high-risk births requires two junior doctors during the daytime and evening and one at night. This works out at (365 x 42.5 hours / 1900 =) 8.2 FTEs.

The work associated with the presence of a twenty-eight-cot neonatal IC unit will occupy four obstetricians. An additional 0.5 FTEs are required for administration and management and, since 15 per cent of these practitioners' time is devoted to training and 25 per cent to scientific research, these activities will account for another 1.5 FTEs.

Assessment of foetal growth and condition and diagnosis of congenital anomalies necessitates ultrasound scanning. Although some of this work is done by an obstetrician, a unit caring for high-risk expectant mothers is also expected to require one FTE scanner operator.

The Committee believes that various other staff are required, including a social worker to counsel expectant parents and parents whose babies are in IC. This individual could also give financial advice, help arrange supervision for the parents' other children and liaise with the parents' employer(s) regarding leave arrangements. It is anticipated that these tasks will account for an average of 1 hour per admission per week. Given an average total length of stay (including prenatal and postnatal confinement) of five weeks, the social work requirement amounts to (438 x 5 / 1514 =) 1.5 FTEs for third-line obstetrics and neonatal IC together.

The registration of diagnostic and treatment data is very important in relation to the evaluation of perinatal treatment. To this end, 1.5 FTE archivists should be employed to serve the two units.

A twenty-eight-cot IC unit requires twenty associated HC cots. In order that HC can be provided close to home, and in view of the fact that there is an additional demand for primary neonatal HC, it is desirable that a region's HC capacity is distributed across several hospitals. The table therefore details the staffing requirements of a ten-cot HC unit. Such a unit would need one nurse in constant attendance for every three cots. Allowing for management activities as well, a ten-cot HC unit should therefore have twenty nursing FTEs. In an HC unit, a junior doctor's span of control is roughly one and a half times that of his/her counterpart in an IC unit. Hence, 4.5 FTEs are required for a ten-cot HC unit. Two FTE paediatricians are required for patient care in such a unit, 0.2 FTEs for outpatient after-care and 0.3 FTEs for research activities undertaken in tandem with the perinatal centre. In view of the prevalence of developmental problems amongst children who have been through HC, an HC unit should also have a paediatric physiotherapist and developmental psychologist for (outpatient) supervision.

No allowance has been made by the Committee for the radiated impact of a perinatal centre on the staffing requirements of support departments within the hospital or on the staffing requirements in other medical disciplines.

*Table* Direct staffing requirements associated with perinatal IC, not allowing for radiated impact on other hospital departments.

| | third-line obstetrics | neonatal IC | neonatal HC |
|---|---|---|---|
| number of places | 22 | 28 | 10 |
| nursing staff | FTEs | FTEs | FTEs |
| patient care | 20 | 108 | |
| delivery rooms | 6 | | |
| management | 2 | 6 | |
| training and research | 1 | 4 | |
| after-care and follow-up | | 2 | |
| subtotal: nursing staff | 29 | 120 | 20 |
| medical specialists | | | |
| patient care | 4 | 8 | 2 |
| patient transit supervision | | 1 | |
| management | 1 | 3 | |
| training and research | 2 | 4 | 0 |
| after-care and follow-up | | 2 | 0 |
| subtotal: medical specialists | 6 | 15 | 3 |
| junior doctors | 8 | 13 | 5 |
| ultrasound scanner operator | 1 | | |
| developmental psychologist | | 3 | |
| physiotherapist | | 1 | |
| social worker | 1 | 1 | |
| archivist | 1 | 1 | |

Annex **E**

# Glossary

*ADHD*
: attention deficit and hyperactivity disorder

*apnoea*
: temporary cessation of breathing due to immaturity of the respiratory regulation system in a premature neonate, or resulting from closure of the air ways

*BPD*
: bronchopulmonary dysplasia, permanent lung damage following ventilation

*cardiotocography*
: the simultaneous registration of (variations in) foetal heart-rate and maternal uterine activity

*Doppler-test*
: ultrasound test to determine blood flow rates (in the case of an expectant mother, both foetal and uterine blood flows)

*eclampsia*
: pre-eclampsia (see definition below) accompanied by convulsions or coma (complete loss of consciousness)

*ECMO*
: extra-corporeal membrane oxygenation: ‘artificial lung’ treatment

*fellow*
: medical specialist who has spent an additional two or three years studying a particular field within his specialism (in this case, neonatology)

*HC*

high care: additional care for neonates who no longer require ICHC typically involves respiratory support in the event of apnoea attack, parenteral nutrition or further examination for brain damage. In the period following release from IC, a neonate's vital functions remain very unstable and the resumption of ventilation can be necessary. The physical location of the HC provision depends on the likelihood of readmission to IC being required.

*HELLP syndrome*

a medical condition that occurs only during pregnancy, involving the destruction of red blood cells (haemolysis), liver-function disorder (elevated liver enzymes) and a low blood platelet count; the condition can form a serious threat to maternal and foetal vital functions and often occurs in combination with pre-eclampsia

*HFV*

high-frequency ventilation involving a different respiratory principle to that involved in conventional ventilation

*IC*

intensive care neonatal intensive care is indicated for neonates with seriously impaired vital functions

*ICSI*

intra cytoplasmatic sperm-injection the direct injection of a sperm cell into an egg cell in IVF

*intra-uterine insemination*

introduction of sperm cells (from the recipient's partner or from a donor) to the uterus

*IRDS*

Infantile Respiratory Distress Syndromea medical condition caused by surfactant deficiency

*IVF*

in vitro fertilisation test-tube conception

*LNR*

Landelijke Neonatologie Register (Dutch) National Neonatology Registry)

*LVR*

Landelijke Verloskunde Register (Dutch) National Obstetrics Registry)

*NICU*

neonatal intensive care unit licensed under section 18 of the Hospital Provision Act / Section 2 Exceptional Medical Procedures Act to provide intensive care for neonates

*NVK*

Nederlandse Vereniging voor Kindergeneeskunde (Netherlands Association for Paediatric Medicine)

*NVOG*

Nederlandse Vereniging voor Obstetrie en Gynaecologie (Netherlands Association for Obstetrics and Gynaecology)

*NOi*

nitrogen monoxide inhalation therapy ventilation whereby nitrogen monoxide (NO) is added to the air supply in order to promote dilation of the blood vessels in the lungs

*OHC*

obstetric high care for ill expectant mothers

*ovarian hyperstimulation*

hormonal treatment to promote maturation of egg cells

*parenteral nutrition*

provision of necessary nutrients by infusion where ingestion of nutrients cannot yet be tolerated. Prolonged parental nutrition requires the insertion of 'long lines', which increases the risk of infection.

*PICU*

paediatric intensive care unit in which intensive care is provided for children

*POPS*

Project on Pre-term and Small-for-Gestational-Age Infants, a long-term follow-up study in the Netherlands involving an almost complete annual cohort of premature children

*pre-eclampsia*

high blood pressure during pregnancy, accompanied by protein loss in the urine, entailing various risks, including kidney damage, liver damage and serious neurological problems for the mother (see eclampsia), as well as serious growth retardation and brain damage in the baby and ultimately still birth

*TTS*

twin-transfusion syndromecondition affecting monozygotic twins during pregnancy: the placenta contains blood vessels joining the circulatory systems of the two foetuses, which interfere with the provision of a balanced blood supply

*ultrasound diagnostics*

anatomical examination of a foetus using ultrasound techniques

*WGBO*

Wet op de geneeskundige behandelingsovereenkomst (Medical Treatment Contracts Act)

*WMO*

Wet medisch-wetenschappelijk onderzoek met mensen (Medical Research involving Human Subjects Act)