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MEDICAID: NEONATAL INTENSIVE CARE UNIT COSTS

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I. INTRODUCTION

Neonatal intensive care units (NICUs) are hospital departments with the special diagnostic devices, medical equipment, and services necessary to provide continuous care to critically ill newborns. Between 150,000 and 200,000 infants (4 to 6 percent of all newborns) are admitted annually to NICUs. The majority are low-birth-weight newborns weighing less than 2,500 grams (Office of Technology, 1987).

Neonatal intensive care appears to be both very effective and very expensive. Research has found that neonatal intensive care is largely responsible for the dramatic decline in birthweight-specific mortality rates (see literature reviews in Budetti at al., 1981 and Office of Technology Assessment, 1987). At the same time, neonatal intensive care ranks among the most expensive services of all hospital care. In 1984, the average hospital cost of low birthweight infants ranged from $12,000 to $39,000.

This combination of high cost and effectiveness presents policy makers with a challenging dilemma. There is a desire to promote the use of neonatal intensive care as a means of saving lives, yet there is also a strong incentive to control the burgeoning costs of medical care. The tension between providing care and controlling costs is particularly acute for the Medicaid program which is the major source of public funding for maternity and newborn care for the poor. While actual Medicaid expenditures for neonatal intensive care are unknown, a survey of thirteen states found that an average of 6 percent of their Medicaid-covered newborns were admitted to NICUs and that average Medicaid expenditures for these newborns was $11,600, representing over 20 percent of all Medicaid expenditures for maternity care in these states (Kenney et al., 1986).

Given their expense and effectiveness, it is not surprising that NICUs have been studied extensively during the last two decades. This research has documented the effectiveness of neonatal intensive care in reducing infant mortality, although it has also shown that little progress has been made at reducing mortality among the smallest and most premature infants--those who weigh less than 750 grams. Furthermore, research has shown that the risk of mortality, especially for infants of very low birthweight (weighing less than 1,500 grams), varies considerably across NICUs. Despite improving NICU survival rates, the proportion of survivors diagnosed with serious handicaps has not changed significantly. Finally, cross-facility studies have found that the survival rate of very low birthweights infants born in hospitals with the most sophisticated NICUs is significantly higher than the survival rate of infants born in other hospitals, and that the distribution of neonatal intensive care costs is highly skewed.

The previous studies also leave a full-plate of policy-relevant cost questions unanswered. For example, they reveal little about how the burden of neonatal intensive care costs are distributed among the various public and private payers. Furthermore, extrapolations from these individual studies to national or state-level estimates of costs are subject to considerable imprecision, given the variation in outcomes and costs among hospitals, the nonrepresentativeness or small size of the samples of hospitals, and the absence of detailed information in national databases that could be used to generalize the results of small studies.

With this limited set of information, policymakers must now confront a growing demand. for neonatal intensive care among current and future cohorts of newborns. First, the increasing incidence of illicit drug use (especially cocaine) among women of childbearing ages, and inadequate access to prenatal care among women of lower socioeconomic status, imply that an increasing number of infants with adverse birth outcomes will need neonatal intensive care (Institute of Medicine, 1985). Second, future legislation or judicial decisions that restrict access to abortion will likely increase the rate of adverse birth outcomes (Corman and Grossman, 1985). Third, improvements in neonatal intensive care treatments, such as surfactant replacement therapy, will improve the survivability of extremely low birthweight infants (those weighing less than 1,000 grams). Finally, treatment patterns appear to be shifting so as to add to the number of infants who will need neonatal intensive care. For example, infants at the extreme limit of survivability (23 to 25 weeks gestation, and 500 to 600 grams) are no longer being considered stillborn, and are now increasingly being resuscitated as live-born infants in the delivery room.

Given the expanding role of expensive NICU technology and the shortcomings of current information, state and federal officials responsible for Medicaid programs face an array of difficult decisions as they attempt to budget future activities and design or refine policies to fund options that might reduce NICU use and costs.

The Objective of this Study

The purpose of this study is to identify important research and policy issues pertaining to Medicaid and NICUs, and to identify data sources and research strategies for addressing those issues. Based on a review of the clinical, cost-effectiveness, and health policy literature on NICUs, we have identified several knowledge gaps with important policy implications, and have made specific recommendations about the direction and focus of future studies. In particular, we recommend strategies for estimating total Medicaid expenditures for infants admitted to NICUs and the resource-cost of care provided to these infants (that is, the economic value of the resources used to care for these infants). This report addresses several other issues of importance to HCFA:

- Access to NICU care by Medicaid-covered infants
- Variations in outcomes and costs across hospitals
- The long-term health consequences for NICU survivors
- The cost-effectiveness of programs to facilitate discharging infants earlier from NICUs
- The special neonatal intensive care needs of infants born to substance-abusing mothers and mothers infected with Human Immunodeficiency Virus (HIV)

Study Design

A review of the clinical, cost-effectiveness, and health services literature on NICUs provides the foundation for the research strategies presented in this report. Our literature review was guided by a computer search of published literature dating back to 1980 and the clinical experience of the project staff. In addition, we identified relevant articles and studies from the lists in the materials that we read, and from telephone conversations with other researchers working on NICU policy issues. Our literature review focuses on the policy issues that have direct or indirect relevance to the program. For each piece of literature, we assessed its data sources, samples of neonates and NICUs, and evaluation methodology.

Our efforts to design appropriate research strategies and identify reliable data sources were supported by telephone conversations with health services researchers, representatives of private health organizations, and staff members of state Medicaid and vital statistics offices. We also relied on our previous experience with Medicaid eligibility and claims data to address the suitability of these data.

The extent to which the alternative data sources will be suitable for a specific research issue will depend on the research issue being addressed, the level of analytical precision desired, and whether the data can support the generalization of the study results to broader populations, such as residents in a particular state or all persons covered by Medicaid. We used six criteria to evaluate the adequacy of alternative data sources: accuracy, comprehensiveness, timeliness, accessibility, flexibility, and cost. Accuracy is the extent to which the data reflect actual events, characteristics, and costs. **Comprehensiveness** encompasses two components--the completeness of the sample (that is, whether the data are available for all the persons included in the study, or for a reasonably sized representative sample of the study population), and the completeness of the data (that is, whether the data cover all critical issues under study). Timeliness refers to the extent to which the data pertain to the appropriate time period of interest and can be obtained without excessive delays after the event under study occurs. **Accessibility** refers to whether the necessary data can be collected, including the logistics of obtaining the data and whether consent is required to obtain the data. **Flexibility** reflects whether a data-collection strategy can be modified to accommodate changes in research goals, budgets, or the program environment. **Cost** refers to whether the data can be obtained at reasonable expense without undue burden on respondents.

Not all of the specific data sources reviewed during the course of this study are discussed in this report, particularly those that did not rigidly meet one or more of the six criteria. For example, due to changes in NICU technology, the eligibility criteria of the Medicaid program, and the recent spread of crack use and HIV, data from the early 1980s were considered to be too old to be applicable to future studies. However, any special attributes of these excluded data were noted and incorporated into our recommendations for future data collection efforts.

Outline of the Report

The remainder of this report is as follows. Chapter II provides a general overview of policy issues pertaining to NICUs, thus serving as background for our discussion of Medicaid and NICU policies in Chapter III. Chapter IV summarizes the literature on Medicaid expenditures for infants admitted to NICUs, and recommends alternative data sources and research strategies for future studies to estimate these Medicaid expenditures. Chapter V reviews the literature on the costs of care for infants admitted to NICUs, and recommends alternative research strategies and data sources for future studies. Chapter VI discusses research on the access of Medicaid-covered infants to NICUs and variations in their outcomes. Finally, Chapter VII summarizes the conclusions of the report.

II. OVERVIEW OF NEONATAL INTENSIVE CARE UNITS

In order to evaluate the impacts of NICUs on Medicaid program costs, the implications of Medicaid policies on the care received by Medicaid-covered newborns, and research strategies to study these issues, one must understand the characteristics of neonatal intensive care and the organization of the perinatal-care system. This chapter provides the necessary background and context for the subsequent discussions of Medicaid policies and NICUs. Areas covered in this chapter are the role of NICUs in reducing infant mortality, a typology of NICUs and NICU patients, NICU admission and discharge decisions, the health and developmental consequences for NICU survivors, and emerging trends in NICUs.

Defining Neonatal Intensive Care Units

During the 1960's, advances in perinatal medicine and the development of associated medical technology, especially mechanical ventilation, led the way to many hospitals introducing NICUs. The primary growth in these units occurred in the 1970's. In response to this growth, the American Medical Association, the American College of Obstetricians and Gynecologists, the American Academy of Family Physicians and the American Academy of Pediatrics joined efforts to form the Committee on Perinatal Health in 1976. This Committee proposed guidelines for the regionalization of maternal and perinatal health services that was centered around a three-tiered system of hospital care (Committee on Perinatal Health, 1977). Under these guidelines, Level III facilities serve as regional centers, providing the most sophisticated and intensive neonatal services. At a minimum, Level III hospitals have the capability of providing ongoing respiratory care and are staffed by full-time neonatologists. Level II hospitals provide many but not all of the neonatal intensive care services available in Level III hospitals. Level I facilities provide only normal newborn care. The Committee on Perinatal Health defined regionalization as a system where by high-risk mothers and infants are screened and referred or transferred to the appropriate level of care.

Despite these guidelines and subsequent efforts by member organizations, there is no uniform definition of Level III and Level II care. In general, each hospital classifies its own neonatal services (Office of Technology Assessment, 1987). Furthermore, the distinction between Level II and Level III facilities is blurred, because many Level II hospitals possess the minimum capabilities for Level III hospitals, and there is significant variability in the capabilities among Level III hospitals. In principle, Level II hospitals provide short-term respiratory care, stabilize very sick or premature infants, and then transfer the more complicated cases to Level III hospitals.

Because of these ambiguities in defining levels of NICUs, there is no definitive count of NICUs according to Level II and III. The most current and comprehensive count of NICUs is from the American Hospital Association's (AHA) Annual Survey of Hospitals. In this survey, specialized neonatal services are classified into two categories: neonatal intensive care and neonatal intermediate care. Hospitals reporting that they provide neonatal intensive care services are most likely to be Level III facilities, although some are likely to be Level II facilities. Hospitals reporting that they provide neonatal intermediate care are principally

Level II hospitals, although a few may be Level III hospitals.' The net effect is that the number of hospitals reporting that they have a NICU is probably an upper-bound estimate of the number of Level III NICUs. First, hospital administrators probably err by overstating the capability of their facilities, resulting in a upperbound estimate. Second, only if many Level III hospitals reported as neonatal intermediate care, would the AHA count not be an upperbound.

From 1980 to 1989, the number of hospitals reporting having NICUs increased from 413 to 720, and the number of NICU beds increased from 6,187 to 11,594. During this same time period, the number of hospitals reporting neonatal intermediate care units increased from 145 to 400, and the number of intermediate care beds increased from 1,743 to 4,377 (American Hospital Association, 1990(a) and 1990(b)). The percentage increases in the number of NICUs and the number of NICU beds differed across regions of the country. For example, between 1983 and 1986, the number of NICU beds increased by roughly 12 percent in the Northeast and Midwest, but increased by 29 percent and 33 percent in the West and South. Although the differential growth rates resulted in a convergence in the supply of NICU beds across regions, occupancy rates declined in the West and South. During this same time period, the number of NICU beds increased by over 23 percent in metropolitan areas, but decreased by 1 percent in rural areas, while total births increased by 7.6 percent in metropolitan areas and decreased by 3.3 percent in rural areas (Schwartz, 1991).

The **Role of** NICUs in **the Decline of Infant Mortality Rates**

During the first half of this century infant mortality rates fell 70 percent, to about 30 per 1,000 live births, largely from declines in post-neonatal mortality (age 28 days to under one year) (U.S. Bureau of Census, 1975). This decline has been attributed to changes in environmental and socioeconomic conditions that reduced the effect of infectious diseases and improved nutrition (McCormick, 1985; Pharaoh and Morris, 1979). After modest declines during the 1950's and early 1960's infant mortality rates began a sharp decline. From 1960 to 1980, infant mortality rates fell 52 percent, from 26 to 12.6 per 1,000 live births. Reductions in neonatal mortality (age less than 28 days) accounted for over three-fourths of this decline (Buehler et al., 1987). Finally, during the 1980's, the rate of improvement in infant mortality fell to about one-half of that achieved during the 1970's, with infant mortality declining to 10.08 per 1,000 live births (National Center for Health Statistics, 1987).

NICUs are an important reason for the improvements in infant mortality since the late 1960's. Because the likelihood of infant death increases sharply with falling birthweight (for infants less than 3,500 grams), declines in infant mortality may arise from either reductions in the frequency of low birthweights or reductions in birth-weight specific mortality rates. For the period 1960 to 1980, 91 percent of the decline in infant mortality was due to reductions

'This characterization is based on past analyses of the AHA Annual Hospital Survey data, by the National Perinatal Information Center, which has assisted the AI-IA in the design of the survey instruments regarding neonatal services (Rachel Schwartz, National Perinatal Information Center, personal communication).

in birth-weight specific mortality (Buehler et al., 1987).[2] Technological improvements in and the regional coordination of NICUs, through perinatal regionalization, have played a major role in the reductions of birth-weight specific mortality (Office of Technology Assessment, 1987 and 1988; McCormick, 1985; Williams and Chen, 1982; and Williams, 1979).[3] However, these gains have principally occurred for birthweights greater than 750 grams; only modest improvements have been achieved for smaller birthweights (Hack and Fanaroff, 1989; Britton, Fitzhardinge, and Ashby, 1981; Hirata, Epgar, and Walsh, 1983).[4]

The successful diffusion of NICU technology during the 1970's may also partially explain the slowdown in the decline of infant mortality during the 1980's. In a recent study, the OTA (1988) concluded that this slowdown is related to increases in the percentage of infants born weighing less than 1,000 grams, and slowed improvement in the mortality rate of moderately LBW infants (between 1,500 and 2,500 grams). The OTA speculates that the slowed improvement in the mortality rate of moderately LBW infants may result from diminishing returns to the spread of NICU technology, especially in the treatment of respiratory distress syndrome (RDS), the most common cause of neonatal death. Under this explanation, dramatic improvements in birth-weight specific mortality rates may depend on the development of improved technologies to treat RDS.[5]

Although NICU technology has been a major contributor to the improvements in infant mortality rates since the late 1960's, there is evidence to suggest that, for some cases, NICU technology may have postponed death from the neonatal period to the postneonatal period. The total postneonatal mortality rate (postneonatal deaths per 1,000 neonatal survivors) fell by 45 percent between 1960 and 1980. However, for infants weighing between 500 and 999 grams, the postneonatal mortality rate increased 100 percent during this same period, and the postneonatal mortality rate for infants weighing between 1,000 and 1,499 grams improved by only 17 percent (Buehler et al., 1987). In addition, broncho-pulmonary dysplasia, a condition that can follow treatment for RDS, accounts for roughly one-half of the deaths due to perinatal conditions that occur in the postneonatal period (Buehler et al., 1987).

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[2]For corroborating evidence, see David and Siegel (1983).

[3]Other contributing factors include improved intra-partum care, fetal monitoring and cesarean sections (Bloom, 1984; David, 1983; and McCormick, 1985).

[4]The OTA (1987) reports pooled estimates across several studies of neonatal mortality in NICUs during 1980 to 1985. These pooled mortality rates by birthweight categories are 67 percent for newborns weighing 501 to 750 grams, 34 percent for newborns weighing 751 to 1,000 grams, and 12 percent for newborns weighing 1,001 to 1,500 grams.

‘Some observers have speculated that the recent slowdown in the improvement in the U.S. infant mortality rate may in part be explained by an increasing likelihood of resuscitating extremely LBW, less viable newborns. In the past such infants would not have been counted as live births.

Characterization of NICU Patients

Approximately four to six percent of all newborns born in the U.S. are admitted to a NICU. For an individual newborn, the determinants of a NICU admission are not only a function of birthweight and illness severity, but also of local staffing, bed availability, geography, and other factors. And although larger hospitals usually have designated NICUs, intermediate care units, and term nurseries, in general, atypical patients tend to rise to the highest level of care available.

There are five general subgroups of NICU patients: (1) triage--infants presented to the NICU for evaluation, but ultimately not admitted, (2) sick full-term, (3) uncomplicated prematurity, (4) very LBW or ill prematures and (5) full-term requiring surgery or special procedures. In the following sections we describe this typology in detail. The estimates of proportions of patients in each category are derived from related research at three Boston hospitals (Richardson 1991). Stiles et al. (1991) reported a state-wide NICU census from North Carolina which confirms our estimates. They defined patients receiving three levels of care: intensive (31 percent), intermediate (37 percent), and convalescent (32 percent). Although the percentages may vary at other locations, the actual categories and relative proportions are likely to remain similar.

Observation and Triage

Many high risk situations arise in the perinatal period even for full term/normal birth-weight infants. Infants who are at risk often require short term evaluation to triage the ill patients into intensive care and treat and release those who do not require such care. In this group are several typical types of patients, for example, infants with transient depression following successful delivery room resuscitation or with retained fetal lung fluid, amniotic fluid aspiration or mild meconium aspiration. Perhaps the largest group are infants who carry a significantly elevated risk for newborn sepsis as a result of perinatal infection exposure. Such infants receive a “sepsis workup” and often antibiotic treatment. Infants of diabetic mothers are frequently admitted for several hours after birth to ensure stable blood sugar. Infants with non-emergent congenital anomalies may also be evaluated in the triage area because of the clustering of resources and the improved efficiency in evaluating such patients. Similarly, technical issues may bring infants to the NICU such as intravenous placement, cardiac evaluation and special procedures.

There is no literature on neonatal triage with the exception of one British study which analyzed the wide variation in NICU admission rates as a function of perceived adequacy of the normal term nurseries and presence of a pediatric house officer (Campbell, 1984). Triage applies only to obstetric hospitals and not to childrens’ hospitals with outbom populations. There appears to be a wide variation in practice, not only according to infant severity of illness but also according to the availability of NICUs beds.

The definition of triage is necessarily post-hoc. For example, at Brigham and Women’s Hospital (Boston, MA) any infant staying less than twenty-four hours in an NICU is considered as “triage.” Approximately twenty percent of all births receive such short stay evaluation. The median length of stay is three-to-four hours. Such short stay/triage patients are approximately equal in number to actual NICU admissions (that is, infants staying longer than 24 hours). Because of their exceedingly brief stays they account for less than five percent of the hours of care relative to true NICU admissions, but may put major demands on staffing because of the one-on-one care needed for evaluation and administrative disposition, and because of the sheer volume. Hospital billing policies on these infants vary, ranging from charging all infants for a full NICU day, to charging an hourly rate, to charging only those infants in the NICU at the hour of hospital census.

Sick Full-Term Infants

The distinction between this group of patients and the triage patients described above is often simply that the medical risks were realized--that is, the infant became ill and was admitted (retained) in the NICU. The degree of illness covers a broad spectrum from simply prolonged triage to critically ill infants with overwhelming sepsis, pneumonia or meconium aspiration. Approximately 25 percent of NICU admissions fall in this category. Their treatment is usually intense but brief. If the infants survive, the convalescence is short and such infants can usually be discharged directly home.

Uncomplicated Prematurity

This is the single most common diagnosis in NICUs, accounting for 44 percent of true NICU admissions. A simplified definition is that of infants whose principal problem is prematurity. These babies are not ill but are too immature to be discharged. They usually require one-to-three weeks of intermediate care to permit growth, monitor for apnea and wean from an incubator. The mortality risk is small but occasional complications do occur. Such patients can be cared for in intermediate settings in either regional or community hospitals but require greater than average nursing skill.

Very Low Birthweight or 111 Premature Infants

This class of patient is the "typical" NICU patient. Although they constitute only 25 percent of NICU admissions, they account for 45 to 50 percent of bed days. Their small size demands a high level of skill and technology regardless of the degree of illness. The length of stay is determined principally by birthweight and the length of time required to gain sufficient weight for safe discharge. A typical one kilogram infant, gaining 10 to 20 grams per day without complications, would require 50 to 100 days to reach a discharge weight of 2,000 grams. Such growing infants eventually join the ranks of the uncomplicated pre-term infants. A small fraction of this group sustain damaging sequelae of prematurity which chronically prolongs their hospitalization and results in catastrophic expenses. Stiles et al. (1991) reported that 8 percent of patients in North Carolina NICUs were more than 90 days old and 3 percent were still on mechanical ventilation.

Full Term infants Requiring Surgery or Special Procedures

This group of infants accounts about six percent of NICU admissions. These infants require highly specialized technology. The size of this group varies across NICUs, and reflects the presence of highly specialized services, for example, cardiac catheterization or surgery, or neurosurgery. Often such infants have rare congenital anomalies including heart defects, major gastrointestinal or genito-urinary anomalies which require surgical repair or palliation. Also included in this group are infants requiring dialysis or temporary heart-lung bypasses, also referred to as extra corporal membrane oxygenation (O'Rourke et al., 1989). Such infants incur major expenditures, not only for the operating room and ICU services but also because of the chronic disabilities resulting from the underlying anomaly or illness.

NICU Admissions

Studies of the effectiveness of NICUs generally distinguish between infants who were born in a hospital with a NICU (inborns) and infants who were transferred to a NICU from a community hospital (outborns). One means by which infants come to be born in perinatal centers is through the referral or transfer for maternal care of high risk deliveries.

Several studies have examined the effectiveness of transferring very low birthweight or premature newborns to Level III facilities. Blake, et al. (1975) concluded that seriously ill newborns may be transported safely to a perinatal center, when transported by a trained staff using a transport incubator, which has facilities for warming, oxygenating, monitoring and mechanically ventilating a sick newborn. The condition of % percent (113) of the infants in the study improved or remained static during transport. Furthermore, there was no correlation between neonatal survival rates and distance transported. Beverly, Foote, and Howe1 et al. (1986) and Modanlou et al. (1980) found that the survival rate of LBW outborn infants was not significantly different from that of LBW inborn infants, and Cordero, Backed, and Zuspan (1982) found the survival of very LBW infants transferred to a perinatal center was significantly higher than similar infants kept at a community hospital.[6] Finally, Sims, Wynn, and Chiswick (1982) found the neonatal survival rate of infants transferred to a NICU was 66 percent, whereas the survival rate of similar infants denied transfer because of bed or staff shortages was 30 percent.

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[6]The results of these three hospital-based studies must be viewed with caution, since they are potentially subject to selectivity bias. The health status of LBW newborns who are transferred may be different from those LBW newborns who remain at a community hospital. First, the sickest and most premature newborns are likely to die in the community hospital before transport. Approximately 30 percent of LBW deaths occur within four hours of birth (Paneth, et al., 1984), and about one-half of deaths among newborns weighing less than 800 grams occur during the first day (Britton, et al., 1981; Hirata, et al., 1983). Second, the infants chosen for transfer may be selected based on their likelihood of survival. Marcus, et al. (1988) found that for infants weighing 1,750 grams or less, the more viable newborns were more likely to be transferred from a Level I hospital, but for infants weighing more than 1,750 grams, the less viable infants were likely to be transferred.

The efficacy of maternal transfer of high risk deliveries to Level III hospitals has also been documented in several studies (Bowman et al., 1988; Lobb et al., 1983; McCormick, Shapiro, and Starfield, 1985; Modanlou et al., 1980; and Paneth et al., 1982). Although the birth of a premature or LBW infant cannot always be anticipated, there is substantial evidence that antenatal transfer of high risk pregnant women significantly decreases neonatal morbidity and mortality.

The choice of the hospital of birth may be influenced by numerous factors. First, a principal goal of efforts to regionalize perinatal services is to provide early obstetrical risk assessments and to arrange prenatal referrals or maternal transfers of high-risk deliveries to tertiary centers. Therefore, high-risk women living in communities with an operational perinatal regional system are more likely to give birth in a Level III hospital. In turn, women are less likely to give birth in Level III hospitals if they live in communities without regionalized perinatal services or in communities located far from Level III hospitals, such as rural areas. Second, a woman's health insurance coverage may also affect the hospital of birth. Women with Medicaid coverage or without insurance may have special access problems. However, hospitals that serve a disproportionate share of Medicaid and uninsured patients are frequently teaching or tertiary hospitals. Women enrolled in health maintenance organizations (HMOs) or preferred provider organizations (PPOs) may face contractual constraints and strong economic incentives that could limit their access to Level III hospitals. Finally, increasing competition among hospitals for privately insured patients, coupled with the expanding number of Level II NICUs in community hospitals, may result in high risk deliveries being diverted from Level III to Level II facilities.

Although there is no documentation in the published literature, it seems likely that extremely LBW infants and infants with life-threatening congenital anomalies who are born in a hospital with a NICU are more likely to be resuscitated than are similar infants born in hospitals without a NICU. There are no clear guidelines dictating the initial delivery room care of extremely LBW infants. Practices vary across hospitals, even for those with NICUs, ranging from observation with limited intervention to immediate intubation and resuscitation at birth for every live-born infant (Hack and Fanaroff, 1986). Decisions to resuscitate depend on the personal philosophy of the primary physician, along with varying degrees of input from parents. Concerns over litigation and peer review may also play a limited role.

The in-hospital availability of neonatal intensive care may influence a physician's decision of whether to immediately initiate resuscitation and to transfer an infant to a NICU in several ways. First, a strong desire to preserve life may compel a physician to try all that is immediately available, including transfer to the NICU. The presence of a NICU may sufficiently improve the small possibility of an infant's survival to justify, in a physician's mind, heroic efforts. Second, transferring infants to a hospital with a NICU means that there will be a delay before intensive care services can be initiated. This delay, along with extra handling of the fragile infants, may reduce the perceived probabilities of survival sufficiently to convince a physician not to resuscitate and transfer an extremely small newborn. In support of this explanation, a study of the determinants of inter-hospital transfer of LBW newborns found that transferred newborns weighing less than 1,750 grams were in better condition than similar infants who were not transferred (Marcus et al., 1988). Finally, physicians practicing in tertiary centers may perceive higher probabilities of survival for extremely LBW infants, than do physicians practicing in community hospitals.[7]

NICU Discharges

NICU discharges fall into one of five categories: discharged directly to home, step-down care, back transport, withdrawal of life support, or death while under treatment. The types of infants discharged directly to home are NICU survivors who only require neonatal intensive care in intermediate settings (for example, in Level II facilities) or sick full-term infants who convalesce quickly. NICU survivors who require long lengths of stay (LOS) are often transferred from the highest level of neonatal intensive care to units providing intermediate or normal levels of care. This class of infants includes “boarder babies,” who are medically-cleared for discharge but remain in the hospital awaiting social-service evaluation. Step-down care refers to such transfers that occur within the same hospital. However, many infants are transferred to a Level III hospital for neonatal intensive care from community hospitals. These infants may be transferred back (or back-transported) to the community hospital while convalescing or waiting for social-service evaluation. The possible advantages of back-transport include preserving Level III NICUs for seriously ill neonates, improving the efficiency of bed use in Level I and II facilities, improving parental visitation and reducing costs.[8]

The final two types of discharge involve infant deaths despite continuing aggressive treatment to save the infants’ lives, and the decisions to halt heroic measures and to withdrawal life support. Withdrawal of life support is a complex and emotionally-charged decision, and broad latitude has traditionally been given to the physicians and parents involved. These decisions may be complicated by ethical ambiguities, by conflicting value structures of individuals involved in the decision, and by uncertainty of the outcomes (Strain, 1983).

Under the 1984 Child Abuse Prevention and Treatment Act, medical neglect in the treatment of disabled infants is defined as child abuse. State child-abuse agencies were given oversight responsibility for implementing this law. The current regulations promulgated under this law provide for “reasonable medical judgement” to be used in making decisions about the care of disabled newborns. These regulations allow physicians to consider whether the treatment would merely prolong dying, or would be “virtually futile” in terms of newborn

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‘A study by Hack and Fanaroff (1986) suggests that endotracheal intubation and respiratory support are being applied to a growing percentage of extremely LBW newborns. This changing practice pattern may be due to improved probabilities of survival.

‘Bose et al. (1985) concluded that neonatal back-transport can be cost-effective. They found that a program for back-transporting from the University of Utah Hospital to community hospitals saved an average of $320 per infant. The average daily bed charge and charges for laboratory tests and medications were significantly less for back-transported infants compared with a similar group of infants who remained in the tertiary center for convalescence. These reductions were large enough to offset the charges for back-transport.

survival, or the treatment itself would be inhumane (Strain, 1986). Although many hospitals have established formal review committees to consult in such decisions, it appears that most decisions to terminate treatment are made between parents and physicians (Office of Technology Assessment, 1987).

Categories of neonates where such decisions are considered include severely asphyxiated infants, preterm infants with major intraventricular hemorrhage, infants with uncontrollable seizures and minimal or no head growth, infants with certain chromosomal abnormalities, such as trisomy 13 to 15, and infants with lethal congenital anomalies (Ragatz and Ellison, 1983).

Health and Development Consequences of NICU Graduates

Health and development consequences of NICU graduates (survivors) encompass short-term to long-term physical and psychosocial problems. The "short-term" consequences seen among NICU graduates involve managing problems that had their onset in the NICU, monitoring for the emergence of later sequelae, providing routine pediatric care, assuring appropriate referrals and counseling parents regarding their own activities in fostering the physical and psychosocial development of the infant. The complexity of management for any given infant will depend on the number of acute and chronic problems encountered, and the severity and duration of each (Ballard, 1988; Taeusch and Yogman, 1987; and McCormick, forthcoming). By the end of infancy (about age 2 years), most of the problems related to the NICU and much of the increased risk of acute routine morbidity should have resolved (Hack and Fanaroff, 1983). At this juncture, the proportion of children with severe adverse outcomes are generally well established (Office of Technology Assessment, 1987). More recent data suggest, however, that less severe, more common problems and dysfunction are being defined as the children enter school age and beyond (McCormick, 1989; and Northway, 1991).

Several factors influence consideration of outcomes of intensive care in infancy compared with adults. The often amazing resilience of a young, still developing organism, on the one hand, coupled with the relatively high rates of morbidity routinely still experienced in infancy make prediction for any single infant or groups of infants difficult. In particular, this observation suggests caution in attributing morbidity to NICU experience in the absence of an appropriate comparison group in many instances. The need for appropriate comparisons is further reinforced by the fact that the full potential of a still-developing organism is difficult to project, and the effect of neonatal and subsequent events in altering that developmental trajectory is, likewise, difficult to estimate -- particularly when many interventions are aimed at "preventing" adverse outcomes. A further caveat in considering both shorter- and longer-term outcomes among NICU graduates reflects the lack of well conceptualized and standardized measures of health status for infants and young children that are capable of summarizing status across a number of dimensions and ranking severity. Most studies of outcomes examine specific issues, for example, psychosocial development (intelligence quotient and development quotient). As a result, estimating the prevalence and needs of multi-problem children is not readily achieved. Likewise, delineation of the need for specific services (for example, respiratory therapy, nutritional support) across conditions is made difficult by the heterogeneity and relatively low prevalence of the conditions affecting neonates (especially congenital malformations) in contrast to the adult case which is dominated by a few highly prevalent problems (for example, myocardial infarction). Most information on outcomes focuses on the very low birthweight infant; where such data are available for heavier birthweight infants, it will be cited.

Short-Term

Leaving a NICU is not the end of trouble for NICU graduates. They generally continue to need elevated levels of care compared with normal birthweight infants. In the first year of life, the most frequent health problems encountered in the NICU graduate are:

- The remaining (and hopefully resolving) complications of the newborn period such as bronchopulmonary dysplasia and retinopathy of prematurity (Hack and Fanaroff, 1983; Avery et al., 1987; Horbar et al., 1988; and Ng et al., 1988);

- Generally transient problems associated with immaturity such as transient alterations in tone and difficulty with state regulation which may impair development (Ballard, 1988 and Taeusch and Yogman, 1987);

- Increased incidence/prevalence of the more usual conditions seen in infancy such as ear infections, lower respiratory tract conditions, and surgical conditions such as hernias and strabismus (Bowman and Yu, 1989, McCormick, Shapiro, and Stat-field, 1980; Hack et al., 1981; Shankaran et al., 1988; and McCormick et al., forthcoming).

Generally, very LBW NICU graduates experience increased rates of rehospitalization. The rehospitalization rate for NICU graduates is between 40 and 50 percent versus about 10 percent for normal birthweight infants (those with weight greater than 2,500 grams). In addition, NICU graduates have longer total lengths of stay (Bowman and Yu, 1989; McCormick et al., 1980; Hack et al., 1981; Shankaran et al., 1988; McCormick et al., forthcoming; and Kitchen et al., 1990). In addition, such infants also require more outpatient care, an average of 15 visits per infant compared with 7 to 11 for general populations (Shankaran et al., 1988; McCormick et al., forthcoming; and McCormick, Shapiro, and Starfield, 1981). Much of this care involves returning to the tertiary care center and thus may be more expensive on a per unit of service basis. Factors which increase the risk of short-term morbidity and use of medical care include lower socio-economic status, presence of a congenital malformation and/or developmental delay, maternal hospitalization during pregnancy, Medicaid status, and usual source of pediatric care from a hospital clinic. On the other hand, lack of insurance decreases the risk of hospitalization.

Less well characterized are the need for and use of other services, such as physical therapy, home nursing and equipment rental. In addition, out-of-pocket costs, travel costs to obtain care, and opportunity costs to the family in providing care have received little examination (McCormick et al., 1991).

Little research has addressed the health problems and services use of heavier NICU graduates. One recent abstract reported a rehospitalization of close to 20 percent at six months of age, and about half of these hospitalizations were unrelated to the reason for NICU admission (Gray et al., 1991).

NICU graduates also need preventive services. These include routine well-baby care, especially immunization on schedule for chronologic age, and hearing and vision assessments. In addition, many infants benefit from Early Intervention Program services, community-based programs that offer nursing, physical therapy and developmental services tailored to the needs of the child (Brooten et al., 1986 and JAMA, 1990). Both physician-based and community-based services play a primary role in providing guidance to the parents as to the expected behavior of immature infants and to strategies for managing problems, as well as assessment of progress with referral as needed and reassurance when appropriate.

Intermediate-Term

By the end of the second year, most of these acute problems will have diminished in intensity. The minority (10 to 15 percent) of very LBW NICU graduates will be more clearly identified as experiencing severe handicapping conditions, largely neuro-developmental. Such conditions include severe cerebral palsy, mental retardation (IQ less than 70), hydrocephalus and/or severe seizure disorder (Office of Technology Assessment, 1987; Hoy, Bill, and Sykes, 1988; Aylward et al., 1989; Escobar, Littinberg, and Pettiti, 1991; and Pharoah et al., 1990). Children with such handicaps are likely to need extensive rehabilitation services, social support and special educational approaches (Butler, Rosenbaum, and Palfrey, 1987; Gortmaker and Sappenfield, 1984; and Singer, Butler, and Palfrey, 1986).

While, generally, the evidence indicates that very LBW graduates become more like normal birth-weight peers in incidence/prevalence of health problems and health care use, few studies have examined this issue other than studying neurodevelopmental outcomes. Any further characterization of service needs is likewise difficult.

Long-Term

For NICU graduates, "long-term" currently refers primarily to early school age. In part, this truncation reflects the fact that results from earlier populations might have limited applicability due to the rapid transition in NICU technology. Even in the older literature, however, few studies extended to adulthood. The literature on longer term outcomes can be divided into four areas: neurodevelopmental outcomes, pulmonary outcomes, other health problems, and use of health and education services.

Neurodevelopmental Outcomes--The estimates of prevalence of severe neuro-developmental handicap among NICU graduates suggest that few new cases will be identified in the pre-school and school-age periods. Relative to normal birth-weight infants, a higher proportion (one-quarter to one-third) of very LBW graduates will experience difficulties in school. These difficulties tend to be related to some combination of specific cognitive problems as reflected by decreased scores on specific subscales, behavior problems and disadvantaged family environment (McCormick, 1989; and McCormick, Gortmaker, and Sobol, 1990). Few studies have examined enough infants/children to estimate accurately the relative contribution these and other factors have on school difficulties. Without such estimates, efforts to develop better predictive models of which NICU graduates might be at risk will be constrained.

Pulmonary Outcomes--Increasing evidence suggests that respiratory distress in the neonatal period and/or the sequelae of medical management confer long-term (to adulthood) decreases in pulmonary function proportional to the severity of the neonatal respiratory disease. This altered pulmonary function includes both obstructive and reactive components, the latter manifested as wheezing which may result in a diagnosis of asthma. Other than neonatal RDS, other factors which might influence the risk and/or severity of subsequent pulmonary problems are not well characterized, but might include intervening acute lower respiratory infections and passive smoking (McCormick, 1989 and Northway, 1991).

Other Health Problems--Virtually no description of later health problems of NICU graduates is available. Overpeck, Moss, and Hoffman et al. (1989) have analyzed the National Health Interview Survey -- Child Health Supplement data, and found that decreasing birthweight confers increased risk for limitations in activities of daily living, a rating of fair/poor health and other standard measures. However, the sample of very LBW children was too small for more detailed analyses.

Use of Health and Educational Services--Other than the proportion needing some type of educational services, little is known about health services use or the specific types of educational services required. Recent, and as yet unpublished, data indicate that 7 percent of very LBW children at school age were hospitalized in the year prior to assessment compared to 1.8 percent of normal birth-weight children (McCormick, 1991).

Prevention of Learning and Behavior Problems

The increased prevalence of learning and behavior problems raises the question of preventability. Pre-existing evidence from special pre-school programs for the disadvantaged and for persons with physical disabilities suggest the possibility of benefits (Darlington et al., 1980 and Shonkoff and Hauser-Cram, 1987). A recently reported multi-site randomized trial of an early educational intervention in pre-term LBW infants resulted in substantially higher IQ scores and lower frequency of reported behavior problems at age three (Kitchen et al., 1990). The persistence of these effects and the expected reduction in need for special educational services remains to be established. Further, the efficacy of alternate intervention packages (especially less expensive ones) also requires further investigation.

Emerging Trends

Recent developments in technological advancement, the market for health care and the social environment are having a profound impact on the demand and supply of NICUs, and diminishing the relevance of past studies. Three areas of particular importance are (1) technological advances that are improving the survivability of newborns weighing less than 750 grams, (2) social forces that are increasing the demand for NIC, and (3) market forces that are diluting the regionalization of perinatal care.

Improving Survivability for Extremely LBW Infants

Conventional NICU technology is approaching limits set by either the small physical size of extremely premature infants or the lethality of selected congenital anomalies. Major survival gains can only come from the prevention or delay of preterm birth, a science and technology which is not likely to be available for years (Institute of Medicine, 1985). In the meantime, incremental improvements will continue. Improved obstetric care will result in the delivery of healthier, but still extremely LBW infants. The use of the newly approved surfactant replacement therapy (SRT) will also result in improved survival (Gitlin et al., 1987; Enhorning et al., 1985; Kwong et al., 1985; Shapiro et al., 1985; Maniscalco, Kendig, and Shapiro, 1989). SRT involves the installation of either artificial or animal extract surfactant into the trachea of infants whose lungs are too immature to produce enough. This drug effectively ameliorates the severity of neonatal respiratory distress syndrome and improves survival. While SRT may marginally shorten the LOS of infants who would previously have survived, the "new" survivors will be extremely LBW infants with good expected outcomes, However, these "new" survivors will actually absorb a larger fraction of the limited NICU beds because of their extremely long length of stay (Maniscalco, Kendig, and Shapiro, 1989). Shortening that length stay is limited by available nutritional technology and simply the need for time for the infants to grow.

There are other evolving technologies which will impact on NICU care in the next decade. Extra corporal membrane oxygenation technology is likely to improve, which will permit the withdrawal and return of oxygenated blood from veins rather than arteries, with substantial lower costs and risk. This may in turn promote the diffusion of this technology and its substitution for conventional ventilation. In-utero surgery is a potential break-through technology, but will affect only small numbers of infants with selected congenital anomalies. New prophylactic regimens for reducing the rate of intraventricular hemorrhage (IVH) may prove effective (Bandstra et al., 1988 and Kaempt et al., 1990). These will improve the long term outlook for NICU survivors but are unlikely to affect NICU costs. Similarly, new strategies for treating chronic lung disease with corticosteriods (Cummings, D'Eugenio, and Gross, 1989) may shorten the length of stay for this small but very expensive group of subgroup of patients, but prospects for prevention remain uncertain (Avery, Tooley, and Keller, 1987).

Social Forces Increasing the Demand for NIC

In addition to the increasing demands placed on NICUs by the improving survivability of infants born less than 750 grams, social forces are in place to expand the demand for NICUs among current and future cohorts of newborns. First, the increasing incidence of illicit drug use, especially cocaine, among women of childbearing ages (General Accounting Office, 1990; JAMA, 1989), the increasing rates of fetal alcohol syndrome and inadequate access to prenatal care among women of lower socioeconomic status (Institute of Medicine, 1985) portend a growing number of infants with adverse birth outcomes who will need neonatal intensive care. Second, if future legislation and judicial decisions restrict access to abortions, the rate of adverse birth outcomes will likely increase (Corman and Grossman, 1985; Joyce, 1990). Finally, fears of malpractice suits are leading to the practice of defensive medicine, in which moderate risk infants are transferred to the highest level of care available, with only secondary consideration given to appropriateness and effectiveness.

Market Forces Diluting the Regionalization of Perinatal Care

The importance of regionalization to reductions in neonatal mortality has been verified in studies of the effectiveness of transferring high-risk deliveries and newborns, as well as studies of the effects of regionalization on regional neonatal mortality rates (McCormick et al., 1985; Walker et al., 1985). However, recent changes in the health care market may be undermining these advances. As outlined in a recent case study of perinatal regionalization in six cities, the major threats to regionalization are increasing hospital competition and the proliferation of alternative delivery systems, such as health maintenance organizations (HMOs) and preferred provider organizations (PPOs) (Allison-Cooke, Schwartz, and Gagnon, 1988).[9]

A major way in which hospitals compete for patients is through the scope and quality of services. The desire to compete for a portion of the high-risk deliveries and infants market may be a major factor in the recent rapid expansion of Level II NICUs (or what the AHA refers to as neonatal intermediate care units). First, childbirth is frequently a family's first contact with hospitalization, and the transferring of a mother or infant to a perinatal center may threaten a community hospital's future relationship with the family. Second, community hospitals are in a better position to attract HMO and PPO contracts, if they are able to offer a wide range of services.

Allison-Cooke, Schwartz, and Gagnon identified several possible mechanisms by which increasing competition and the increasing supply of Level II NICUs might adversely affect neonatal intensive care and regionalization. One, increasing competition may reduce the spirit of cooperation between hospitals necessary to maintain the voluntary referral patterns. Two, the increasing supply of Level II facilities may lead to excess capacity, which will result in higher costs and lower quality of care. Level II NICUs in community hospitals may not be able to establish the minimum volume of patients necessary to maintain staff skills, and these facilities will generally lack the depth of pediatric support available at perinatal centers. Three, the current supply of neonatal nurse specialists may be inadequate to properly staff the growing number of Level II NICUs. Finally, a reluctance to transfer sick newborns may result in some infants being inappropriately retained at a Level II hospital."

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[9] In the text we have been referring to perinatal regionalization as if it were a single model of inter-hospital organization. But in fact, perinatal regionalization involves numerous models, varying in degrees of centralization, composition and referral patterns. See Allison-Cooke, et al. (1988) for a discussion of alternative models.

[10] A reluctance by the staff of a Level II facility to transfer sick newborns may also arise from excess confidence in their ability to care for the newborn.

At present there is very little evidence to evaluate the impacts of the growing number of Level II facilities on costs and quality of care. First, little is known about the staffing and technology available at these facilities, or what range of care they can competently provide. Second, there are very few studies of the transfer patterns from community hospitals or of the quality of care provided in Level II NICUs. One study of all live-born births in New York City in 1976 found that Level II hospitals transferred less than 4 percent of their LBW inborns to Level III, whereas Level I hospitals transferred almost 50 percent. Furthermore, the risk of neonatal mortality for LBW infants born in Level II hospitals was almost 40 percent larger than LBW infants born in Level III hospitals. When the comparison is restricted to newborns weighing between 501 and 1,250 grams, infants born in Level II hospitals have a higher neonatal mortality rate than infants born in Level I hospitals, even after controlling for birthweight, gestational age, race, and sex (Marcus, et al., 1988; Paneth, et al., 1982). These results suggests that some excess mortality in Level II hospitals might be avoided if these hospitals promptly transferred more of their infants to Level III NICUs.

Allison-Cooke, Schwartz, and Gagon also identified the growth of HMOs and other alternative delivery systems as a potential threat to perinatal regionalization because these systems encourage patient referral and transport among hospitals based on financial and contractual arrangements, rather than established medical relationships. In addition, the financial incentives of HMOs discourage expensive specialty referrals and transfers to tertiary units.

III. NICUs AND MEDICAID: ISSUES AND KNOWLEDGE GAPS

The purpose of this chapter is to explore the policy issues and knowledge gaps associated with Medicaid programs and NICUs. As the principal payer of health care for poor women and children, Medicaid programs will have an important financial impact on NICUs. Medicaid reimbursement policies will affect the revenue and financial viability of NICUs. Furthermore, demand for NICUs coupled with the reimbursement policies may substantially strain Medicaid program budgets. Despite the importance of these financing issues, few studies on NICUs and Medicaid have been undertaken. This chapter reviews the existing literature and outlines the Medicaid policy issues that demand further study, including payment systems, expenditures, access to care, variations in outcomes, and drug-exposed and HIV-infected infants.

Medicaid as a Payer of Neonatal Intensive Care

Medicaid eligibility criteria and payment policies are two primary policy tools that states can use to establish some "control" over Medicaid expenditures. Eligibility policies affect expenditure levels by defining and limiting the number of individuals who qualify for Medicaid coverage. Payment policies directly affect total expenditures, and indirectly affect the access of patients to care. Payment policies may also have an impact on the quality of the care that patients receive.

In this section, we review the limited evidence on Medicaid expenditures for infants who receive neonatal intensive care. Then we review the recent changes in eligibility criteria for pregnant women, and discuss the possible impacts of the changes on Medicaid expenditures for neonatal intensive care. Finally, we briefly review Medicaid hospital reimbursement systems and discuss the shortcomings of Medicare Diagnostic Related Groups for classifying neonates.

Medicaid Expenditures for Neonatal Intensive Care

Almost no information is available on national Medicaid expenditures for infants who require neonatal intensive care, for two primary reasons: (1) each state collects and manages its own Medicaid eligibility and claims files, and (2) it is not always possible to identify NICU infants and their costs. In most states, newborns are initially given their mothers' Medicaid identification number. Although it is usually possible to search through the specific claim items to identify mother-infant combinations who received neonatal intensive care, it is not generally possible to separate maternal cost from infant costs. Furthermore, line-item claims data for mothers and infants enrolled in prepaid health plans are unavailable.

The study that comes closest to producing national figures on Medicaid neonatal intensive care expenditures and utilization by Medicaid-covered infants is based on 13 states that responded to a 1985 survey (Kenney et al., 1986). In the 13 reporting states, 6.1 percent of Medicaid-covered live-born babies received neonatal intensive care annually, but the figure ranged from 2.6 percent in Michigan to 20.3 percent in Florida. The eight-fold difference in the range reflects cross-state differences in access to NICU care, Medicaid eligibility and payment policies, and population characteristics. The range of estimates also reflects problems in obtaining consistent measures across states, particularly in terms of how states identify infants admitted to a NICU.

The average of 6.1 percent is consistent with the national estimates of 4 to 6 percent of all newborns who receive neonatal intensive care (Office of Technology Assessment, 1987). However, one might expect a higher percentage among Medicaid-covered newborns, because they are generally considered to be at higher risk. The per-infant Medicaid expenditures for infants admitted to a NICU in the 13 states included in this study averaged $11,800, ranging from $2,028 in Oregon to $29,414 in Nevada.[1]

Too, only a few studies have reported Medicaid utilization among newborns admitted to NICUs in a specific hospital or region, and those that have been published are largely out-of-date for assessing current policies. One such study (McCarthy et al., 1979) determined that, during the first four months of 1976, 15 percent of newborns admitted to a NICU in a perinatal center in Colorado were covered by Medicaid. The per-infant charges for these infants was $11,163, compared with $10,004 for infants with other third-party coverage (these costs are given in 1977 dollars). Medicaid reimbursed the hospital for 63 percent of these charges. Another study (Marcus et al., 1988) found that 48 percent of infants transferred from Level I hospitals to Level III hospitals in New York City in 1976 were covered by Medicaid. It is not possible to form reliable national or state-specific estimates of Medicaid NICU expenditures from such limited local data. Furthermore, the age of the data would severely compromise the value of any estimates that could be formed.

Medicaid Eligibility and Its Effect on NICU Expenditures

Medicaid is the largest program that provides health services to the poor; however, not all low-income individuals are eligible. Eligibility depends on categorical criteria (aged, blind, disabled, and single parent families with dependent children), as well as on income and financial assets. Although the states have considerable discretion in establishing income and asset eligibility ceilings, the states have very few options in defining categorical eligibility status.[2] Until the mid-1980s eligibility for low-income pregnant women and children was

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[1]In Kenney et al. (1986), it is unclear whether the states reported NICU expenditures only for infants or for both mothers and infants.

[2]Federal matching funds are available only for populations that meet the federal categorical eligibility standards. However, the states can allocate state money to cover individuals who do not meet the federal categorical definitions. For example, some states have used their state funds to provide Medicaid coverage for individuals from poor, intact, two-parent families. In addition, the program is linked with Supplemental Security Income, which, however, is largely unimportant for low-income expectant mothers.

linked to eligibility for Aid to Families with Dependent Children (AFDC).[3] This linkage essentially excluded low-income pregnant women who lived in two-parent households, as well as low-income childless pregnant women. Because the state AFDC payment standards were (and still are) below the federal poverty level, many categorically eligible women and children living below the federal poverty level were still not financially eligible for Medicaid.

States have the option of establishing medically needy programs in which Medicaid coverage is extended to individuals who meet the Medicaid categorical eligibility criteria, but whose income net of medical expenses is less than the medically needy income standards set by the state. The medically needy income standards cannot exceed 133 1/3 percent of a state's AFDC payment standard. About two-thirds of the states offer medically needy programs. These programs are particularly relevant to families that incur catastrophic health expenses, such as neonatal intensive care.

In response to a growing awareness of the cost-effectiveness of prenatal care and of the high human costs of inadequate prenatal and newborn care, Congress authorized a series of Medicaid expansions between 1984 and 1990:

- Categorical eligibility criteria have been eliminated, expanding coverage to all low-income pregnant women and children regardless of family structure.
- For pregnant women and children, the Medicaid income eligibility criteria are no longer linked to the AFDC income eligibility criteria. As of 1990, states were required to expand Medicaid coverage to pregnant women and children up to age 6 living at or below 133 percent of the federal poverty level. States have the option of expanding eligibility to pregnant women and children up to age 1 who live at or below 185 percent of the federal poverty level.
- Beginning in July 1991, states are required to provide Medicaid coverage to all children born after September 30, 1983, in families whose income is up to 100 percent of the federal poverty level. By the year 2002, all such children up to age 19 will be covered. (States currently have the option of extending coverage to such children between the ages of 6 and 8.)
- States can no longer place absolute limits on the annual number of Medicaid-reimbursed inpatient days for infants in NICUs in Medicaid disproportionate-share hospitals.
- Beginning in 1991, states must continue Medicaid coverage up to age one for all infants born to Medicaid-eligible women, as long as the infants remain in their mothers' households and the mothers still meet the eligibility criteria for pregnant women.

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[3]One exception was made for children living in intact families, whose family income met the state AFDC eligibility standards. States had the option of providing Medicaid coverage for these children (referred to as Ribicoff children). Roughly one-half of the states chose this option during the early-1980s.

Forstates with medically needy programs, these changes have uncertain implications for Medicaid expenditures on neonatal intensive care. First, these changes may dramatically increase the size and alter the composition of the population served by Medicaid. If the number of Medicaid-covered births increases, then Medicaid expenditures for infants admitted to NICUs will increase, unless NICU admission rates decline sufficiently. However, the new eligibility criteria may reduce the incidence of NICU admission among infants who would have eventually qualified for Medicaid coverage through the spend-down provision in the medically needy programs; the criteria may do so by enhancing access to prenatal care and improving the birth outcome among women who otherwise would not have been eligible for Medicaid.' Thus, studies of NICUs and Medicaid that rely on data prior to the late 1980s may misrepresent the current and future course of events.

Information about the impacts of the recent Medicaid expansions is just becoming available (U.S. General Accounting Office, 1991; Senner and Eatmon, 1988; Piper, Ray, and Griffin, 1990, and Sable et al., 1990). One published study of expanding eligibility to married women during pregnancy found that the total proportion of live births covered by Medicaid in Tennessee increased by 30 percent, from 22 percent to 29 percent. The greatest increase occurred among married women younger than age 25 and with less than 12 years of education. However, the study found no concomitant improvement in the early use of prenatal care, birthweight, or neonatal mortality (Piper, Ray, and Griffin, 1990). Similarly, the Medicaid expansion in Arkansas increased the proportion of Medicaid births from 23 percent to 27 percent of all births, but apparently had no substantial effect on birth outcomes (Senner and Eatmon, 1988).

Medicaid Payment Systems

Little is known about the impact of state Medicaid reimbursement practices on access to NICUs by Medicaid-covered neonates, nor on the quality of care they receive. However, if Medicaid reimbursement rates are below a hospital's costs of providing neonatal intensive care, or if prospective payment systems do not control for systematic variation in resource use, then hospitals will face financial incentives which could reduce access and quality. (These issues are discussed later in this chapter.) In this section, we review Medicaid hospital reimbursement systems and illustrate the potential problems of prospective payment systems as they pertain to the shortcomings of Medicare Diagnostic Related Groups (DRGs) for reimbursing neonatal care.

As of mid-1987, 42 of the state Medicaid programs reimbursed hospitals for inpatient services on a prospective payment basis; 7 states plus the District of Columbia continued to use retrospective cost-based systems. The states that were using prospective systems adopted four alternative models: flat rate, budget, negotiation, and DRGs (Congressional Research Service, 1988). Twenty-one states were using a flat rate system. In a typical flat rate system, each hospital's payment rate is equal to that hospital's base-year average costs per day or per case, adjusted for inflation. Four states were using budgeted systems, in which rates paid to

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[4]The Medicaid expansions would apparently increase the Medicaid expenditures for neonatal intensive care unambiguously in states without a medically needy program.

hospitals are based on projections of utilization and hospital revenue requirements. Three of the four states were using the budget model to develop per-diem payment rates for each hospital; one state was paying hospitals on a premium basis, in which each hospital received periodic lump-sum payments for the care of Medicaid patients for that time period. Three states were establishing hospital payment rates by negotiating with each hospital. The remaining 14 states were using DRG prospective payment systems. In these systems, payments may vary by hospital or class of hospitals, as defined by size, geographic area, teaching status, or other factors. Although these states have generally adopted the Medicare DRG system, most states have developed their own set of weights based on Medicaid data, because the composition and health care needs of Medicaid patients differs from those of Medicare patients (Congressional Research Service, 1988; and Hellinger, 1986).

To illustrate some of the potential problems of existing prospective payment systems for neonatal intensive care, we now discuss DRGs for newborns. The Medicare DRG system divides newborns into one of seven groups:

- Died or transferred (DRG 385)
- Extreme immaturity or respiratory distress syndrome (DRG 386)
- Prematurity with a major problem (DRG 387)
- Prematurity with no major problem (DRG 388)
- Full term with major problem (DRG 389)
- Neonates with other significant problems (DRG 390)
- Normal newborn without significant complicating diagnosis (DRG 391)

Several recent studies have shown that these seven DRGs do not adequately classify newborns (especially those who need neonatal intensive care) into groups whose resource use is homogeneous (Berki and Schneier, 1987; Poland et al., 1985; Phibbs et al., 1986; Lagoe et al., 1986; and Schwartz et al., 1989). The DRG system markedly underestimates the costs and lengths of stay (LOS) of high-risk newborns. Furthermore, the mean resource use for DRGs 385, 386, and 387 differs systematically and substantially across levels of hospitals (Lagoe et al., 1986). For example, the mean LOS for DRG 386 (extreme immaturity or respiratory distress syndrome) in a Level III hospital was 45.8 days; in Level II and Level I hospitals, the mean LOSs were 23.3 days and 9.4 days. These differences suggest large variations in the severity of illness among newborns that are not captured by DRGs, clearly creating inequities across types of hospitals that may adversely affect the quality of care.

The failure of DRGs to classify neonates into homogeneous groups creates predictable, systematic variation in resource use. Thus, the DRG system creates incentives for hospitals, especially Level II hospitals, to select less expensive, less severely ill neonates (Allison-Cooke, Schwartz, and Gagnon, 1988). If some hospitals choose to skim off the less severely ill neonates, maternal and neonate transfer patterns, quality of care, and the financial positions of Level II and Level III hospitals could seriously be affected. To ameliorate these problems, most states alter the federal DRG model by liberalizing transfer and outlier payment policies, and by establishing different payment rates for different hospital peer-groups (for example, tertiary care facilities or teaching hospitals) (Allison-Cooke, Schwartz, and Gagon, 1988; and Hellinger, 1986).

In response to the shortcomings of DRGs for neonates (and other pediatric cases), the National Association of Children's Hospitals and Related Institutions, Inc. (NACHRI), with funding from HCFA, developed an alternative case-mix classification system, referred to as Pediatric-Modified Diagnostic Related Groups (PM-DRGs). In the most recently published version of PM-DRGs, 83 of the 467 DRGs were modified to yield categories that provide more effective distinctions among complex and expensive children's conditions.[5] Overall, PM-DRGs explained about 47 percent more of the variation in children's LOS after outliers were removed than do DRGs (NACHRI, 1986; and Lichtig et al., 1989a), particularly among neonates. PM-DRGs replace the 7 DRGs for neonates with 46 new groups. Some of the changes are as follows: (1) a single major diagnostic category has been created for only and all neonates, (2) deaths and transfers are no longer lumped into a single group, (3) birthweight (rather than diagnosis) is used as the primary variable for differentiating categories of neonates, and (4) the duration of mechanical ventilation, the presence of major problems, and surgery are used to group individuals into specific categories.[6] The PM-DRGs explained the variance in LOS for neonates (after the removal of outliers that exceed 150 days) over twice as well as DRGs--53.3 percent versus 23.6 percent (Lichtig et al., 1989b).

Although the PM-DRGs are an improvement over Medicare DRGs, questions still remain about the fairness of a per-case prospective payment system for neonatal care. Variations in local delivery systems and the cohesiveness of perinatal regionalization will affect the capacity of hospitals to control their patients' LOS and costs. For example, Level III hospitals in communities without established patterns of back-transfer do not have the same opportunity to control their patients' LOSs, as would a similar facility in a fully integrated, perinatal regional system.

Completing the PM-DRG classification system requires two data elements in addition to the information on the Uniform Hospital Discharge Data Set: birth-weight and the duration of mechanical ventilation. Several state Medicaid programs have adopted portions of the PM-DRG methodology, including New York, New Jersey, Ohio, Texas, and Colorado (Lichtig et al,, 1989b; and J. Muldoon, NACHRI, personal communication 1991). For example, the systems in place in New York and New Jersey collect information on birthweight but not the duration of mechanical ventilation.

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[5]NACHRI has continued to work developing PM-DRGs, and the latest version has not yet been published.

[6]Discharge status was not used to define separate PM-DRGs for neonates who go home versus those who are back-transferred, because it was believed that this was a payment and not a classification issue (Lichtig et al., 1989b).

Medicaid Patients' Access To Care

Given the high costs of neonatal intensive care, concern has been expressed about whether high-risk mothers and children who are poor will have appropriate access to this care. Concern about access is heightened by the findings of the Office of Technology Assessment (1987) which show that the proportion of very-low-birthweight infants treated in Level III hospitals varies substantially across regions and racial groups. While the Medicaid program seeks to improve access to care, high-risk infants covered by Medicaid may continue to lack adequate access due to the peculiarities of the Medicaid reimbursement system and the nature of neonatal intensive care.

We address this issue first by examining the various Medicaid policies that affect access to neonatal intensive care. We then focus on two indicators of access: (1) the extent to which Medicaid-covered infants are born in hospitals that systematically differ from the hospitals in which other infants are born, and (2) the extent to which the duration of hospital stays for Medicaid-covered infants differs from the length of stay for other infants. We also discuss access to neonatal intensive care among infants born in rural areas.

Medicaid Polices That May Affect Access to NICUs

Reimbursement policies are a major determinant of the access patients have to care. If Medicaid reimbursements fail to cover the costs that hospitals incur to serve Medicaid-covered infants, then those infants are likely to face restricted access to care. Reimbursements may be inadequate for several reasons:

- The reimbursements may be below the average cost of providing neonatal intensive care.
- The reimbursements may cover the average cost of an NICU, but Medicaid-covered infants may be more likely to incur above-average costs.
- The Medicaid prospective payment systems do not control for systematic variation in resource use across hospitals.
- Medicaid programs often institute utilization-control mechanisms that place hospitals at risk of not recovering payment for some part of Medicaid patients' stays if the use of neonatal intensive care is deemed to be inappropriate ex post.
- Medicaid payments to physicians may be below the payments that physicians could earn from treating other patients.

Virtually no empirical evidence is available on the adequacy of Medicaid reimbursements for NICU stays. However, there is anecdotal and preliminary empirical evidence which suggests that, in general, Medicaid rates do not cover the costs incurred by hospitals in caring for Medicaid patients (Congressional Research Service, 1988).

Two small studies of NICU costs indicate that in the late 1970s Medicaid payments failed to cover the cost of NICU care. In a study involving 26 patients in a Boston hospital, Medicaid paid only for 70 percent of the hospital's cost of neonatal intensive care (Kaufman and Shepard, 1982). Another study of a single hospital found that Medicaid paid only 62 percent of charges for infants treated in the NICU, well below the percentage of charges paid by other third-party payers (McCarthy et al., 1979). We did not find any more recent studies, but is seems likely that the cost-control measures instituted during the 1980s are unlikely to have increased the extent to which Medicaid reimbursements cover hospital NICU costs.

A shortfall between Medicaid reimbursements and NICU costs need not cause hospitals to deny access to Medicaid-covered infants in the short-term. Although hospitals would prefer to receive full reimbursement of the costs of caring for LBW infants, they may continue to admit Medicaid-covered infants even if their reimbursements do not cover total costs. Hospitals have fixed costs that they must cover. Kaufman and Shepard, (1987) estimated that the fixed costs of operating a NICU were about 45 percent of total costs. As long as Medicaid reimbursement covers the variable cost of caring for Medicaid-covered LBW infants, then hospitals with vacant bassinets will likely be willing to treat these infants. In a case-study of regional perinatal systems in six cities, Allison-Cooke, Schwartz, and Gagnon (1988) found some evidence that Medicaid payments covered variable costs, and that hospitals felt that "some payment was better than none." However, access may eventually be problematic if the flow of privately insured infants is sufficient to maintain high occupancy rates.

Two other Medicaid reimbursement policies that might affect access to neonatal intensive care are prospective payment systems and fixed limits on the number of days for which Medicaid will reimburse hospitals. First, as outlined above, prospective payment systems (even the PM-DRGs) do not account for systematic variations in NICU resource use or the local availability of Level II or III NICUs across hospitals. In addition, Schlesinger et al. (1987) found that physicians reported that hospitals in states with Medicaid prospective payment systems were more likely to discourage the admission of Medicaid and uninsured patient, than were hospitals in states with cost-based payment systems. Second, although recent legislation prohibits Medicaid programs from imposing fixed annual inpatient day limits for NICU patients in disproportionate-share hospitals, such limits may be imposed on non-disproportionate-share hospitals. To the extent that Medicaid programs impose annual inpatient day limits and other utilization control restrictions, the access of Medicaid-covered infants to NICUs in for-profit hospitals and Level II facilities may be restricted. Studies indicate that utilization control mechanisms hinder access to care by Medicaid patients, and that for-profit hospitals are less likely to treat Medicaid patients than are either public or private non-profit hospitals (Congressional Research Service, 1988; and Schlesinger et al., 1987).[7]

'Proposed Oregon Medicaid payment reforms deserve special mention. The reforms, which Oregon health officials hope to have in place by July 1992, would rank treatments in order of "costs and benefits." Medicaid-covered women and children (but not the elderly) access to specific treatments will be based on the availability of funds and the position of treatments in the "cost and benefits" ranking. As Medicaid funds run low, the state would eliminate procedures from coverage, starting from the bottom of the list. Some procedures

Finally, it is well documented that Medicaid payments to physicians are well below market rates (Congressional Research Service, 1988). Since physicians are not receiving their full market value for caring for Medicaid patients, they may provide a less resource-intense treatment regimen to Medicaid patients.

Access Issues Concerning Hospital of Birth

As discussed in Chapter II, the location and type of hospital in which a woman gives birth may influence decisions to resuscitate extremely LBW infants or to admit high-risk infants to an NICU. Although no studies have been undertaken on whether Medicaid reimbursement policies affect mothers' choices of or access to hospitals, Medicaid-covered infants may be more likely to be born in or transferred to Level III hospitals.

First, perhaps due to restrictive reimbursement policies or the geographic location of Medicaid beneficiaries, hospitalized Medicaid patients are concentrated in non-federal public hospitals, large urban hospitals, and teaching hospitals (Melnich and Mann, 1989; and Congressional Research Service, 1988). These hospitals are more likely to have a Level III NICU. Second, if Medicaid payments are less than the average cost of caring for these patients, Level II hospitals may be more inclined to transfer high-risk and high-cost Medicaid-covered women and infants to Level III hospitals relative to similar, privately insured women and infants.[8]

In addition, Medicaid prospective payment systems may give hospitals an incentive to "skim off" the more profitable patients, by selectively transferring more expensive and severely ill neonates to Level III hospitals. In states that place absolute limits on the annual number of inpatient days per beneficiary, proportionate-share Level II hospitals have financial incentives to skim off the less severely ill neonates, or risk receiving only partial payment for infants who require extra-long lengths of stay.

Even if Medicaid-covered mothers and infants are more likely to be cared for in Level III facilities, it does not necessarily imply that they are receiving good quality or an appropriate of level care. On the one hand, a goal of perinatal regionalization is to channel the more severely ill neonates into perinatal centers, where these infants can receive the highest level of neonatal intensive care. Thus, if Medicaid reimbursement policies encourage the transfer of high-risk cases, then such policies may improve the quality of care. However, this same pattern of transfers may create serious financial inequities for Level III hospitals, if Medicaid reimbursements are below costs, in which case the transfers could conceivably

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at the very bottom of the list may even be eliminated at the beginning of the fiscal year (Children's Defense Fund Reports, 1990). Under the current rankings, the treatment of extremely LBW infants is close to the bottom of the list (Medicine and Health, 1991).

[8]Maternal and infant transfers from Level I hospitals are less likely to be affected by Medicaid reimbursement policies, since these hospitals do not have the capacity to treat high-risk mothers and infants. However, it is possible that Medicaid coverage may affect a hospital's decision about whether someone is "high risk."

threaten the quality of care provided by the Level III hospitals. Furthermore, financially driven transfer patterns may lead to inappropriate levels of care. For example, some of the "high-risk" Medicaid-covered patients who are transferred to Level III hospitals may be safely and more cost-efficiently cared for in Level II hospitals. Or some of the lower-cost, lower-risk patients retained at the Level II hospitals may be cared for more appropriately at Level III hospitals.

Variations in LOS

Medicaid reimbursement policies may affect decisions about step-down care, back-transfer, or termination of treatment, which may lead to in reimbursement-driven variations in NICU LOSs. For example, it is well recognized that per-case prospective payment systems (such as DRGs) encourage reductions in LOS. Given this incentive, hospital administrators may encourage their medical staff to transfer recovering neonates more quickly to intermediate care units or to back-transfer such neonates to community hospitals. The quality-of-care implications of such behavior cannot be assessed at this time, since the appropriate timing of these decisions has not been studied adequately, and uniform standards of care have not been established. On the other end, community hospitals may be reluctant to receive back-transfers if they perceive that reimbursement will be inadequate, especially if the hospital suspects that an infant will be a "boarder baby" who will require a long non-medical LOS. If perceived inadequacies in Medicaid reimbursement hinder back-transfers, it could lead to LOS in more expensive perinatal centers, and possibly increase Medicaid expenditures or financial losses for the perinatal centers.

Some Medicaid prospective payment systems reimburse hospitals according to a fixed per-diem rate. Such systems could encourage longer than medically necessary LOS. The typical NICU survivors require very intensive care during the first week or few weeks after admission to the NICU. But as the infants' conditions improve, their care requirements gradually decline; for example, they no longer require one-on-one nursing care. After the first week of neonatal intensive care, the total cost per day of neonatal intensive care generally declines, although there may be occasional increases for infants whose conditions worsen or who die (Kaufman and Shepard, 1982). If a hospital receives fixed per-diem payments for neonatal intensive care, its costs will likely exceed payment during the early stage of the hospitalization, but a cross-over will occur at some point, whereby the hospital's costs will be less than the per-diem payment.[9] Therefore, hospitals will have an incentive to recoup some of the earlier losses, by increasing the LOS after reaching the cross-over point. This action would lead to an inefficient use of resources and will increase Medicaid expenditures. However, if a hospital faces an excess demand for its NICU bassinets, then its ability to extend LOSs will be constrained.

Although unlikely, it is conceivable that inadequate reimbursement may affect the timing of the decision to terminate treatment. If a hospital is receiving inadequate payment to cover the cost of a seriously ill neonate who is not responding to therapy, then it would have a

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'Kaufman and Shepard (1982) found that during 1977 the Medicaid cross-over point at Brigham and Women's Hospital in Boston was about 60 days.

financial incentive to decide to terminate care sooner rather than later. However, powerful forces would counteract the financial incentives: (1) the moral implications of such decisions are imposing, (2) attending physicians do not face the same financial incentives as the hospital, (3) these decisions may be made in consultation with ethics committees, and (4) the doctor-parent relationship is an important factor.

Access in Rural Areas

We have not found any studies that have directly tested the hypothesis that high-risk pregnancies or newborns among rural residents are less likely to be cared for in perinatal centers than are high-risk pregnancies or newborns among urban residents. However, urban-rural differences in access to health care services, in perinatal survival rates, and in the supply of NICU beds suggest, but do not prove, that there is differential access to NICUs in urban and rural areas. Furthermore, due to the high poverty rates in rural areas, Medicaid programs play an important role in improving the access of rural residents to neonatal intensive care.

Research on access to care in rural areas reveals that the limited supply of physicians and health resources constrain the availability of care, create longer travel and waiting times, and frequently lead to inferior quality of care in rural areas (Office of Technology Assessment, 1990; Rowland and Lyons, 1989). Hospitals are usually smaller, farther away from residents, and less adequately equipped than are urban hospitals. With the exception of regional referral hospitals, rural hospitals generally do not offer the technological sophistication and specialty care available at most urban hospitals. Distance, transportation difficulties, and inadequate financing often combine to reduce the access of rural residents to regional centers.

Urban-rural differences in infant, neonatal, and fetal mortality rates suggest that access to NICUs is greater in urban areas than in rural areas. Adjusting for race, the 1987 infant mortality rate is approximately 2 percent higher in rural areas than in urban areas: 10.07 per thousand versus 9.88 per thousand.[10] In contrast, the rural neonatal mortality rate (deaths occurring before the 28th day of life) is substantially lower than the urban neonatal mortality rate. However, the lower rural neonatal mortality rate is completely offset by a higher rural fetal mortality rate (fetal deaths of 20 weeks or more gestation). When fetal and neonatal deaths are combined (perinatal deaths), the rural perinatal mortality rate is about 2 percent higher than the urban perinatal mortality rate (Office of Technology Assessment, 1990). It may be that babies who would die at or before birth in rural areas could be successfully resuscitated and live, for at least a short time, if they had better access to perinatal centers.

As with other specialty services, access to perinatal centers in rural areas may be hampered by limited supply. In urban areas, 6.4 percent of community hospitals with less than 300 beds reportedly contain a NICU, while only 1.7 percent of similar rural hospitals reportedly contain a NICU (based on an analysis of the AHA's 1987 Annual Survey of Hospitals) (Office of Technology Assessment, 1990). And while the supply of NICU beds has increased dramatically in urban areas--by over 20 percent between 1983 and 1986--the supply

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[10]Infant mortality is measured by the annual number of deaths of infants less than one year of age divided by the annual number of live births.

of NICU beds in rural areas has declined by about 1 percent (Schwartz, 1991). Although there appears to be wide rural-regional variation in the percentage of very LBW births that occur in perinatal centers (Office of Technology Assessment, 1990), we did not find any studies that compared the likelihood in rural and urban areas that high-risk pregnancies or neonates are cared for in perinatal centers.

With respect to Medicaid policy, a larger percentage of rural residents than urban residents live in poverty, and differences across regions are dramatic. In 1987, 18.3 percent of residents under age 65 in non-metropolitan statistical areas had incomes below the federal poverty level, compared with only 12.6 percent of residents in metropolitan statistical areas. Rural residents in the South had the highest poverty rates at 55.3 percent, while only 6.6 percent of rural residents in the Northeast had incomes below the federal poverty level. Furthermore, poor rural residents are less likely to have Medicaid coverage and more likely to be uninsured than are poor urban residents. This is particularly the case for farm-rural residents, because their farm assets often make them ineligible for Medicaid benefits (Rowland and Lyons, 1989).

In summary, we found no studies that examine whether the access of rural Medicaid-covered mothers and infants is more restricted than the access of privately insured rural residents. But rural providers face the same incentives created by Medicaid reimbursement policies that urban providers face, and access of rural residents to NICUs depends more on decisions to transfer high-risk mothers and infants.

Variations in Outcomes

The extremes of state-specific neonatal mortality rates vary substantially. For all races in 1980, the highest state-specific neonatal mortality rate was 15.8 per 1,000, while the lowest state-specific rate was 4.4 per 1,000. Differences among states are not surprising, because population risk factors, the prevalence of LBW, and access to care, especially neonatal intensive care, differ widely among states. However, it is surprising that differences in mortality risk are so large, and that these risk differentials remain even within race and birth-weight categories (Marks et al., 1987). Similar but far less dramatic differences are found when the states are aggregated into four regions: West, North Central, South and Northeast (Allen et al., 1987).

Race and birthweight-specific mortality differences are influenced not only by maternal and infant characteristics, but also by the availability and quality of medical care. The fact that differences in state and region-specific rates persist even after birthweight and race are controlled for suggests that differences in access to care and quality of care contribute to the observed differences in mortality risks. Below, we review the literature on the variation in mortality and morbidity among NICUs, and discuss the possible explanations for these variations. We conclude this section with a brief discussion of their implications for Medicaid.

Variations in Neonatal Mortality

Although birthweight is the major determinant of mortality, large differences in birth-weight specific mortality exist across NICUs. Researchers in multicenter trials of surfactant (Horbor et al., 1989) and the Collaborative European Multicenter Study group (1982) reported marked differences in mortality among NICUs. The National Institute for Child Health and Human Development (NICHD) NICU Network demonstrated as much as a 50 percent variation in the survival of infants of less than 1,000 gram weight among seven participating centers (Hack et al., 1990). Schwartz et al. (1990), using a large multi-hospital discharge data base, showed significant variation in birthweight-specific mortality even among Level III centers.

Several studies provide evidence that these differences might reflect quality of care. These studies have addressed quality-of-care issues by seeking to explain differences in mortality based on information on a variety of patient and community characteristics and then attributing unexplained differences to differences in the quality of care. Williams (1979) demonstrated marked variation in neonatal mortality rates in California hospitals, even when linked birth/death records were used to adjust for birthweight and maternal risk factors. The Collaborative European Multicenter Study Group (1982) compared two NICUs and exposed an unexplained high mortality rate which suggested deficiencies in the quality of care. After using a blood gas analysis to adjust for the severity of illness between two British NICUs, Tarnow-Mordi et al. (1990) found nontrivial residual variation in mortality rates. Paneth et al. (1982) performed a series of studies on New York hospitals which showed that location of birth in Level I or II versus Level III units led to demonstrable differences in mortality rates. Gortmaker et al. (1985) showed similar variations in birthweight-adjusted mortality between Level III and non-Level III hospitals. Shapiro and McCormick (1982) demonstrated substantial variation in newborn mortality rates for hospitals within the same region. However, no study has examined variations in individual practices and linked them with variations in birthweight-specific mortality.

Variations in Neonatal Morbidity

A few careful inter-institutional studies of variations in complications of prematurity or neonatal intensive care among NICUs have been undertaken. The best sources of such comparisons are secondary analyses of multi-site studies of new therapies. Unfortunately, such inter-institutional variations are frequently viewed as "noise" to be filtered out statistically, or unexplained differences that are potentially controversial are often not published. Nonetheless, the studies do exist demonstrate marked variation in morbidity rates for selected adverse outcomes.

Long-Term Neurologic Sequelae--Perhaps the most thoroughly studied neonatal outcomes are the long-term neurologic sequelae of NICU survivors (McCormick, 1989). These have generally been reported as case series from diverse institutions with differing populations over changing eras of neonatal intensive care, and have been remarkably difficult to compare (Aylward et al., 1989). A few collaborative inter-institutional studies have been performed (Shapiro et al., 1983; and The Infant Health and Development Program, 1990) but have not focused on variations. Most studies have focused on infancy, since monitoring longer-term neurologic follow-up is difficult due to the expense of long-term tracking. Thus, while overall outcomes are well characterized, variations among institutions are not. However, the existence of such variation would be expected, since the sequelae associated with poor outcomes do vary, as noted below.

Bronchopulmonary Dysplasia--Bronchopulmonary dysplasia (BPD) is a chronic lung injury of newborns due to prematurity and ventilator-induced barotrauma. The long-term implication of chronic illness in newborns is different than in adults, because BPD may induce major life-time expenditures. Marked variation in rates of BPD have been demonstrated by Avery et al. (1987), Horbar et al. (1988), and Kraybill et al. (1987 and 1989). This variation persisted after adjustments for birthweight and sex. None of these studies was able to adjust fully for the severity of illness among the population, but one indicated differences in ventilator management techniques associated with higher or lower BPD rates (Kraybill, Bose, and D'Ercole, 1987). Similar inter-institutional differences were noted in collaborative studies of the efficacy of artificial surfactant (Horbar et al., 1989).

Necrotizing Enterocolitis--Necrotizing enterocolitis (NEC) is a fulminant, and is often a lethal illness of prematures. It is related to the degree of prematurity and possibly to care practices (Kliegman and Fanaroff, 1984). In addition, there are epidemics of NEC which suggest an infectious etiology. Inter-institutional comparisons are few. One secondary analysis of a multi-institutional drug trial showed significantly higher NEC and sepsis rates in one participating hospital (Johnson et al., 1985). The NICHD NICU Network reported NEC rates of 3 to 19 percent (Uauy et al., 1990).

Nosoeomial Infection--Nosocomial bloodstream infection and pneumonia are significant problems in the NICU. There is evidence that bacteremia is related to such care practices as lipid infusions and central catheters (Freeman et al., 1990), and to the ICU environment, such as space per patient (Goldmann, Freeman, and Durbin, 1983) and overall census and the acuity of the unit. Bacteremia rates ranged from 7 to 26 percent in the NICHD 10-NICU network, even within narrow birthweight strata (Pert-in et al., 1989).

Explanations for Variations in Mortality and Morbidity

There are several possible explanations for these variations--the evolution of technology, the quality of obstetric care, the quality of NICU care, and baseline population risks:

- The rapid evolution of NICU technology means that small disequilibriums in technology diffusion would lead to transient differences in mortality and morbidity between institutions. And historical comparisons, even across short time frames, would identify short-term differences associated with the speed at which new technologies are adopted.

- The outcome of neonatal intensive care depends heavily on the quality of obstetric intervention. NICUs of equivalent skill and quality may still compare unfavorably if the quality of their hospitals' obstetric care differs.

- The most important possibility is that quality of NICU care may differ among institutions. Such variations would offer important opportunities to improve care. Rather than poor care, it is also possible that selected clinical practices may be deleterious, but this possibility has yet been determined due to the generally homogeneous practice style in each local institution.

- Different NICUs care for populations with different baseline risks. Birthweight, gestational age, race, sex, birth outside of a perinatal center, and socioeconomic status have all been shown to affect mortality risk. Severity of illness may be the major factor that mediates these population differences.

Medicaid Issues

A primary issue for Medicaid policy is whether Medicaid-covered newborns are disproportionately likely to be treated in facilities that exhibit characteristically poorer outcomes or to be treated by less-skilled physicians. Restrictive Medicaid reimbursement policies, especially relatively low Medicaid reimbursement rates, are possible reasons for this scenario. A related issue is whether Medicaid-covered newborns are treated differently than privately-insured newborns in the same hospital. At this time, these issues have not been studied, since, as explained in the above literature review, very little is known about the magnitude and the causes of variations in quality of care across facilities.

If Medicaid-covered newborns are receiving lower quality care, then they may demonstrate a higher prevalence of disability and long-term service need than necessary, thus leading to higher total long-term Medicaid expenditures.

Special Populations of Interest

The dramatic spread of the HIV infection and the alarming rise in substance abuse among women of childbearing ages have profound implications for the women and their children. The spread of HIV and cocaine abuse has also strained public health systems in high-incidence communities. Although this spread is not specifically a Medicaid problem, the Medicaid program is likely to be a major payer for the health care of HIV-infected or cocaine-using pregnant women and their children.

Drug-Exposed Infants

In this section, we document the effects of maternal drug use, especially cocaine, on newborns, and review estimates of the prevalence of maternal drug use. Finally, we discuss its implications for Medicaid expenditures.

Maternal Drug Use and Adverse Birth Outcomes--In-utero exposure to cocaine affects developing fetuses in three ways: (1) the substance directly enters the fetus by passing through the placenta, (2) it changes the fetal environment (for example, by reducing the flow of blood and oxygen to the fetus), and (3) it produces changes in the mother's central nervous system that places the fetus at risk. Cocaine use during pregnancy has been associated with substantial reductions in gestational age, birthweight, head circumference, birthweight for gestational age, and Apgar scores (Burket, Yasin, and Palow, 1989; Chasnoff, 1989; Chasnoff et al., 1989; Chasnoff et al., 1988; Chouteau et al., 1988; Dixon, 1989; Fulroth et al., 1989; GAO, 1990; Kaye et al., 1989; MacGregor et al., 1987; and Ryan et al., 1987). Cocaine use during pregnancy has also been associated with increases in neurological or neurobehavioral problems in infants, premature or precipitous labor, abruptio placentae, and congenital malformations (Burket et al., 1990; Chasnoff, 1989; Chasnoff et al., 1989; Chasnoff et al., 1988; Chavez et al., 1989).

Although the available evidence points a damning finger at maternal cocaine use, it still is not possible to separate the direct from the indirect effects of maternal cocaine use on adverse birth outcomes. First, cocaine users frequently abuse other drugs, especially heroin (Chasnoff, Burns, and Burns, 1987; Kaye et al., 1989; Fulroth, Phillips, and Durand, 1989; MacGregor et al., 1987; and Ryan, Ehrlich, and Finnegan, 1987). The limited number of studies that have compared adverse outcomes among cocaine and heroin users, heroin but not cocaine users, and cocaine but not heroin users lead to mixed and generally insignificant differences. Second, the majority of the studies do not control for socioeconomic and behavioral correlates associated with cocaine use that could lead to adverse birth outcomes, such as the lack of adequate prenatal care, poor nutrition, smoking and other bad health habits. However, the few studies that do control for a subset of these correlates generally find that the association between maternal cocaine use and adverse birth outcomes remains significant.

Prevalence of Maternal Drug Use--No national studies have been undertaken on the prevalence of substance abuse during pregnancy or of the characteristics of women who abuse drugs during pregnancy.[11] The studies that are available tend to be small scale, frequently rely on hospital-based, unrepresentative samples, and generally lack specific information on the frequency, degree, and type of substance abuse. However, it is clear that the prevalence rate has increased dramatically during the past decade, especially for crack cocaine (an inexpensive, smokable free-base cocaine).

While not explicitly examining the issue of maternal drug use, a recent national survey revealed that a large number of women of childbearing ages are current users of illicit drugs (cocaine, heroin, PCP, marijuana, amphetamines, methamphetamines, and barbiturates). The 1985 National Household Survey on Drug Abuse conducted by the National Institute on Drug Abuse estimates that six million women between age 15 and 44 had used one or more illicit drugs in the past month, and about one million (or 3.5 percent) appear to be current users of cocaine. About 5.3 percent of 15- to 21-year-old women were current users (American Association for Marriage and Family Therapy, 1990).

“The National Maternal and Infant Health Survey collected some information about maternal drug use for a national sample of mothers. However, relatively little drug use was reported by the respondents and the sample of reported drug users is too small to serve as a basis for developing national estimates.

National estimates of the annual number of infants prenatally exposed to drugs range from 100,000 infants exposed to cocaine to 375,000 exposed to illicit drugs (General Accounting Office, 1990). Neither of the estimates is based on a nationally representative sample of births.[12] The General Accounting Office's (GAO) analysis of the National Hospital Discharge Survey of 1986 identified 9,202 infants nationwide with indications of maternal drug use during pregnancy. A similar analysis using the 1988 survey data identified 13,765 such infants. However, both of these numbers are a significant undercount, because physicians and hospitals do not screen and test all women and their infants for drugs (GAO, 1990).

Another view of the magnitude of the problem is had by examining the incidence of infant drug exposure in large cities, where overall drug use, especially cocaine use, has risen sharply in recent years. For example, a study in New York City estimated that 5 percent of all live births were exposed to crack, and a study in the District of Columbia estimated about 15 percent. In a study of 1,000 mothers giving birth in eight Philadelphia city hospitals during an eight week period in 1989, cocaine use was detected in 16.3 percent of the mothers (American Association for Marriage and Family Therapy, 1990). A study in a Detroit hospital, accounting for more than 7,000 births in 1989, found that the 42 percent of infants were drug-exposed (GAO, 1990). In a study of 715 pregnant women in Pinellas County, Florida, 14.8 percent tested positive for illicit drug use (Chasnoff, Landress, and Barett, 1990). The GAO (1990) audited medical records from two, nonrandomly-selected hospitals from each of the following cities: Boston, Chicago, Los Angeles, New York and San Antonio. The hospitals selected accounted for 44,655 births in 1989 and primarily served a population receiving Medicaid or other forms of public assistance. The study identified 3,904 infants (8.7 percent) as drug-exposed; hospital-specific percentages range from 1.3 percent of births from a hospital in San Antonio, to 18.1 percent from a hospital in Chicago. Finally, the House Select Committee on Children, Youth and Families surveyed 18 hospitals around the country in 1989; 15 of these hospitals reported a three to four-fold increase in the number of drug-exposed infants between 1985 and 1988.

Although one has to be cautious when comparing figures across these city or hospital-specific studies, since the study populations vary and the means of identifying maternal drug use differ,[13] the collective weight of these studies point to an important national problem

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[12]The estimate of 100,000 cocaine-exposed infants was reported in the President's 1989 National Drug Control Strategy Report. The estimate of 375,000 is based on a survey of 36 (of 40) hospitals responding to a survey by the National Association for Perinatal Addiction Research and Education. The overall incidence of substance abuse in pregnancy based on discharge diagnosis was 11 percent, with a range of 0.4 to 27 percent.

[13]For example, the surveys conducted by the National Association for Perinatal Addiction Research and Education (NAPARE) have shown that the reported incidence in drug use among pregnant women is directly proportional to the thoroughness of hospital testing protocols. Drug screening protocols vary from no defined protocol, to testing if a mother reported drug use or if the infant manifested drug withdrawal symptoms, all the way to requiring systematic screening and testing of every mother and infant for potential drug use or exposure.

and to catastrophic public health problems in some major cities. Large numbers of infants, especially in major cities, may suffer from serious health and behavioral problems as a result of in utero drug exposure.

Implications for Medicaid Expenditures--The implications for Medicaid expenditures of the large number of drug-exposed infants depend on whether drug-exposed infants are more likely to be covered by Medicaid and to have higher health care expenses than are non-drug-exposed infants. The limited available evidence suggests that Medicaid programs are experiencing substantially higher expenditures because of the larger number of drug-exposed infants. But there is insufficient data to reliably quantify these increases.

Given the progressive nature of cocaine and heroin addiction, abusers of these drugs are likely to be poor and unable to maintain long-term employment (Chasnoff et al., 1990). Because of the association between maternal drug use and poverty, drug-exposed infants are more likely to be covered by Medicaid or to be uninsured than are non drug-exposed infants. However, there are no good national or state-level estimates of what percentage of drug-exposed infants are covered by Medicaid. But in one study of maternal drug use among women giving birth at 12 New York City hospitals, 90 percent of the women were unmarried and 70 percent of the women were covered by Medicaid (Kaye et al., 1989).[14]

The health problems of drug-exposed infants often lead to longer and more complicated hospitalizations that are reflected in higher hospital charges. For example, Kaye et al., (1989) found that about 45 percent of infants exposed to heroin or heroin plus cocaine required neonatal intensive care, and that 22 percent of infants exposed to cocaine but not heroin required neonatal intensive care. The mean post-delivery LOS for infants exposed to heroin plus cocaine was 31 days. The GAO (1990) found that in the three hospitals for which they were able to obtain charge data hospital charges for drug-exposed infants were up to four times greater than those for infants with no indication of drug exposure. For example, at one hospital the median charge for drug-exposed infants was $5,500, while the median charge for non-exposed infants was $1,400. These findings are based on simple comparisons of medians; there was no control for socioeconomic or behavioral correlates. At these same three hospitals roughly 20 percent of drug-exposed infants received neonatal intensive care, while only about 7 percent of non-exposed infants received neonatal intensive care (unpublished data provided by the GAO). A study of drug-exposed and non-exposed infants from Harlem Hospital found that after controlling for the effects of maternal smoking, alcohol use, age, race, gravity, prenatal care and sex of the infant, use of cocaine in conjunction with other drugs (excluding marijuana) increased hospital costs by $12,386 (significant at p less than 0.01) (Phibbs et al., 1991). Much of the increased costs was incurred after the infants were medically cleared for discharge, while they were waiting for social service evaluation.[15]

[14]Sixty-nine percent of the non-drug using control group was unmarried, but there was no comparative percentage for Medicaid coverage.

[15]The availability of social services and foster care placements will affect the length of "boarder stays." Thus, the costs for this care are likely to be higher where substance abuse problems are more pervasive.

Polydrug use increased the costs until medically cleared by $8,450 (significant at p less than 0.01).[16]

The studies to date have not clearly defined the long-term effects and costs of drug-exposure. If maternal drug use has a protracted effect on exposed infants, then the total costs may be much larger. Furthermore, studies to date have not adequately distinguished the health and cost impacts of crack use from non-crack cocaine use. The limited evidence to date suggests that the impacts may be larger for crack use (Kaye et al., 1990; Phibbs, Bateman, and Schwartz, 1991). If so, this could have major cost implications for local public health departments and the Medicaid program.

HIV-Infected Infants

The problem of HIV infected children cannot be separated from the problem of maternal drug use. Roughly three-quarters of the nation's pediatric acquired immunodeficiency syndrome (AIDS) cases are associated with drug use by one or both parents (Hegarty et al., 1988). However, HIV-infected newborns are not an important issue for neonatal intensive care. First, the incidence of newborn HIV infection is low and HIV-infection does not appear to be an independent risk factor for a NICU admission.

Although increasing at an alarming rate, the overall number of pediatric AIDS cases is still relatively small. The total number of cases reported diagnosed as of December 31, 1990 is 2,786; 84 percent of these were linked to a mother-at-risk (Center for Disease Control, 1991). Between 60 and 70 percent of mothers-at-risk are intravenous drug users, and another 15 percent are sexual partners of intravenous drug users (Novick et al., 1989). In 1989,645 pediatric AIDS cases were diagnosed, and as of January, 1991, 782 cases were reported diagnosed in 1990 (Center for Disease Control, 1991).[17] Nearly half of the pediatric AIDS cases have been reported in New York, New Jersey and Florida. In contrast, only about seven percent of the cases have been reported in California.

It is well recognized that the number of AIDS cases is only the tip of the iceberg, and that there are many more individuals infected with HIV (MMWR, 1990). Roughly 50 percent of HIV-infected adults will develop clinically defined AIDS within ten years from the date of infection. But even before they are diagnosed with AIDS, these adults will experience a deterioration in their immune systems and an increase in health care utilization. For HIV-infected children, the AIDS incubation period is much shorter and the cumulative mortality rate is higher; and in addition to the opportunistic infections that characterize adult HIV-related disease, infected children are particularly inclined to recurrent episodes of bacteremia, meningitis and other bacterial infections (Hegarty et al., 1988).

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[16]The costs and charges reported in the text do not include costs or charges for physician services, which will increase the total costs or charges by 15 to 20 percent (Phibbs, Bateman, and Schwartz, 1991).

“This number will surely increase because of a reporting lag, especially for cases diagnosed during the last quarter of 1990.

Because NICU admissions generally occur within the first few days of life, knowledge of the annual incidence of HIV transmission to newborns is essential to understanding the possible implications of HIV infection on the demand for neonatal intensive care. The Center for Disease Control estimated in 1990 that the annual incidence of HIV infection in newborns is between 1,500 and 2,000 compared to 782 diagnosed AIDS cases (MMWR, 1990). The estimates were based on the following two assumptions: (1) the estimated infection rate among child-bearing women is 1.5 per 1,000, and (2) one out of three infants born to HIV-infected mothers will be infected.[18]

There is very little known as to the likelihood that HIV-infected newborns will be admitted to a NICU. In a recent survey of 44 private hospitals, 14 percent of the bed-days of HIV-infected children were for intensive care. In a similar survey of New York City hospitals, nine percent of bed-days of HIV-infected children were for intensive care (Andrulus et al., 1990). The age categories used in the survey do not permit one to distinguish newborns from other children. Therefore, it is not possible to identify to what extent intensive care days represent neonatal intensive care use. In all likelihood, the majority of intensive care days are for pediatric intensive care, since the typical pattern of care for pediatric AIDS cases requires repeat hospital admissions for severe, reoccurring bacterial infections (Hegarty et al., 1988). Although there is no indication in the published literature that HIV infection of newborns is an independent risk factor for a NICU admission, HIV infection is associated with other risk factors for neonatal intensive care, in particular fetal drug exposure, poverty and inadequate prenatal care (Novick et al., 1989).

In conclusion, HIV infection among newborns does not appear to be a significant issue for neonatal intensive care. The annual incidence of newborn HIV infection is relatively low, especially in comparison to the number of infants born at LBW (2,000 versus more than 260,000). Furthermore, the life-threatening bacterial infections, which characterize pediatric AIDS cases, do not generally manifest during the newborn hospital stay. In fact, definitive diagnoses of HIV infection are generally not made until a child is several months old.[19]

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[18]The formula for estimating the annual incidence of newborn infection is

$$1.5/1000 \times 1/3 \times \text{annual number of births.}$$

The two assumptions mentioned in the text are based on epidemiological studies of perinatal HIV transmission and of HIV infection among child-bearing women.

“Because maternal IgG antibodies cross the placenta, even newborns testing seropositive for HIV antibodies may not be infected. Only about 30 percent are infected.

Early Discharge with Medical Services and Technology

Medicaid programs could conceivably save a large amount of money, if the hospital stays of very LBW infants can be safely and economically reduced by the substitution of community-based medical services and technology. A study by Brooten et al. (1986) found that early hospital discharge with home follow-up care was sage and cost-effective. In this study, special instruction, counseling, home visits, and daily on-call services of hospital-based nurse specialist were provided to a group of very LBW infants randomly selected for early discharge. Infants in the early-discharge group were discharge on average 11 days earlier, weighed 200 grams less, and were two weeks younger at discharge than the randomly-selected control group. Over the 18 month study period, the early-discharge group experienced an average net-savings of $18,560 (p less than **0.01),** although the two groups did not differ in health status.

Below we review the types of medical services and technology that could be used to facilitate early discharge, and then we discuss the relevance of this strategy for the Medicaid population.

Types of Medical Services and Technology

The types of services that could be used to facilitate early discharge would depend on the type and severity of the problem. In view of the general types of complications for very LBW infants, however, most services would involve four main areas: pulmonary, sensorineural impairment, nutrition, and movement. In addition, each type of service would involve equipment -for treatment and/or monitoring, and professional personnel to educate parents and to provide ongoing support both within the home and within clinical settings.

For children with residual symptomatic chronic pulmonary difficulties (bronchopulmonary dysplasia), management ranges from the use of bronchodilators and theophylline for reactive airway symptoms/apnea (with annual influenza shots) to oxygen dependence with or without ventilator support. Besides oxygen (and consumable supplies such as tubing and nasal cannulas) or ventilator (with **tracheostomy** supplies), such children will also require apnea monitors, oxygen saturation monitors (used by parents/respiratory therapists), and potentially accurate scales for monitoring weight changes which may signal impending cardiopulmonary failure and need for diuretics (Ballard, 1988).

Sensorineural impairment includes visual and hearing difficulties ranging from mild impairment to blindness and deafness. For the latter, hearing aids may be needed; for the former corrective lenses, and, for retinal detachment associated with retinopathy of prematurity, recurrent surgery. Children with sensorineural impairment also require specialized developmental services to foster appropriate developmental skills. It should be noted that prompt identification of sensorineural impairment is critical to prevent further disability. In contrast to adults, for example, a child who experiences severe visual defects may suppress vision in an eye resulting in failure to develop appropriate neural pathways, which may lead to blindness or a lack of depth perception.

Nutritional support may simply involve special high calorie and/or elemental formulae. However, children with other chronic problems and/or severe sequelae of necrotizing enterocolitis may require special supplements, glucose-monitoring equipment, naso-gastric tube feeding (with meals or overnight) or gastric tube placement with stoma supplies (Ballard, 1988; Taeusch and Yogman, 1987; and McCormick, forthcoming).

Movement difficulties (for example, cerebral palsy) may require muscle relaxants, splinting/bracing, walkers, crutches, surgery, and (as children age) wheelchairs/special beds.

Since so many of the term children in NICUs involve children with a wide variety of congenital malformations, the type of technologies and supports would be difficult to estimate without some special surveys across a wide variety of subspecialty medical and surgical clinics.

The deployment of such technology in the home requires technical support from appropriate technologists for monitoring but also to educate parents and their supports who will be the primary care givers. In addition, access to high quality primary and referral medical services to deal with the often acute and unpredictable decompensations as infants experience many of the common illnesses of infancy.

Currently, coordinating and paying for such services, and providing care falls mainly to the parents. Although third party payors finance most medical services, many technologist services (especially home-based) are not reimbursed. Depending on the local situation, some services (for example, occupational or physical therapy) may be provided through Early Intervention Services, which in many sites are community supported, or through other programs such as Crippled Children's, Easter Seals, or March of Dimes. Nutritional services may also depend on the formulae and requirements of local WIC programs. In view of the multiplicity of sources of services and payment mechanisms, providing a coordinated set of services for a multi-problem child may require substantial coordination efforts and advocacy to demand mandated services (Hobbs and Perrin, 1985).

Relevance for Medicaid Population

Successful early-discharge programs can be developed for Medicaid recipients. In the study by Brooten et al. (1986), 75 percent of the early-discharge group were Medicaid recipients. However, strategies to control NICU expenditures by discharging infants early with medical services and technological support may be more difficult to implement for Medicaid populations. These strategies rely on parents as the major care providers and require those parents to have a high level of technical competence, parenting skills and stamina. The situation may be further complicated, when the high prevalence of multiple births among very LBW infants is considered, so that parents may be dealing with two or more children simultaneously. This reliance on parents may reduce the relevance of these strategies for medicaid recipients given that they are largely single parents and young mothers with limited educational backgrounds coming from disadvantage environments with their own health problems. Such populations may also be disproportionately dependent on fragmented clinic-based care, and rely on public transportation to obtain medical services. Poor families may reside in settings, both urban and rural, that make the deployment of home-based services with home visits from technologists difficult and/or dangerous. The additional bureaucratic hurdle of dealing with the welfare establishment may only add to the burden of obtaining services. Finally, access to information about services, providers and advocacy may be limited by reduced local resources (hence long waiting lists) and the woman's own lack of self-esteem and experience with self-efficacy.

Health and Developmental Consequences for NICU Survivors

The proportion of NICU survivors with severe handicapping conditions is relatively low, and site-to-site variations are not well described (Escobar, Littinberg, and Pettiti, 1991). Among those without severe handicapping conditions, a substantial but incompletely characterized proportion will have less severe physical and/or developmental difficulties requiring special services. In general, the care needs of NiCU survivors are highly variable. Besides the complications of the newborn period, NICU graduates experience a higher incidence of health problems common to infancy. Furthermore, NICU graduates have an increase need for well-child prevention and surveillance for emerging problems.

In this section, we discuss several implications of these health and developmental consequences for Medicaid: (1) Are the number of children with disabilities and severe impairments increasing due to the spread of NICU technology? (2) Is the average expenditure per Medicaid-covered child increasing? However, little research exists to answer these questions.

The first question reflects the extent to which the total number of children with disabilities or severe impairments is increasing due to the spread of NICU technology, hence, even if the proportion of Medicaid-covered newborns remains the same, Medicaid expenditures may increase. The data are controversial; however, most studies report decreases in the proportion with severe disability (Pharoah et al., 1990; Edmond et al., 1989; Shapiro et al., 1983; and Sargal et al., 1988). While the number of infants surviving without severe handicap is increasing more rapidly than the number of disabled survivors, the number of disabled survivors is also increasing. However, available studies deal only with neurodevelopmental handicaps. The proportion discharged with symptomatic complications of the neonatal period, acute intervening morbidity and less severe neurodevelopmental and physical problems is unknown and likely to vary substantially by site.

The second question reflects the expenditures per child. As noted above, expenditures are likely to vary with the number of problems and their severity, and the availability of other resources. In addition, expenditures will vary with the efficiency with which services are provided. This efficiency includes proximity of services (to reduce travel time and increase compliance), coordination among providers (case management), and advocacy to obtain needed services financed by agencies other than Medicaid. Reliance on busy primary care medical providers, even within HMO settings, to provide this coordination may prove to be insufficient, especially with disadvantaged parents. In particular, individual neighborhood clinics or HMOs may not have sufficient volume of the various types of relatively unique problems affecting the pre-term and term NICU graduates to warrant the specialist services needed.

The situation is further complicated by the fact that third party payors (generally other than fee-for-service Medicaid) treat different referral services which NICU graduates may require differently. While pulmonary referrals are readily reimbursed, referral services for neurodevelopmental services may not be reimbursed until a clear disability (such as, cerebral palsy) or condition (such as, seizures) emerge. Such "developmental" services are considered the purview of the primary care pediatrician or other providers. However, such differentials in payment practices hamper providing consistent, coordinated care.

Finally, interrupted Medicaid eligibility in the short-term (such as, interruptions caused by the medically needy provisions or changes in parents' employment) may actually increase long-term expenditures due to failure to obtain needed preventive services or early surveillance (Braverman et al., 1989). Young adults and young families are among the least well insured groups in the U.S. An unexpected premature birth or birth with a major anomaly often pushes such families into the "medically needy" category in the neonatal period (Palfrey et al., forthcoming). Depending on the subsequent health events and employment, the family may become intermittently eligible for Medicaid during major health problems. Further, if intervening health and/or developmental problems are neglected due to lack of resources, expenditures under Medicaid may be higher.

Data Needs

In order to address the various Medicaid issues raised in this Chapter, HCFA will need data pertaining to a variety of issues. Table III.1 lists the key data items HCFA will need to address the central issues surrounding Medicaid and NICU costs. The data items are aggregated into four major categories: data about infants and their mothers, data about hospitals, data about costs and charges, and data about reimbursements. Under each of these broad areas are listed the principal associated variables needed to measure outcomes and characteristics in that area. We will return to this list at the end of the report and discuss the extent to which the available data sources can meet these needs.

TABLE III.1

DATA NEEDS

Infant Data

- Birth Weight
- Gestational Age
- Apgar Score
- Complications of Labor Delivery
- Abnormal Conditions of Newborns
- Diagnosis Codes
- Congenital Anomalies
- Procedure Codes
- Maternal Characteristics
  - Sociodemographic
  - Prenatal care
  - Risk factors for pregnancy
- Payor
- Inborn/Outborn
  - Birth Hospital
- Health Status at Discharge
- Discharge Status
- Date/Age of Death
- Place-of Death
- Cause of Death

Hospital Data

- NICLJ Level
- NICU Size
- NICU Occupancy Rate
- Teaching Status
- Urban/Rural

Cost/Charge Data

- Hospital Charges
  - Total
  - Cost Center
- Cost-to-Charge Ratio
  - Aggregate
  - Cost Center
- Hospital Input Measures
- Physician Charges
  - Total
  - Procedure

Reimbursements

- Source
  - Medicaid
  - Private Insurance
  - Other
- Hospital Reimbursement
  - Total
  - Cost Center
- Physician Reimbursement
  - Total
  - Procedure

IV. MEDICAID EXPENDITURES FOR INFANTS ADMITTED TO NICUs

A main focus of this study is to identify strategies for measuring Medicaid expenditures for infants admitted to NICUs. However, before we begin the discussion of alternative strategies, it is important to clarify terminology regarding expenditures, charges and costs. For the purposes of this report expenditures and reimbursements will refer to the amount of money spent by third party payers, in particular Medicaid. Charges are the dollar values of the bills that providers submit to patients and third party payers for the care provided to patients. Charges submitted to Medicaid programs generally exceed Medicaid expenditures, but in some cases they may be equal. For example, some hospitals that are reimbursed by a negotiated per-diem rate or by DRGs may choose to report the Medicaid reimbursement rates as their charges, rather than the standard charges they would submit to other third party payers. Cost refers to the economic value of the resources used to provide patient care. Few studies of neonatal intensive care costs attempt to measure actual costs of each facility; most studies measure costs indirectly by multiplying a hospital's charges by that hospital's cost-to-charge ratio. Cost-to-charge ratios are usually calculated from data provided by hospitals in the Medicare annual cost reports.

In thinking about the strategy required to estimated Medicaid expenditures for infants admitted to NICUs, we begin by assessing the types of data needed and the extent to which those needs are met by the current literature. We then consider the extent to which data needs could be met by current Medicaid data systems, other data sources, and some specialized studies.

Types of Expenditures

We believe there is value in distinguishing three types of Medicaid expenditures for newborns admitted to NICUs: (1) expenditures for care received in NICUs; (2) total expenditures for all the newborn's hospital care until they are discharged either to home, to a non-hospital institution, or to death; and (3) total expenditures for health care received during some time period after hospital discharge, such as the first year of life. Care provided in NICUs is among the most expensive of all types of hospital care, and Medicaid expenditures for this care will be influenced by regional, across-hospital and temporal variations in practice patterns, technology diffusion, extent of perinatal regionalization, and reimbursement policies. Although direct NICU expenditures are the dominant portion of total expenditures for a very LBW infant, the infant is likely to spend a substantial period in a hospital's regular pediatric unit. The expenditures for this regular pediatric care can be large, especially for "boarder babies" (Hegarty et al., 1988; Phibbs, Bateman, and Schwartz, 1991). Because approximately 30 to 40 percent of NICU graduates are readmitted to a hospital within the first year of life, and they may require extensive outpatient treatment, Medicaid programs will also incur high expenditures even after a newborn is discharged (Shankaran et al., 1988; McCormick, 1989; McCormick, Shapiro, and Starfield, 1980).

Literature Review

As mentioned previously, there are no current, complete or detailed estimates of national Medicaid expenditures for infants receiving neonatal intensive care. Among available studies, the study by Kenney et al. (1986) comes closer to providing national figures. This study included state-reported annual aggregate Medicaid neonatal intensive care expenditures for 17 states between 1983 and 1985. Kenney et al. reported large variations in the expenditures per infant in neonatal intensive care (ranging from $2,028 to $29,414) and in the percentage of Medicaid-covered live-born babies that received neonatal intensive care (ranging from 2.6 to 20.3 percent), but they were unable to identify the source of the variation. There was no indication as to whether these figures included expenditures for all hospital care outside of the NICU, infant transfers, or in-hospital physician services. Furthermore, there was no indication whether states reported expenditures for infants only, or combined maternal-infant expenditures. Possible explanations for the reported differences also include differences in patient characteristics, practice patterns, mix of hospitals, reported expenditures, coverage limitations, and payment levels, as well as statistical variation. In a study by the Maryland Department of Health and Mental Hygiene (Stuart et al., 1990), seven percent of Medicaid-covered newborns were treated in a NICU, which was higher than the 3.8 percent for both self pay and third-party-covered newborns. Analysis of Medicaid-financed obstetrical care in California, Georgia and Michigan in 1983 found that six, nine and six percent of newborns received neonatal intensive care (E.M. Howell, Systemetrics/McGraw Hill, Inc, personal communication, 1991).

The only other studies are reports from individual hospitals of payer source and payment levels (Kaufman and Shepard, 1982; McCarthy et al., 1979). Finally, we know of no studies that detail Medicaid expenditures for infants according to LBW categories, congenital malformations, drug-exposure or infants born to mothers infected with HIV.

Data Needs for Estimating Medicaid Expenditures

In order to plan effectively, Medicaid needs to know several items related to the costs of NICUs. Some of these items pertain to overall expenditures and use, and can be obtained from the states' Medicaid databases or from hospitals with a relatively modest effort. Examples of useful aggregate measures include: (1) total Medicaid expenditures on newborns, (2) total Medicaid expenditures on newborns receiving neonatal intensive care, (3) overall expenditures on newborns receiving neonatal intensive care, (4) average Medicaid expenditures on infants receiving neonatal intensive care, and (5) time trends for all these items. Other data items are needed to analyze the variation in NICU expenditures, and to assure comparability of estimates across the 50 Medicaid programs. These items require that data be collected on the expenditures for the treatment of specific infants, and that the characteristics of these infants be linked to the expenditure data. Finally, some issues require longitudinal data, either for the aggregate data or for the infant-specific data.

With this in mind, the data needed to estimate the three types of Medicaid expenditures for infants admitted to NICUs can be classified into three categories: infant-level information, Medicaid reimbursement and hospital characteristics. Finally, it would be desirable to have a similar set of data items for a comparison group of infants not receiving neonatal intensive care. All the data sources described below contain information on Medicaid-covered infants not receiving neonatal intensive care.

Infant-Level Information

The most fundamental item is the identification of infants admitted to a NICU. Although LBW, gestational age and a LOS in excess of five days can be used to proxy NICU admission, accurate estimates require specific information on whether infants are treated in a NICU. Use of proxy measures will lead to imprecision due to local and state variations in NICU availability, practice patterns and degrees of perinatal regionalization. In order to distinguish expenditures for direct NICU care from expenditures for all inpatient care, it will be necessary to know the beginning and end dates of neonatal intensive care.

Information on newborn characteristics is also essential to explaining variations in expenditures across Medicaid programs. Birthweight and gestational age are the most important predictors of NICU length of stay and newborn hospital costs; therefore, differences in the distributions of birthweight and gestational age across Medicaid programs will result in different program expenditures. Other important predictors are (1) major secondary diagnoses, including congenital malformations, (2) procedures performed, especially surgeries and the duration of mechanical ventilation, and (3) discharge status, especially death. Policy interest in the cost-effectiveness of preventive health services would suggest collecting information on prenatal care and maternal characteristics.

Two other data needs are the ability to track expenditures for patients' care between hospitals and over time. Because a large proportion of infants requiring neonatal intensive care are transferred from and back-transferred to community hospitals, an accurate assessment of expenditures for all inpatient care will require the ability to track expenditures for individual infants across hospitals. And, the ability to track expenditures over time is necessary to estimate total Medicaid expenditures during the first year of life for NICU graduates (as well as for a comparison group).

Medicaid Reimbursement

To measure the three types of expenditures, information is required on Medicaid reimbursements for care received in NICUs, all newborn hospital stays (including transferring and referring hospitals), and all health care received during the first year. Reimbursement information should include all inpatient and outpatient physician services, and all covered pharmacy and ancillary service charges.

The type of hospital reimbursement system used by state Medicaid programs will determine whether a study could conceivably separate expenditures for care received in a NICU from expenditures for the total hospital stay. In states where Medicaid programs reimburse hospitals on a prospective per case basis, such as DRGs or flat rates, it will not be possible to separate reimbursements for direct NICU care from reimbursements for the total hospital stay.

There are two sources of information on Medicaid expenditures: the 50 state Medicaid Management Information Systems (MMIS) and provider billing records. The most complete source of information is the states' MMIS, which contains records of all claims from all providers submitted to state Medicaid programs. The MMIS is discussed more completely in the next section. Hospital billing and medical records could be used for studies based on a sample of hospitals serving Medicaid patients; however, unless these studies also survey the physicians providing inpatient and outpatient care, such a study would miss a substantial proportion of Medicaid expenditures.

Hospital Characteristics

Information on hospital characteristics may be valuable in explaining intra- and inter-state differences in expenditures. Desirable information includes the level of the NICU, teaching status, hospital location (rural, urban, or inner city), the local supply of NICU bassinets and the extent of perinatal regionalization.

Using Medicaid Data to Study Medicaid Reimbursement for Neonatal Intensive Care

A fundamental data source for a study of the cost of neonatal intensive care to state Medicaid programs is the state-specific MMISs. These databases provide operational data for Medicaid programs including information on eligibility and paid claims. The MMISs can also be a rich source of data for research purposes. However, the comprehensiveness and quality of MMISs vary widely across states, rendering studies that seek to compare Medicaid activities across several states difficult to implement. In this section we briefly describe key features of MMIS eligibility and paid claims files, and some issues specific to the analysis of Medicaid reimbursement for neonatal intensive care.

Medicaid Eligibility and Paid Claims Files

Medicaid program administration involves two primary functions: determining eligibility and paying claims on behalf of eligible participants. Traditionally, eligibility determination has been performed by the agency responsible for administering cash assistance programs (like AFDC and SSI). More recently eligibility workers in some states have been outstationed to hospitals, clinics and other locations. Information on factors that affect eligibility for Medicaid is collected and processed by program eligibility workers. In some states this information is collected and entered on-line on the eligibility file; in other states information is collected on hardcopy forms and entered later. Once eligibility is established, all members of the covered household are issued an identification number and a Medicaid card.[1] The

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[1]In situations where only the infant is covered by Medicaid, such as under the recent Medicaid expansions and the earlier "Ribicoff Children" provisions, only the infant would be given a Medicaid number.

Medicaid card serves to document the holder's eligibility for Medicaid and provides the information necessary to file a claim on behalf of the beneficiary.

When beneficiaries require Medicaid services they must obtain services from providers who are willing to accept Medicaid payment as payment in full for the service. Claims for covered services are submitted by the provider to the Medicaid Fiscal Intermediary (FI)--an agency of the state government or an entity acting on the government's behalf--which processes the claim. The claim contains information on type of service rendered, the service provider, dates of service, and amount reimbursed by Medicaid, as well as the beneficiary's Medicaid number and some limited information identifying the beneficiary. Information on diagnosis at the time of the service and procedures rendered varies both across states and within states by provider type. Information on provider charges for the service are usually included on the claim, but the exact nature of the charge data varies from state to state and even within provider types in a single state. For example, charge data may reflect private pay charge, Medicaid allowable charge, expected reimbursement, or some estimate of "true" cost.

To process claims, the FI receives from the eligibility agency a machine-readable list of all persons who are eligible for Medicaid during a given month. As providers submit claims, the FI performs a series of checks to ensure that the services are covered and that the person was eligible for Medicaid during the period in which the services were rendered. If the claim is eligible, the FI makes payment up to the applicable limits. Claims may be denied for many reasons, including the following: the service was not covered; payment or service limits for the beneficiary had been reached; the person was not certified as eligible for Medicaid when the service was rendered; and the necessary information furnished on the claim was inaccurate or incomplete. Providers frequently resubmit claims when they are denied and are given a specified period of time within which they are allowed to do so. Claims that have been resolved and paid are referred to as "adjudicated" claims.

Although HCFA has specified a minimum dataset for state MMISs, there is considerable variation in content and quality of MMISs across states. Eligibility files usually contain the following types of information for each beneficiary: Medicaid identification number, most recent dates of eligibility, reason for eligibility, and information identifying the beneficiary such as age, race, sex, and address.

Three problems arise with the assignment of Medicaid identification numbers that affect the ability of a study to collect a full Medicaid claims history for a single person over a specified period of time: (1) a single person may have multiple Medicaid numbers; (2) mothers and newborns may share the same Medicaid number at the time birth-related services are rendered; and (3) Medicaid numbers may be configured in ways that make it difficult to identify claims for a mother/child unit. The most common reason for a single person to have multiple identification numbers is if the person has had, lost and regained Medicaid eligibility or if the person moves from one county to another. Some MMISs track changes in Medicaid numbers for individuals over time, while others do not. When the MMIS does not track these changes, this must be done relying on the beneficiary's name and other identifying information, and becomes a time consuming experience, given variations in spelling of names, address changes, etc.

In a number of states, when a woman gives birth, her newborn is given her Medicaid identification number and the newborn does not receive its own number until the mother applies for Medicaid on behalf of the newborn and its eligibility has been verified. If the newborn has to stay in the hospital after the mother is discharged, this process is expedited and the newborn will have its own Medicaid number beginning with the claim for services following the mother's discharge. When mothers and newborns share the same Medicaid number and thus, the same hospital claim at the time of delivery, it is virtually impossible to distinguish between the costs of care to Medicaid for the mother and those for the newborn. This inability to separate mother and newborn reimbursements may lead a study to analyze mother and newborn reimbursements as a unit. If the study also includes states that do issue a separate Medicaid number to newborns at birth--often the case with states that reimburse hospitals using a DRG system[2]--the claims of mothers and newborns in those states would have to be linked to be consistent with those of states that do not separate mothers and newborns.

However, linking mothers and newborns can also be problematic. In some states when members of the same family are eligible for Medicaid, the Medicaid numbers assigned to each member contain a root that is common to all family members with suffixes specific to each family member. When this configuration is used, linking claims for mothers with claims for their newborns is greatly simplified. However, when this configuration is not used, mothers and newborns must be linked using names and information on the claim from the birth delivery provider, a process which requires a great deal of manual intervention and introduces random error.

As noted, paid claims files usually contain information on the type and name of the provider submitting the claim, the dates of service, the amount Medicaid reimbursed for the service, and a few items identifying the beneficiary including the Medicaid identification number. The claims files also usually contain principal and secondary diagnostic (ICD9-CM) codes and procedure (usually CPT-4) codes, but these codes do not provide a reliable means to identify infants admitted to a NICU. Although decision algorithms based on these codes will be able to correctly identify some infants who are treated in a NICU, other infants will be incorrectly labeled as being treated in a NICU, and still other infants will be incorrectly labeled as not receiving neonatal intensive care. For example, there is a specific ICD-9-CM diagnostic code for respiratory distress syndrome (769), a condition that usually requires neonatal intensive care, but the diagnostic codes for LBW divide infants into only two codes: (1) extreme immaturity, usually less than 1,000 grams (765.0), and (2) other preterm infants, usually 1,000 to 2,499 grams (765.1). Although almost all newborns with birthweights less than 1,000 grams are treated in NICUs, the probability of an infant being treated in a NICU decreases dramatically as birthweight increases from 1,000 to 2,499 grams. Finally, some states do not record the complete ICD-9-CM codes.

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[2] Although states reimbursing hospitals by DRGs are more likely to give newborns separate identification numbers, the line item information on hospital claims is likely to be less reliable than in states that reimburse on costs or per diem basis, since DRG payments do not depend on line item charges.

Inpatient claims will sometimes contain line-item information reflecting the number of days of intensive and special care and units of various types of ancillary services. It is likely that neonatal intensive care use will be documented on paid claims only in states that maintain line-item information for hospital claims on their MMISs. States that reimburse hospitals through DRGs may be less likely to maintain line-item information. The NICU is then likely to be identified by a revenue center (or some other type of) code. The start and end dates of NICU care per se, are not likely to be present even when line-item detail is maintained. Rather the start and end dates of claims for the full hospital stay (and usually the admission and discharge dates for the stay) must be used to delimit service use.[3]

In assessing the total expenditures for an inpatient stay for a newborn who has been in an NICU, the expenditures for services provided in the hospital, but billed through individual practitioners must also be included. Individual practitioner claims can be matched by searching for dates of service that fall within the hospital admission and discharge dates. In assessing the total expenditures for a NICU graduate during the first year of life, adjudicated claims with service dates falling within the relevant time periods will have to be tracked. The success of this endeavor will depend, in part, on how well the MSISs track changes in Medicaid numbers for individuals over time.

Linking Medicaid Data with Vital Records

In analyzing Medicaid reimbursements for NICU use it will be important to identify characteristics of newborns that are correlated with such use. As discussed above, low birthweight, prematurity, congenital anomalies, drug exposure in utero, and, perhaps, having an HIV-positive mother are associated with the use of neonatal intensive care. Incorporating these measures into analyses of NICU use is problematic because they are not precisely or reliably reported on claims records. For example, ICD-9-CM codes for LBW divide infants into only one of two groups: (1) less than 1,000 grams (765.0), or (2) 1,000 to 2,499 grams (765.1). Furthermore, unless reimbursement is dependent upon diagnoses, then these data are not likely to be reported reliably.

On the other hand, birthweight and length of gestation are found on the birth certificates of all states and birth certificates will be available for virtually all members of a study sample who give birth in a study state.[4] While the quality of birthweight data on birth certificates is generally believed to be quite high, data on gestational age is not quite as accurate since it relies on a woman's recollection of the date of her last menstrual period or a practitioner's estimate of the gestational age of the newborn. In fact, our experience reviewing birth

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[3]Some hospitals submit bills on regular intervals, such as every two weeks, that may not completely capture an individual patient's complete hospital stay. In these cases, more than one claim will be filed for a single hospitalization.

[4]Information on drug-exposure is included on the birth certificates of only a couple of states (for example, New Jersey and New York) as is information about fetal alcohol syndrome. Therefore, incorporating measures of drug or alcohol exposure into analyses of NICU use or expenditures will require primary data collection.

certificates showed a small, but significant, number of birth certificates with quite unlikely combinations of birthweights and gestational ages (Mathematica Policy Research, 1990).

Although birth certificates are readily available for any study sample of newborns, an important consideration for using these data in combination with Medicaid eligibility and claims data is how birth certificates will be matched to Medicaid records for the same person. Birth certificates seldom contain Medicaid identification numbers. Thus, matching mothers' and newborns' names, matching dates of birth with dates of service on claims for delivery services, and matching hospital of birth on birth certificates and claims for delivery services must be used to link birth certificates and Medicaid data.

The linking of Medicaid and Vital records gained prominence when the Omnibus Budget Reconciliation Act of 1989 (OBRA-89) mandated a national linked database to support research on Medicaid services, prenatal care, and infant mortality. Specifically, OBRA-89 mandated that the data base contain data on any infant up to age one and that it contain data from "the infant's birth record, any death record for the infant, and information on any claims submitted (to Medicaid) for health care furnished to the infant or with respect to the birth of the infant." Given the complexity and potential costs of constructing such a data base, the National Center for Health Statistics funded a study of the feasibility of constructing such a database.[5] If such a data base is constructed it would provide a great deal of the data needed to examine the characteristics of Medicaid-covered infants who use NICUs and the variations in the patterns of use across states.

Although it was beyond the scope of this project to survey all 50 Medicaid programs, we have identified 11 states that have some experience merging Medicaid data and birth certificates. These states are Arkansas, Georgia, Kentucky, Maryland, Michigan, Missouri, North Carolina, South Carolina, Tennessee, Utah and Washington. The majority of these states do not appear to link birth certificates and Medicaid data on an ongoing basis; rather the efforts seemed to be confined to one to several years. Several of the states we spoke with indicated that decisions to match these data were constrained by state budget policies. The state of Missouri has the most extensive experience with matching birth certificates and Medicaid claims. They have linked files for 1980 to 1982 and from 1985 to 1988. For 1985 and 1986 they have also linked Medicaid files to the Uniform Hospital Discharge Data Set (UHDDS), but this file does not contain information on charges (Land, 1991).[6] In addition, Mathematica Policy Research (1990) has recently completed a study that linked birth certificates and Medicaid data for Florida, Minnesota, Texas, North Carolina, and South Carolina.

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[5] A contract to conduct this feasibility study and to develop a process for building the data base was granted to Mathematica Policy Research. The final report from this project is expected to be available in early 1992.

[6] Missouri also collects a short report on all infants admitted to a NICU, which has been linked to birth certificates. This report contains information on admission and discharge dates, diagnoses and hospital identification. Missouri has also added an item to their birth certificate to indicate if the mother was covered by Medicaid.

The Importance of Performing a Feasibility Study

Although a few differences between state-specific MMISs were highlighted above, it is almost impossible to overestimate the extent of the large and small differences encountered in working with Medicaid data from a number of states and the level of effort required to bring some measure of consistency to those data. Differences in the content of MMISs across states stem from a number of factors. The most important is probably the state's Medicaid reimbursement policy, which governs which data items are needed on the MMIS in order to pay claims accurately and efficiently. The second most important factor is the state resources available to maintain the MMIS; states with sufficient budget may invest in a more complex and more detailed MMIS, and are more likely to have sufficient staff to maintain the system. This second feature is also likely to affect the quality of the data on the MMIS. However, in general, in any state, the more closely linked a data item is to the payment of a claim, the more likely it will be subject to careful screening before it appears on the MMIS and the more accurate it is likely to be. For example, in states where diagnosis does not determine reimbursement on a hospital claim, even if diagnosis appears on a hospital record layout, diagnosis may not be filled in for all records or may contain errors.

_A number of factors also affect the ability of a state to fill a request for claims data in a timely fashion. A major factor that affects the timeliness of filling a request for claims is the average amount of time between service receipt and the appearance of a paid claim for service on the MMIS. Our experience is that 6 months to a year is sufficient for 95 percent of all services to appear on adjudicated claims files (Mathematica Policy Research, 1990). The longer span applies particularly to high-cost, "denied" claims that have to be submitted more than once before payment is received. Another major factor in the timely receipt of data is the interest of the state in filling that request. States receive many internal and external requests for data. A commitment on the part of state staff to providing data can make the difference between a request that takes one month or 12 months to process.

Many states do not maintain their MMISs in-house, but rather contract out the maintenance of systems to private companies known as Fiscal Agents. The quality of the Fiscal Agent will affect both the quality of the MMIS and the ability of the Fiscal Agent to process a request for claims in a timely way. The period during which a state is converting from one Fiscal Agent to another is often not a good time to request MMIS data. Moreover, the physical conversion of the MMIS from the system of one Fiscal Agent to another can carry with it additional data quality problems.

Therefore, because states vary widely in Medicaid reimbursement policy, and the content and quality of MMISs, as well as in their ability to process requests in a timely fashion, a thorough feasibility study is required to determine whether NICU-research questions can be answered with available data and within the required schedule. A feasibility study may consist of telephone calls to state Medicaid staff and the collection of file layouts and relevant manuals. These efforts should build upon the experiences of the Tape-to-Tape project and the Medicaid Statistical Information Systems. However, receiving test data extracts and interviewing state staff in person will decrease the occurrence of unanticipated problems when the research study is under way.

Other Possible Data Sources

State-Wide Hospital Discharge Data

Several states regularly collect hospital discharge data for all discharges from all hospitals within their state. We have identified 21 states that collect charge (generally UB82) data from all discharges, and another 6 states collecting information from the Uniform Hospital Discharge Data Set (UHDDS). The National Association of Health Data Organizations, which identified these states for us, currently has a contract with the Office of Provider Studies in the Agency for Health Care Policy and Research to examine state-level data. The goal of their study is to make recommendations for a national reporting system by comparing hospital reporting requirements, content and layout, as well as private sector hospital data. Their report is due in the fall of 1991.

Of the 21 states collecting charge data, 15 states collect charge data and units of service by accommodation and ancillary service cost centers. These states are Connecticut, Florida, Georgia, Idaho, Maryland, Massachusetts, Nevada, New Jersey, New York, North Carolina, North Dakota, Pennsylvania, Texas, Washington, and West Virginia. Although Missouri does not collect this information on a regular basis, the state has worked with the Missouri Hospital Association to get the data for special studies. These data also contain information on admission and discharge status, principal diagnoses and procedures, as well as expected payer. Some states have augmented the uniform discharge reports by requiring hospitals to report birthweight for all infants born in hospital (for example, New Jersey, New York and Maryland), or by merging the discharge reports with birth certificates (for example, Maine, Washington and, starting in 1992, Georgia) or the UHDDS set (for example, Georgia, Maryland, and, starting in 1991, New York).

We are not able to assess the quality of these data, but there is likely to be substantial variation in accuracy and comprehensiveness among hospitals within states. Another unknown is the success states have achieved in matching the discharge data to birth certificates. In the state of Washington a 95 percent match level was achieved, but high risk infants (for example, those with long LOSs) were over represented among the unmatched discharges (Conal, 1991).[7]

Infants treated in a NICU can potentially be identified in these data sets by the NICU center accommodation charges and units of service (typically days). Infants covered by Medicaid can likely be identified by expected payer. However, these reports do not contain information on payment received.[8] Therefore, it will be impossible to directly measure how much the Medicaid programs spent on the care of these infants using those datasets by themselves. In states reimbursing hospitals based on DRGs, modified PM-DRGs, other per-

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[7] Access to these data may be subject to data/privacy protection review boards.

[8] Expected payer does not necessarily equal actual payer; although it is not clear if this is a big problem for infants receiving neonatal intensive care. Expected payer is likely to be an undercount, because the high cost of neonatal intensive care will encourage hospitals to enroll the medically-indigent newborns in Medicaid programs.

case systems or per-diem rates it may be possible to calculate approximate Medicaid payments. The hospital discharge data typically contain all the information required to calculate a patient's DRG classification. Once known, a patient's DRG category can be matched with the hospital-specific DRG payment schedule. In states where hospitals are paid per-diems, the number of days spent by Medicaid-covered infants in different cost centers can be multiplied by the hospital-specific, cost center-specific per-diem rates. Summing over all cost centers will yield an estimate of Medicaid payments. This procedure could be modified to account for any total inpatient day limits, but nevertheless, this procedure would not account for all administratively denied payments. Before proceeding with a large scale study using this estimation approach, a trial study would be advisable, checking the predicted Medicaid payments against actual payments for a small sample of Medicaid-covered infants.

These methods could not be used to estimate directly Medicaid expenditures in states reimbursing hospitals on a cost basis. An alternative approach for these states would be to calculate hospitals' cost to charge ratios from their annual cost reports, and convert reported charges to costs. This would entail additional data collection and preparation, adding to the costs of such studies. This approach might also be used to calculate approximate Medicaid expenditures for infants born to mothers in capitated Medicaid plans, if these plans are required to submit patient-level charge data.

Using state-wide hospital discharge data to study Medicaid expenditures for infants receiving neonatal intensive care has the advantage of being able to identify almost all the of infants receiving such care. However, it also has several shortcomings. First, these data do not contain information on physician charges for inpatient care, which account for 15 to 20 percent of total charges for neonatal intensive care (Phibbs et al., 1991). Second, because infants cannot be tracked as they are transferred across hospitals, these data cannot support analyses of total expenditures for hospital care. Third, the birthweight may not be available for infants transferred from their hospital of birth to a Level II or III hospital. Finally, these data cannot support analyses of post-discharge Medicaid expenditures.

Private Sector Data

There are several private organizations that collect hospital discharge data that may be used to estimate Medicaid expenditures for infants receiving neonatal intensive care. These organizations collect information from member or subscribing hospitals and process the information into a common database. Two such abstracting services are the National Perinatal Information Center (NPIC) and Health Knowledge Resources (HKR).[9] NPIC has about 50 member hospitals, all with NICUs, from which NPIC collects the annual Medicare Cost Reports, billing data, UHDDS (Uniform Hospital Discharge Data Set) (which contains expected source of payment), and, from about 80 percent of the hospitals, birthweight. The second organization, HKR, compiles annual databases from the medical records departments

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'Another organization, the National Association of Children's Hospitals and Related Institutions also collect hospital discharge data from about 100 member hospitals. However, they do not collect information on the likely payer, so patients covered by medicaid cannot be identified.

of approximately 850 U.S. short-term, general, nonfederal hospitals with five-million annual discharges. The hospitals are distributed over 40 states and represent a wide distribution by bed size, teaching status, urban and rural, public and private, and primary, secondary and tertiary levels. In addition to clinical information and patient characteristics, the database contains expected source of payment and, for about 50 percent of the hospitals, charge data. The NPIC data is not public use data, but it is available for research either by direct contracts or by subcontracts with NPIC. On the other hand, the HKR data can be purchased, either in its complete form or specially designed sub-samples (for example, hospitals with NICUs) and subsets of data items. The cost of HKR data will vary depending upon the specific nature of the purchase, but the cost may be as high as $25,000 (Prevost, 1991).[10]

Although these private sources of discharge data could support studies similar to those described for state-wide discharge data, such studies would be subject to two additional limitations. First, the hospitals participating in abstracting services generally include only a minority fraction of hospitals from each state. Second, the participating hospitals are generally a self-selected group and will not be representative of all hospitals within a given state or the country as a whole. This would complicate the task of deriving state-wide estimates of Medicaid expenditures.

Survey Data

The singular, most valuable survey data for studying NICUs is the 1988 National Maternal and Infant Health Survey (NMIHS), of which HCFA is a co-sponsor. Information has been collected for three national samples of vital records: 6,000 death certificates for infants, 4,000 reports of fetal death of 28 weeks or more gestation, and 10,000 birth certificates. Among the sample of 10,000 birth certificates, black and LBW infants were oversampled. Roughly 1,500 infants weighing less than 1,500 grams and 1,500 infants weighing 1,500 to 2,499 grams were sampled. The mothers of all infants, fetal deaths and infant deaths included in the sample were be interviewed about access to prenatal care, source of payment, health habits, work patterns, sociodemographic characteristics, and infant health and medical care up to six months after birth. Hospitals and prenatal care providers were surveyed about diagnoses, the care provided (including neonatal intensive care) and charges. In particular, hospitals were asked to attach the UB82 Forms of the sample infants and fetal deaths.

The NMIHS, along with a companion follow-up survey will collect information on the health status and health care utilization of the live born sample. This will include information on out-of-pocket expenditures, health insurance coverage and the names of the providers of care. An attempt will be made to survey these providers about the care given to the sample infants, but not charges for this care. Given the 18 to 30 month recall periods covered by the follow-up survey, these data on health care utilization is likely to be incomplete, especially for the children with major health problems, who are likely to be seen by many different physicians. Therefore, analyses of this data will likely underestimate the health care

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“Hospital chains and consortium are other possible sources of hospital discharge data merged in a common database.

utilization of NICU graduates relative to that of normal birthweight infants. However, the data on long-term health outcomes will still be of importance.

Advantages of using NMIHS to study national Medicaid expenditures include (1) its sample design is nationally representative, providing an opportunity to form national estimates without having to analyze Medicaid data from numerous states; (2) extensive information was collected from mothers, prenatal care providers and hospitals; (3) information was collected on the infants' use of outpatient and inpatient services during the first six months of life[11]; and (4) the survey permits following infants as they are transferred between hospitals.

However, there are two important disadvantages. First, the NMIHS collects information on charges not amounts received; therefore, Medicaid expenditures would have to be estimated. These estimations would be no simple task, requiring information on specific state-hospital Medicaid reimbursement rates. Obtaining this information would entail a telephone survey of the Medicaid programs of all the states represented in the survey. In addition, the accuracy of the estimates would depend on the accuracy of the NMIHS indicators of whether the mother and infant had been covered by Medicaid.

A second disadvantage is that only a minority of hospitals have sent the UB82 Forms to the National Center for Health Statistics (NCHS), which has operational responsibility for the NMIHS. Other hospitals have reported that waiting until UB82 Forms were available would create long delays in their survey responses. In order to avoid further delays, NCHS has advised these hospitals to send in their surveys without the UB82 Forms. NCHS is still uncertain as to the extent of any follow-up effort to obtain the missing UB82 Forms (Sanderson, 1991). Even without the UB82 Forms, there will be enough information to determine the DRG and modified PM-DRG categories of infants. However, this will only be of direct benefit for estimating Medicaid expenditures in those states reimbursing hospitals based on DRGs or modified PM-DRGs. In the remaining states there will not be sufficient information to directly estimate Medicaid expenditures without the UB82 forms. An alternative strategy for these states would be to estimate the "costs" of care for Medicaid-covered infants, and to use these cost estimates as proxy measures of Medicaid expenditures. One strategy for estimating costs is to categorize infants according to DRGs and to use estimates of DRG-specific costs from national studies. One possible source of these estimates is from the work of Schwartz et al., (1989), in which DRGs and DRGs with adjustments for birthweight were compared for their abilities to explain variations in costs and LOS. The DRGs with birthweight adjustment explained 51 percent of the variation in costs, where as DRGs alone explained only 19 percent. The NMIHS data could support estimates based on DRGs and birthweight adjustments.[12] It may be possible to assess the accuracy of these measures by comparing them with estimated Medicaid expenditures for the portion of the NMIS sample with UB82 Forms.

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[11]As mentioned above, the data for health care utilization beyond the first six months will be less reliable due to recall errors.

[12]Another potential source of the DRG-specific cost estimates is the HCFA-sponsored study by Susan Payne (Boston University) and Rachel Schwartz (NPIC) on Pediatric Prospective Payment Systems. The HCFA project officer for this study is John Petry.

Two other sources of survey data deserve mention. The AHA Annual Survey of Hospitals and the AHA 1989 Survey of Newborn Services provide valuable information on hospital facility characteristics, patient volume and staffing. These data could be merged with data from Medicaid claims, hospital discharge data and NMIHS, and they may contribute to a better understanding of variations in Medicaid expenditures. These data also provide some useful aggregate numbers; NICUs, NICU bassinets, NICU admissions, and NICU-patient days. These data could be obtained for a modest cost of between two and three thousand dollars.

Summary of Research Strategies

The previous discussion covers studies of differing levels of effort, ranging from major to modest. Below we summarize studies of alternative levels of effort, there strengths and their weaknesses.

Studies analyzing Medicaid claims data from more than two or three states would require a major commitment of resources, especially if the effort included an analysis of Medicaid expenditures for care during the first six months to one year of life. A major effort would also be required to study state-wide discharge data from more than one or two states. One advantage of selecting either of these options is that states could be selected representing the wide variety of Medicaid program characteristics, especially with regards to reimbursement policies and the expansions of Medicaid eligibility requirements.[13] This would facilitate more accurate extrapolations to national estimates, by matching non-study states up with study states with similar program characteristics. In addition, sensitivity analyses for these extrapolations to non-study states could be based on the number of Medicaid covered births, states' distributions of births by birthweight categories, and AHA data on the availability and utilization of NICU beds within each state.

Use of Medicaid data has several advantages over hospital discharge data, including the abilities:

- To more accurately identify Medicaid-financed births
- To measure expenditures directly,
- To follow infants and to capture Medicaid expenditures as the infants are transferred between hospitals,
- To capture inpatient physician expenditures,
- To capture outpatient and other inpatient expenditures of NICU graduates, and

[13] Another factor that should be considered when selecting states is whether information on birthweight is reported in Medicaid claims data or whether the states merge Medicaid claims data with birth certificates.

- To be able to determine how many Medicaid-covered infants receiving neonatal intensive care become eligible by the medically needy spend-down option.

One potential data source of Medicaid claims data from numerous states is the Medicaid Statistical Information System (MSIS), which collects and standardized Medicaid claims and eligibility files from approximately 20 states into one database. However, there is a serious limitation to this database. As mentioned above, in most states newborns are initially given their mothers' Medicaid identification numbers. At some later point, infants are given their own identification numbers. Under the current MSIS file construction, there is no way to link infants' new identification numbers with their mothers' identification numbers. Therefore, one cannot link Medicaid claims for infants occurring before and after the infants receive their own identification numbers. The percentage of newborn and NICU admissions that are affected by this linkage problem will have to be evaluated, before a judgement can be made about the suitability of MSIS. However, it would seem unlikely if MSIS could be used to study expenditures during the first six months or year of life.

Studies of state Medicaid claims data and state-wide discharge data could be scaled back to an intermediate level of effort by restricting the number of states to one to three. However, efforts to extrapolate to national estimates would be seriously compromised. These types of studies should instead be interpreted as "case studies," providing estimates of expenditures per Medicaid-covered infant receiving neonatal intensive care under alternative reimbursement methods, and potential savings that could be garnered from efforts to reduce the frequency of LBW births.

Analyses of HKR or NPIC data would also be studies requiring an intermediate level of effort. Because of the non-representative nature of the hospitals included, it would be difficult to extrapolate to state or national estimates. But, these studies could also be considered as "case studies."

Analysis of NMIHS would also require an intermediate level of effort. The advantages and disadvantages of using these data were discussed in the preceding section. The most serious shortcoming is the incomplete record of UB82 Forms, requiring the use of proxy measures for Medicaid expenditures in states not reimbursing hospitals by DRGs. Despite this important shortcoming, the NMIHS is an important source of information about LBW infants and Medicaid-covered mothers and infants.

A still more modest study effort would be to conduct a survey of the 50 state Medicaid offices, asking that they provide information on total number of Medicaid-covered newborns (by eligibility category), the number receiving neonatal intensive care, and the amount of Medicaid expenditures for inpatient and outpatient care by whether the infant received neonatal intensive care. Specific instructions would have to be given to the states to enhance the comparability of reported expenditures, especially with regards to separating expenditures for mothers and infants, and accumulating expenses as the infants are transferred between hospitals. Limitations of such a survey are the likelihood of low response rates, and an inability to assess the comparability and the quality of states' responses. Also, the study would address only a few of the data needs.

Recommendation for Routine Reporting of Birthweight

The inclusion of birthweight on Medicaid claims data would provide Medicaid programs and researchers with valuable information regarding Medicaid expenditures for adverse birth outcomes. Birthweight is the single most important predictor of admission to a NICU and of resource use in the care of neonates. Knowledge of birthweights would facilitate studies of Medicaid expenditures, access to care, quality of care and infant outcomes. The routine collection of birthweight would enable Medicaid programs to formulate better predictions of future expenditures, and to monitor the success of expanded eligibility requirements, as well as other efforts to improve access to prenatal care. Finally, it would seem that birthweight could be added to Medicaid claims data at a small cost.

V. COST OF NEONATAL INTENSIVE CARE FOR MEDICAID PATIENTS

The focus of this chapter is on the hospital costs for infants receiving neonatal intensive care.[1] As the major payer for health care of the poor, Medicaid programs have a deep interest in the cost of providing this care, as well as their expenditures. First, the rising cost of health care has major implications for federal and states' budgets. Second, differences between Medicaid reimbursement levels and the cost of care can impact on Medicaid beneficiaries' access to care, and the quality of the care they receive. In particular, if Medicaid reimbursement rates do not cover the costs of caring for Medicaid patients, then Medicaid patients may face barriers to care not experienced by privately-insured individuals, and the care they receive may be of inferior quality.

Before 1981, Medicaid programs were required to reimburse hospitals on the basis of the actual costs they incurred (the economic value of the resources used) in providing care. The Omnibus Reconciliation Act of 1981 repealed this requirement, freeing states to establish new methodologies of their own. The law now provides simply that payment rates for hospitals be "reasonable and adequate" to meet the costs of "efficiently and economically" run hospitals in providing care. The majority of states now reimburse hospitals through some form of prospective payment; only eight states continue to use retrospective cost-based systems. It is in the 42 states reimbursing hospitals through prospective payment that Medicaid-covered infants' access to neonatal intensive care is most likely threatened by inadequate reimbursement.

Literature Review

We did not find any studies that examined the cost of neonatal intensive care for Medicaid patients as a distinct group. However, one study analyzed accounts payment by payer for a perinatal regional center in Colorado. This study found that, during 1976, Medicaid-covered infants constituted only 18 percent of infants treated in the NICU, but 51 percent of all write-offs experienced by the hospital (McCarthy, Koops, Honeyfield et al., 1979). Although it would be unwise to generalize from the experience of this one hospital to other hospitals and other Medicaid programs, the study suggests the possible magnitude of the difference between Medicaid payments and average costs.

In general, the literature on costs of neonatal intensive care is scanty. It was reviewed by the Office of Technology Assessment in 1980 (Budetti et al., 1980) and updated in 1987 (U.S. Congress, OTA, 1987). The English language literature contains a number of U.S., British, and Australian studies (Pomerance et al., 1978; Phibbs et al., 1986, Walker et al., 1984; Shannon et al., 1981; Schwartz, 1989; Phibbs, Williams, and Phibbs, 1981, Schroeder,

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[1]Therefore, we will not discuss the adequacy of Medicaid reimbursement for the follow-up care often required by NICU graduates. There is an extensive, but still incomplete, literature examining the adequacy of Medicaid reimbursement for ambulatory care, which is reviewed by the Congressional Research Service (1988).

Showstack, and Roberts, 1979; NACHRI, 1986; Berki and Schneier, 1987; Lagoe, Milliren, and Baader, 1986; Resnick et al., 1986; Lichtig, Knauf, and Bartoletti, 1989; Boyle et al., 1983; Kaufman and Shepard, 1982; Shankaran et al., 1985; Sandhu et al., 1986; Newns et al., 1984; Yu and Bajuk, 1981; Marshall et al., 1989; and Doyle, Murton, and Kitchen, 1989). Most commonly, studies report unadjusted charges. There is great variability in reported charges which makes such reports difficult to interpret. This variability is not only a function of the distortion between costs and charges, but also of the continuing evolution of the NICU technology, differences in severity of illness in the base populations, differences in inflation adjustment, and genuine differences in the level of technology and costs among NICUs.

Although the variance in estimated costs is substantial, it is clear that neonatal intensive care is extremely expensive, due to extremely high technology and unusually prolonged lengths of stay for the smallest premature survivors. Schroeder, Showstack, and Roberts (1979) studied catastrophic cases and found half of such cases in pediatric referral hospitals were newborns. A study of childrens' hospitals (all tertiary facilities) showed that while only eight percent of admissions were newborns they accounted for twenty five percent of hospital costs (NACHRI, 1986).

Several studies have identified patient characteristics associated with higher costs. Birth-weight is the major determinant with costs ranging from $9,000 for ill term infants to $59,000 for infants less than 1,000 grams in 1984 (OTA, 1987). Bills for some of the smallest survivors (500 to 600 grams) may exceed $300,000. Infants under 1,500 grams account for 25 percent of NICU admissions but 48 percent of NICU days and 56 percent of total NICU charges (Richardson 1991). Another marker for high costs include the need for and duration of mechanical ventilation, which may increase costs two-to-fourfold (for example, from $11,000 to $48,000 for the 1,501-2,000 gram infants). Surgery is also a major determinant of cost (Phibbs, Williams, and Phibbs, 1981).

Only two studies attempted to allocate costs to the component services and their relative contributions over the length of hospitalization. The major cost components are per-diem expenses (for example, nursing time allocation and unit overhead) and ancillary service utilization costs (for example, pharmacy, x-ray, etc.). One study was of a 1984 Australian NICU and the other studied 21 very LBW infants born in a U.S. NICU in 1977 (Marshall et al., 1989; and Kaufman and Shepard, 1982). Both identified ICU nursing time as a major cost, with declining costs per day as the infant moves into the convalescent stage.

There have been specific cost-effectiveness studies of selected neonatal intensive care technologies, but these remain few. Back transport of convalescing infants to community settings has been demonstrated to be highly cost effective (Jung and Bose, 1983). Surfactant replacement therapy (SRT) has been shown to be highly cost-effective; although it does not reduce overall charges, because the improved survival rates induced new charges for the new survivors (Maniscalco, Kendig, and Shapiro, 1989). It did shift utilization from ancillary charges (reflecting illness severity) to room charges (reflecting convalescent care for growing prematures).

The economic impact of NICUs on society has been addressed in a landmark article by Boyle et al. (1983), who performed extensive cost-benefit analyses of neonatal intensive care including estimates of quality-adjusted life years based on survival and morbidity at follow-up.

They reported that NICUs increased both survival rates and costs. For newborns weighing 1,000-1,499 grams, the cost was $59,000 (1978 Canadian dollars) per additional survivor, and $3,200 per quality-adjusted life year gained. The net economic gain was quite sensitive to the discount rate because of the minimum 18 years between society's NICU "investment" and the beginning of societal "payback" by survivors joining the work force. For infants weighing below 1,000 grams, NICUs resulted in improved survival but at a net societal economic cost. Walker et al. (1984) estimated net present value of lifetime earnings per survivor weighing 1,000 grams and found similar results. Shankaran et al. (1985) studied the post-discharge costs of NICU graduates and reported substantial continuing costs for handicapped survivors.

In conclusion, NICUs are an expensive but highly effective array of technologies. The leading determinants of costs are lower birthweight, use of mechanical ventilation and need for surgery. Variations in costs among institutions are incompletely understood, but may represent variations in populations, illness severity, use of advanced technologies, alternative care practices and market pricing. Furthermore, the age of the available studies, plus continuing changes in NICU technology, suggests that these studies may not reflect the current or future state of affairs for very LBW infants.

Measures of Costs

Economic theory of the firm makes the distinction between fixed and variable costs. Fixed costs are the costs of inputs that a firm cannot change in the short-run. The costs of bassinets, mechanical ventilation equipment and the physical plant are examples of fixed neonatal intensive care costs. Nurses salaries, the costs of ancillary services (such as pathology tests, radiographs and drugs) and medical supplies are examples of variable costs. If a hospital were to stop admitting patients to its NICU, the hospital could eliminate its variable costs, but it would still be obligated to pay on its fixed costs. On the other hand, if a hospital admits an additional infant to its NICU, then the hospital incurs additional variable costs (for example, additional nursing hours and additional ancillary services). These additional costs are referred to as marginal costs.

Although hospital pricing strategies vary depending on local market conditions, the general guiding principal is for hospitals to charge each patient their share of average total (fixed plus variable) costs, based on the number of inpatient days and the quantity of ancillary services consumed.[2] For example, the NICU accommodation charges do not reflect the marginal cost (to the hospital) of a day in the NICU, rather they are the average total cost of a NICU bed day. Therefore, it is simply not enough to know that Medicaid payments do not cover all of hospital charges in order to conclude that Medicaid payments do not cover marginal cost and that Medicaid patients are likely to confront problems with access to care or inferior quality of care. As long as Medicaid payments cover the marginal costs of caring for Medicaid patients, then hospitals will not have an incentive to deny them access or to provide lower quality care (at least in the short-run). However, if Medicaid fails to pay its share of the fixed costs, the hospital must either absorb these as losses or pass them on to

[2]This simplified explanation ignores cost-shifting between types of services that may occur in hospital charge structures.

other payors. Furthermore, marginal costs increase dramatically as a hospital approaches capacity, thus the adequacy of Medicaid payments depends on total utilization.[3] With this distinction in mind, we review two alternative approaches to measure the cost of neonatal intensive care: charges and direct measures of resource use.

Charges

The most common approach to measuring cost is to use hospitals' reported charges. Many studies simply report charges, sometimes mistakingly referring to them as costs. Other studies use hospital charges to estimate costs, by multiplying charges by hospital-specific cost-to-charge ratios. Charge data will be available either as total or itemized charges. Itemized charges will break out charges for accommodation and ancillary services consumed by cost centers. For infants' accommodation charges, the relevant cost centers are (1) the nursery, (2) the NICU (perhaps different charges for different levels of care-- maximum, intermediate and recovery), (3) the pediatric unit, and (4) the pediatric intensive care unit. Separate ancillary charges are generally reported for the following services: (1) laboratory, (2) radiology, (3) pharmacy, (4) medical and surgical supplies, and (5) specialized facilities (for example, inhalation therapy, cardiac catheterization and operating room). Although charges for inpatient physician services are not reported by the hospital, studies designed to measure all inpatient costs must obtain physician charges.

Problems with Using Charge Data

There are several problems inherent with using charges to estimate costs:

1. Charges reflect the demand for and supply of the ***output*** being produced (days of NICU care) while cost measures should reflect the supply and demand for the ***inputs*** needed to produce that output (nursing services, supplies, etc).

2. Charges are based on accounting (average) costs, which reflect each hospital's average case-load. Therefore, resource use will be overestimated for infants who have below average severity of illness. Similarly, resource use will be underestimated for infants who have above average severity of illness.[4]

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[3] If marginal cost is covered, but marginal cost is less than average total cost, then in the long-run hospitals may decide that it is no longer profitable to care for Medicaid patients, and they may reduce their overall patient-care capacity to reflect this decision.

[4] Individual-specific charge data, which indicates the length of stay and the specific ancillary services used, would go a long way toward reflecting actual individual-level variation in resource use. Nevertheless, charges for accommodations would still reflect the average intensity of use for all infants rather than actual use for specific patients.

3. The higher the level of aggregation of the charge measures (for example, not reporting separate charges for the different level of neonatal intensive care), the larger is the error in measuring an individual infant's resource use.

4. Comparisons of resource use over time will be confounded by changes in case-mix and pricing policies (for example, cross subsidies) over time.

5. Comparisons of resource use across hospitals will be confounded by differences in levels of aggregation, average case-mixes, pricing policies, capital costs, and accounting procedures, especially how they allocate overhead costs. For example, teaching hospitals may differ in how they allocate teaching costs to different cost centers.

6. Charge data cannot be used to distinguish fiied from variable costs.

The first three items are less of a problem if the goal is to measure the average cost of care for all newborns treated in a hospital's NICU. However, they represent a potentially serious problem, if the goal is to measure costs for sub-groups of patients, such as Medicaid-covered infants. For example, if the average severity of illness of Medicaid-covered newborns differs substantially from privately-insured newborns, then using charges to estimate costs will misrepresent the average cost of caring for Medicaid-covered newborns. Furthermore, this measurement error would also depend on the proportion of Medicaid patients, which differs across hospitals.

Advantages of Using Charge Data

Despite its limitations, charge data is widely accepted and the most commonly used approach to measure hospital costs. The reasons for its acceptance and popularity are that patient-level charge data can be acquired in a timely fashion and at a modest costs from a wide range of sources, including individual hospitals, private insurance claims and state-wide hospital discharge data sets. No expensive primary data collection is necessary. Furthermore, because hospital reimbursements are frequently based on their reported charges, hospitals have a strong financial incentive to maintain complete and accurate accountings of their charges.

Estimating Costs from Charges

The preferred, and the most commonly used, method to estimate costs from charges is to multiply charges by cost-to-charge ratios. As the name implies these ratios estimate the difference between the costs of resources used to produce specific services and the amount that hospitals charge. Greater precision is obtained when cost-to-charge ratios are available for each cost center. Medicaid programs that retrospectively reimburse hospitals based on costs use cost-to-charge ratios to calculate the cost of caring for Medicaid patients. One data source for calculating these ratios is the annual hospital cost reports required of all hospitals caring for Medicare patients. In addition, many states require that hospitals report financial data, and some states calculate cost-to-charge ratios from these reports.

Some studies have used reimbursed charges as a measure of resource use. In these studies charges appear to be multiplied by the average proportion of charges that are actually collected. The assumption is that charges are inflated over costs to account for the costs of bad debt and charity care, and by deflating the charges to reflect actual revenue, one has a better measure of resource use. One serious problem with this approach is that hospitals experience different levels of profitability, and indeed many hospitals experience losses. A second problem is that hospitals' pricing structures may incorporate cross-subsidizations of services, that is, some services may be priced below costs and other services above costs. Therefore, using the average proportion of charges that are collected to deflate charges will add additional error to the estimates. For example, deflating charges that under represent costs would clearly exacerbate the under-estimation problem. In conclusion, the use of cost-to-charge ratios is preferred to using reimbursed charges.

Data Sources

Sources of charge data include (1) state-wide hospital discharge data (principally UB82 reports), (2) discharge data collected by private sources, such as NPIC, HKR or hospital chains,[5] (3) primary data collection of hospital billing or UB82 data, (4) private insurance claims, and (5) Medicaid claims.[6] Sources one and two were described in Chapter IV. The scope of primary data collection could range from a single hospital to a large nationally representative sample of hospitals with NICUs. The first three data sources contain charge data for all types of insurance coverage. Therefore, each of these three data sources can be used to compare the cost of care for Medicaid, privately-insured and uninsured infants.

Private insurance claims data may be obtained directly from private insurance companies or from private companies maintaining medical claims databases, for example, MEDSTAT Systems, Inc. These databases do not include claims for Medicaid patients; therefore, data from private insurance claims would have to be combined with Medicaid claims, in order to compare the cost of care for privately-insured and Medicaid-covered infants.' If HCFA wished to study only the cost for Medicaid-covered infants, then Medicaid claims data alone would be sufficient.

However, the selection of the specific state Medicaid programs to study must be based on a careful review of their Medicaid claims data. Although information on charges are

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'Discharge data from some private abstracting services (for example, HKR) contain only total charges. Some state-wide discharge data also contain only total charges.

[6]Medicare or state-required annual cost reports will be needed from each hospital to calculate cost-to-charge ratios.

'MEDSTAT data have already been used for HCFA sponsored research, for example the Medicaid Quality of Care Study being conducted by Systemetrics/McGraw Hill.

usually included on the Medicaid claim, the exact nature of the charge data may vary across hospitals. In particular, the reported charges may reflect private pay charges, Medicaid allowable charges, expected reimbursements, or some estimate of costs. Therefore, in order to be a good candidate for a joint study of private insurance and Medicaid claims, a Medicaid program must demonstrate a high level of consistency in reported charges. Furthermore, the accuracy of reported charges will likely be better in states where Medicaid reimburses hospitals based on retrospective costs than in states where Medicaid reimburses by prospective payment.

Direct Measures of Resource Use

Designing direct measures of resource use requires detailed observations of patient care and decision rules to allocate capital costs, resources involved in joint products, and resources not directly linked to patient care to different cost centers. To date, this approach has seldom been used to study NICU costs (Kaufman and Shepard, 1982; Newns et al., 1984) , and no standardized approach has yet been developed.

Measuring Neonatal Intensive Care Resource Use

An approach adopted in one study of neonatal intensive care (Kaufman and Shepard, 1982) was to divide NICU costs into three components: infant direct costs, NICU direct costs and hospital overhead.

Infant Direct Costs--Infant direct costs are the nursing and medical staff costs, along with the pharmacy, radiology, pathology, and medical and surgical equipment costs that can be directly assigned to each patient. Detailed observations of clinical and nursing procedures are required to assess the nursing and medical staff time allocated (per day or per shift) for different types of patients. Then to establish the cost of nursing care, estimates of nursing time requirements are multiplied by the sum of nursing salaries and fringe benefits. In order to operationalize these measures (that is, to facilitate estimations without requiring direct observations for each infant), formulas for the time requirements can be established based on patient information that can be found in the medical records.

Since the medical staffs activities can involve the joint products of patient care, teaching, and research, methods to estimate the costs of physicians time are not as straight forward. An approach followed by Kaufman and Shepard was to assign charges billed to patients for physician care (itemized as daily care and special procedures) to the day they occurred. Then these charges were multiplied by the percentage of total charges actually collected as revenue.”

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[8]Using reimbursed charges to estimate physician costs shares many of the same problem as using reimbursed charges to estimate hospital costs. Furthermore, it is not clear that this approach actually corrects for joint production.

Investigations of medical case notes, detailed observations, and discussions with nursing staff can be combined to determine the use medical and surgical supplies. To operationalize the measures of medical and surgical supplies, formulas must be based on information in the medical records. Use of pathology tests, radiographs and pharmacy prescribed items can be determined from the medical records. Costs of these individual items can then be derived from the hospital's charges multiplied by a cost-to-charge ratio for the appropriate department.

NICU Direct Costs--NICU direct costs are the costs that could be assigned directly to the NICU, but not to specific infants, for example, supervisors' salaries, house staffs salaries, neonatal intensive care equipment (maintenance and depreciation) and miscellaneous supplies. These costs can be allocated indirectly to each infant based on the number of days spent in the NICU. This approach can be further refined by defining different levels of NICU care, for example, intensive, intermediate and recovery, and allocating costs across these different levels based on observation and consultation with the nursing and medical staff.

General Hospital Overhead--General hospital overhead consists of a wide range of costs that are essential to the operation of the hospital but that are indirectly associated with NICU care. These include fixed depreciation, licensing costs, taxes, plant security, operations, insurance, data processing, administration, purchasing and accounting. These costs could first be allocated to the NICU and then allocated to patients based on the infants' length of stay. A commonly used formula for allocating these costs to different cost centers is based on square footage. These costs may be further allocated across the different levels of **NICU** care based on either the square footage dedicated to the different levels of NICU care or in proportion to the NICU direct costs. [Note, this approach to allocating hospital overhead will yield results very similar to a hospital's standard accounting procedures as reflected in charges.]

Problems with Using Direct Measures of Resource Use

The major disadvantage is that studies using this method would be significantly more expensive than studies relying on charges. First, standardized methods that could be used across hospitals would need to be developed. This would require direct observation and in-depth interviews with hospitals staffs in numerous hospitals.' Second, different methods would most likely have to be developed for Level I, II and III hospitals, in order to study the costs of infants transferred between the different types of facilities. Third, once the standardized methods were developed, the application of the methods would require extensive medical record reviews and detailed studies of hospital cost reports from numerous hospitals, covering different locations and different ownership types, in order to be generalizable.

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[9] **A** standardized method has not been validated for multiple hospital studies. For example, it may not be possible to use the medical record indicators identified in one hospital to allocate resources in other hospitals. Hospitals may differ in their medical record practices, nursing and medical staffing levels, levels of technological sophistication, and substitution among alternative inputs.

Fourth, because of the large variation in infant-level neonatal intensive care costs, there will be a substantial trade off between precision of the estimates and the cost of data collection. Finally, it may be difficult to recruit hospitals to participate.

Advantages of Using Direct Measures of Resource Use

A principal advantage of direct measures of resource use, over using charges, is improved potential to the improved measures of nursing and medical staff costs, and the division of NICU direct overhead costs into different levels of NICU care. The second principal advantage of using direct measures of cost is that they permit one to distinguish fixed from variable costs, which has important implications for access and quality of care.

Comparisons of Costs with Payments

A major reason for studying the cost of caring for Medicaid patients is to compare costs with reimbursements. In particular, if hospitals' costs exceed Medicaid payments, then hospitals may face financial incentives to limit access or reduce quality of care for Medicaid-covered patients.

In order to examine differences between costs and payments, HCFA can use hospital billing records, Medicaid claims, or private insurance claims. Hospital billing records offer the advantage that they contain information on all patients, including persons with and without Medicaid coverage. Thus, hospital billing records can be used to compare the cost-payment differential for Medicaid and non-Medicaid patients. Medicaid claims could be used only to examine cost-payment differences for subgroups of Medicaid patients, although it would be possible to combine Medicaid and private insurance claims in order to examine differences between Medicaid and non-Medicaid patients. Other advantages of using hospital billing data include: (1) the high-level of detail and reliability of the charge and payments-received information, and (2) the inclusion of uninsured patients. The major disadvantage of using hospital billing data is the expense of primary data collection. In contrast, the claims data are a relatively inexpensive source of information on a large number of patients from different hospitals. But these sources do not contain information on the uninsured, and the quality of the charge information for Medicaid patients may be inferior to that of hospital billing data. (See the discussion of Medicaid claims data in the Data Sources section.)

VI. ACCESS TO CARE AND VARIATION IN OUTCOMES

Issues of access and quality of care transcend source of payment, but Medicaid-covered infants may be particularly vulnerable because:

- The reimbursements may be below the average cost of providing neonatal intensive care
- The reimbursements may cover a NICU's average cost, but Medicaid-covered infants may be more likely to incur above-average costs
- The Medicaid prospective payment systems do not control for systematic variation in resource use across hospitals
- Medicaid programs often have utilization-control mechanisms that place hospitals at risk of recovering no payment for some part of Medicaid patients' stays if the use of neonatal intensive care is deemed inappropriate ex post
- Medicaid payments to physicians may be below the payments physicians could earn treating other patients

As indicated in chapter III, few studies have examined access and quality of care issues across payer groups. Therefore, in this chapter we will discuss the means to study differences in access and quality of care between Medicaid-covered infants, privately-insured infants and uninsured infants.

In order to assess the extent to which Medicaid recipients have adequate access to care and that the quality of that care meets general standards, HCFA will need information about access and quality as well as information about patient characteristics that might influence access and quality. These characteristics include insurance status, severity of illness, and maternal demographics. Furthermore, HCFA will need this information for infants covered by Medicaid, infants covered by alternative insurers, and infants without health insurance. Thus, the general data needs for assessing access and quality will include

- Measures of access such as admissions to Level I, II, and III NICUs, hospitals of birth, transfers between hospitals, and decisions to resuscitate or terminate care
- Measures of the quality of care such as mortality, post-discharge survival rates, and prevalence of disability
- Measures of the severity of illness for all groups of infants
- Measures of the characteristics of the infants and their mothers

- Measures of insurance status
- Measures of hospital characteristics

One fundamental problem confronting all studies of access and quality, as well as costs, is controlling for variations in patients' severity of illness. To date, most studies of neonatal intensive care have relied on birthweight and gestational age. Although these are very important indicators of severity of illness, and they perform well at the tails of their distribution, they perform less well in the middle range of their distribution. Therefore, before turning to a discussion of the specific access and quality issues, we review newborn severity of illness classification methods.

Newborn Severity of Illness Classification

Quantitation of illness severity has been a major focus of recent health services research particularly since the advent of prospective payment systems. Assessing patient status at the beginning of care is essential for (1) the understanding of prognosis, outcome, and resource utilization, (2) case mix adjustment both for financial purposes and for clinical and health policy research, and (3) studies comparing therapies, institutions, or outcomes over time.

Application of such research to newborns has been quite limited. The earliest measure of "severity" or risk for adverse outcome in the neonatal period was based on birthweight. In 1930 the Finnish pediatrician Yllpo argued that infants born weighing 2,500 grams or less were at substantially greater risk of death (Rooth, 1980). This cut-off point was formally adopted by the World Health Organization (World Health Organization, 1950) and confirmed by empirical analyses (Shapiro, 1954). With increasing sophistication of the management of perinatal problems, more refined birthweight categories have been used, and consideration given to the risks associated with prematurity (less than 37 weeks gestation at birth) independent of birthweight. The joint effect of birthweight and gestational age have therefore been used to quantify risk among newborns (VandenBerg and Yerushalmy, 1966; Williams et al., 1983; and Starfield et al., 1982). Although birthweight and gestational age reflect primarily the adequacy of intrauterine growth, these factors may not reflect subsequent events which might alter neonatal outcome, such as problems during birth.

In order to address one class of such events, acute problems during the birth event, Dr. Virginia Apgar developed a score for newborn infants' physiologic status based on observations of their color, heart rate, respiratory effort, muscle tone, and irritability shortly after birth (Apgar, 1966). Low Apgar scores (6 or less out of a total of 10) are considered indications of intrapartum asphyxia, and occur more frequently in association with factors that increase the risk of complications during pregnancy and labor: low birthweight, lack of perinatal care, and maternal age at the extremes of the child-bearing age-range. (Querec, 1978). Infants with low Apgar scores are at increased risk of death and other problems in the neonatal period, and neurodevelopmental delay later in childhood (Nelson and Ellenberg, 1981). As a severity measure, the Apgar score has limitations. Even in conjunction with birthweight and gestational age, it ignores other conditions such as congenital anomalies or respiratory distress syndrome, which may influence the need for intensive care services.

Moreover, the predictive power of the score is greatest at the low end of the scale and scores above six may not discriminate well among infants at quite different levels of severity (Hobel, Yonkelis, and Forsythe, 1978). Finally, its application to very premature infants may not be as valid as for term infants for which the Apgar was developed.

More detailed perinatal risk assessment instruments have been developed (Aubrey and Pennington, 1973; and Hobel, Yonkeiis, and Forsythe, 1978). Information derived from such instruments has been used to adjust for case-mix differences in comparisons of neonatal outcome among hospitals (Littman and Parmalee, 1978; and Minde et al., 1983). The original DRG classification of neonatal cases has been shown to have extremely poor predictive value for length of stay and cost in neonatal intensive care units (Phibbs et al., 1986). Pediatric Modified DRG's have replaced the original 8 categories with 46 categories, and included birthweight and mechanical ventilation in the grouping algorithm. PM-DRG's can account for 46 percent of the variation in charges but cannot be used to stratify severity because all early deaths are placed in a single DRG (Lichtig, Knauf, and Bartoletti, 1989). A prognosis oriented scoring system was developed for extremely low birthweight infants weighing less than 801 grams which did predict mortality and morbidity (Zarfin et al., 1986). However, this focus is too narrow to permit comparisons of a broad spectrum of neonatal intensive care services. The scale used by Littman and Parmelee (1978) mixed diagnosis, therapies and conditions. Similarly, a neonatal transport stabilization score has been developed and validated, but applies only to the pretransport stage and only to outbom infants (Ferrara and Atakent, 1986). It is also a treatment based rather than a physiology based system. Other authors have reported scores which utilize objective physiologic data designed to predict bronchopulmonary dysplasia, a chronic lung disease of newborns, due to both prematurity and ventilator-induced lung damage (Sinkin, Cox, and Phelps, 1990; Palta et al., 1990). However, these scores are not applicable to other outcomes.

These instruments capture substantially more information than the much simpler Apgar score but have limitations, such as incorporation of diagnoses or specific conditions which themselves may vary in severity. Comparability among institutions may be diminished by variation in local diagnostic and therapeutic conventions. Further, since these instruments utilize data from the entire neonatal course, they blur the distinctions between underlying risk, versus treatments, complications, and outcomes. This characteristic makes it difficult to determine to what degree the diagnoses and interventions are appropriate or effective for the individual infant, and limits the usefulness of these instruments as control variables in studies of access and outcome.

What appears to be required is a quantitative assessment early in the neonatal period which is independent of diagnosis but is relevant across a number of conditions present in the neonatal period. Moreover, such a scale should reflect the physiologic status of the infant based on relatively objective measures which are obtained routinely. In order to be readily adopted, such a score should be relatively simple and not require extensive new data collection.

A score which has such characteristics has been developed by Knaus and co-workers for adults admitted to intensive care units (Knaus et al., 1981 and 1985). This APACHE classification system (for Acute Physiology and Chronic Health Evaluation) is based on a brief assessment of pre-admission health and physiologic status. The physiologic status is scored according to the function of various organ systems which would be measured routinely during the first 24 hours of admission. This scoring system has been found to predict the probability of death and intensity of therapeutic services over a variety of diagnoses (Knaus et al., 1981; and Wagner, Knaus, and Draper, 1983). Moreover, the score has been used to assess the relationship between the use of intensive medical care and the probability of survival (Scheffler et al., 1982). The score has also proven accurate in predicting outcomes across hospitals with quite different patient-care mixes (Knaus et al., 1986), and it is capable of demonstrating differences in severity between intensive care admissions to community hospitals and those admitted to university hospital ICUs. Finally, this approach has been extended to assessing care in pediatric intensive care for children beyond the neonatal period with the development of the Physiologic Stability Index (PSI) (Yeh et al., 1984; and Pollack, Ruttiman, and Getson, 1987).

The PSI has been applied to a limited number of newborns. However, the unique physiology of premature infants has required adaptation and validation of a new index, the Score for Neonatal Acute Physiology (SNAP) (Richardson, 1991). Further work is under way to evaluate the utility of SNAP in predicting survival, therapeutic intensity and hospital charges.

In sum, although there are several measures of newborn severity of illness, most of these are either too focused on specific conditions or are too general to fully serve as a basis for distinguishing between infants served by NICUs. In addition, several of these measures blur the distinctions between underlying risk versus treatments, complications, and outcomes. However, until new measures (such as, SNAP) are developed and evaluated, studies can control for newborns' severity of illness by one or more of the following: birthweight, gestation age, Apgar score, DRG or PM-DRG.

Access to Care

Hospital of Birth

As discussed in Chapter III, the location and type of hospital in which a woman gives birth may influence the decision to resuscitate an infant who is at the extreme limit of viability, or to transfer a high risk infant to a Level III NICU. However, there is no clear indication as to how Medicaid reimbursement policies may affect the hospital of birth.

The minimum data needs to study this issue are information on birthweight, gestational age, Apgar scores, payment source and characteristics of the hospital of birth. However, the following information would be needed to support more detailed analyses of access and to determinants of differential access: (1) medical risk factors for the pregnancies, (2) complications of labor and delivery, (3) abnormal conditions of the newborns (for example, birth injury or meconium aspiration) and (4) whether the mother was transferred prior to delivery. Birth certificates from all 50 states and the District of Columbia contain measures of all these data items, except for payment source and characteristics of the hospital.[1] Fetal death certificates from all 51 registration areas contain measures of all these data items, except for payment source, characteristics of the hospital and whether the mother was transferred prior to delivery.

The absence of information on the characteristics of hospitals is not a serious limitation, since birth and fetal death certificates identify the hospital, and thus, could be linked to data from the AHA Annual Survey of Hospitals or the AHA 1989 Survey of Obstetrical and Newborn Services.[2] The absence of information on payment source is a more serious problem. One means to obtain information on payment source is to merge birth certificate information with hospital discharge data. Maine, Washington and New York, which collect state-wide hospital discharge data, currently merge birth certificates with hospital discharge data. In New York, the discharge abstracts contain birth weight which not only improves matching, but also makes feasible the use of unmatched discharge abstracts. Georgia will begin to merge these data in 1992. Over one-half of the states currently collect state-wide hospital discharge data. However, whether they are capable of merging vital statistics and discharge data will depend on whether the state-wide hospital discharge data contain patients' names.

Another potential data source for a study of birth hospitals is the 1988 NMIHS. NMIHS has several important advantages. First, it contains more detailed information of all the data items discussed above, than is available from vital statistics. Second, NMIHS is based on a nationally representative sample of birth certificates (with an over sampling of very LBW infants) and fetal death certificates. Third, NMIHS has observations from all states, except Montana, which would facilitate a comparison of the impacts of alternative Medicaid reimbursement policies.[3]

Transfer Patterns

Medicaid reimbursement policies may influence the decisions to transfer high-risk infants from:

- Level I to Level II or Level III hospitals,

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[1]Information on whether the mother was transferred prior to delivery is available in only 47 of the 51 registration areas.

[2]Besides information on hospital characteristics, it would be desirable to know whether the hospitals are part of a perinatal regional network.

[3]These may not be a sufficient number of observations from each state to compare individual Medicaid programs. However, it may be possible to aggregate up to types of reimbursement systems: retrospective cost, per-diem, DRG, and other per case prospective payment systems.

- Level II to Level III hospitals, and
- Level III hospitals back to community hospitals.

For example, are Medicaid-covered infants more likely to be transferred from a community hospital to a perinatal center at a lower severity of illness than are privately-insured newborns? In order to study the impacts of payment policies on transfer patterns, one needs a data set that keeps track of individuals as they move between hospitals. Only one published study has systematically examined transfer patterns (Marcus et al., 1988). This study combined a file of linked birth and death certificates for all births occurring in New York City during 1976, with data on inter-hospital transfers from the four transport services operating in New York City during 1976. This methodology, which could possibly be replicated in other areas, permitted the researchers to study the transfer patterns of all infants, regardless of payer. In addition, the birth certificates provided information on (1) birthweight and gestational age, (2) Apgar scores, (3) medical risk factors for the pregnancies, (4) complications of labor and delivery, (5) abnormal conditions of the newborns, and (6) whether the mother was transferred prior to delivery.

Medicaid and private insurance claims also permit one to track infants as they are transferred between hospitals. However, there may be insufficient information to assess the newborns' severity of illness. For example, birthweight and gestational age are generally only recorded through the ICD-9-CM diagnoses codes, and not recorded as continuous variables. Although Medicaid claims data has been successfully linked to birth certificates, private insurance companies may not permit their claims data to be linked to vital statistics. Insurance companies may be unwilling to risk compromising the confidentiality of their enrollees.[4]

State-wide hospital discharge data or hospital discharge data from private sources (for example, NPIC, NACHRI or HKR) are not useful for studying transfer patterns, since infants cannot be tracked after they are discharged from a hospital.

The most promising data set to study transfer patterns appears to be the NMIHS. In addition to the three advantages discussed in the previous section, NMIHS collected detailed information from the medical records of all the hospitals in which newborns were treated. This information will be valuable in assessing the newborns' severity of illness prior to transfer.’

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[4]A database of Medicaid and private insurance claims linked to birth certificates could also be used to study hospital of birth.

[5]It is possible that a hospital's staff might overstate the severity of the problem on the medical records to justify transferring an infant. If such a practice occurs, it would reduce the chances of finding a significant result.

Decisions to Resuscitate or to Terminate Care

The decision to initiate or terminate neonatal intensive care has important implications for access to care, outcomes, and costs, as well as important moral implications. It is a major issue at the extreme limit of viability (23-25 weeks, 500400 grams). Even with maximum care such infants have extremely low survival rates ranging from l-20 percent; and survival is unprecedented without active treatment. Many clinicians have questioned the ethics of initiating intensive and expensive therapy in the face of such low probability of survival especially with all the attendant human costs of unsuccessful intensive care. Moreover the high complication and morbidity rate among the few survivors has raised serious concerns about the questionable benefits of neonatal intensive care for such high-risk infants. There is unfortunately a great amount of variability in both survival and morbidity rates for infants in this borderline viability range.

In addition to the medical uncertainty is the legal uncertainty. Federal regulation in the early the 1980's resulted in the so called "Baby Doe" rules. Although these regulations were designed to protect the civil rights of infants with birth defects, the largest category of infants affected by treatment and quality of life of decision-making are these borderline viable infants. The net effect of the political debate and public scrutiny in the NICU has been the gradual shift of clinical practice towards attempted resuscitation of all infants regardless of cost or probability of success (Strain, 1983; and Todres et al., 1988). The threshold for this may vary among institutions.

Unfortunately another impact of the Baby Doe regulations has been the hesitancy to study variations in NICU resuscitation and termination of care policies, since hospitals are reluctant to participate in research that might make them a target for a lawsuit. What evidence there is points to differences both within and among institutions. Goldenberg, Nelson, Dyer et al. (1982) reported a marked disparity between community obstetricians' perceptions of the limits of viability and the actual survival rates for preterm infants. They attributed this misestimate of nearly three weeks gestation to the rapid advancement of NICU technology and the training of obstetricians in an earlier era. Such perceptions of viability on the part of community obstetricians could lead to delivery of extremely premature infants in community hospitals where they would be declared nonviable. Paneth et al. (1982) found marked differences between Level I, II and III hospitals in the success of resuscitation, so that hospital of birth appears to be a major determinant of whether and how well an infant is resuscitated. Todres et al. (1988) surveyed pediatricians on their attitudes towards viability, resuscitation and congenital anomalies. The survey revealed differences in willingness to undertake active intervention. In addition to differences in resuscitation policies for borderline viable infants, there are variations in treatment approaches to infants with multiple congenital anomalies. However, there is very little reported on this because of its controversial nature. There is a single report of selective nonintervention in cases of meningomyelocele (Gross et al., 1983), a report that produced a great deal of furor when it was published (Freeman, 1984).

In summary, there is probably substantial variation among physicians and NICUs in their decisions to initiate and terminate intensive care. The frequency and extent of such decision-making is unknown, and the effect of payer source on these decisions has not been studied. Studies addressing this issue can only be done by careful medical record reviews from several hospitals in several different states. These studies must take into consideration not only birthweight, and NICU policy but also antecedent obstetric care, quality and extent of antenatal counseling, expressed parental values, certainty of gestational age assessments, actual illness status at birth and inevitable uncertainty about long term prognosis. They must also take into consideration the location of birth (inborn, outborn) and the availability of skilled resuscitation. However, because of the moral and legal implications of this research, it may be difficult to recruit hospitals for such a study. Furthermore, those hospitals agreeing to participate may not be representative of all hospitals, that is, they may be at a lower risk for a potential lawsuit.

Variation in Outcomes

Mortality

The risk of neonatal mortality for very LBW infants varies substantially between NICUs. For example, in the mid-19803 the mortality rates for infants with birthweights less than 750 grams varied from 28 percent in one university-affiliated center, to 53 percent in another, and 74 percent in a third (Office of Technology Assessment, 1987). Hack et al. (1991) also found substantial variation among infants weighing 500 to 700 grams in seven different NICUs. Although the observed variation may reflect different case-mixes, it may also reflect differences in the quality of care. Variations in quality of care may result from differences in the quality of the staff and differences in the level of technological sophistication.[6] Medicaid programs have an interest in knowing whether Medicaid-covered newborns are more likely to be treated in NICUs with higher mortality rates, or whether Medicaid-covered newborns receive lower quality care than similar privately-insured infants treated at the same hospital.

If Medicaid-covered infants are more likely to receive lower quality care, or are more likely to have their care terminated, then they would be expected to have higher mortality rates. To address these issues, HCFA will probably need either (1) a data set containing linked birth and death certificates for infants from a large number of hospitals or (2) a data set that contains medical record abstracts for numerous NICUs. These types of data sets are needed to provide a sufficient sample of infants in each of several hospitals so that intra- and inter-hospital comparisons can be estimated precisely. The NMIHS will probably be insufficient for analyzing this issue since it does not contain a sufficiently large number of infants in any one hospital.

All 50 states and the District of Columbia link birth and death certificates, but these data have serious limitations for studying differences in mortality by payer source and among NICU patients. Birth certificates do not indicate whether an infant was treated in a NICU, nor do they indicate the principal payer of medical care. One approach to correct for these shortcomings is to link vital statistics data with state-wide hospital discharge data. Another approach is to link vital statistics data to Medicaid and private-insurance claims data. Both

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[6] One reason for variations in technological sophistication is the natural lag in the diffusion of rapidly changing neonatal intensive care technology.

of these data sets could also be linked to AI-IA survey data, to include characteristics of the hospitals that might influence quality of care. An advantage of these study approaches is the ability to study outcomes from a large number of hospitals, from more than one state, and of different types and locations. To obtain a sufficient number of observations within each hospital, it may be necessary to examine linked birth and death certificates for more than one year.

Another potential data source is medical records. The principal advantage of this type of study is the ability to collect detailed information on newborns' conditions and the care they received. However, data would have to be collected from more than one hospital, and preferably from hospitals in more than one state, in order to address the broader policy questions of whether Medicaid-covered newborns are being treated at lower quality hospitals, and whether they receive lower quality of care within individual hospitals. Again, it may be necessary to collect the information for more than one year.

Early Discharge

To our knowledge only one trial of early discharge has been published (Brooten et al., 1986) which documented safety provided supportive community services (in this case nursing) were available. Clearly, the trend has been toward discharge at lower birthweights once the infant is stable. Generally, decisions are made with some knowledge of family and community services. However, clear guidelines predictive of outcome are lacking.

There is evidence that community based services in the form of early intervention programs can improve outcomes. Among health disadvantaged children, early educational programs result in higher IQs and fewer children in special education (Darlington et al., 1980; and Olds, 1990); early education for handicapped children also improves outcomes (Shonkoff and Hauser-Cram, 1987). This experience is currently being tested in LBW, preterm children with some evidence of equal efficacy (JAMA, 1990). Less well established is the benefit from purely physical therapy based interventions (Tirosh and Rabino, 1989).

There is no evidence on the efficacy of linking these types of services to foster early discharge. Further, the exact package (that is, most economical) of services required for different types of NICU survivors is unknown. Finally, since these services also apply to children at risk from a variety of vantage points (for example, substance abusing families, poor families, etc.), there are increasingly long waiting lists for such services in disadvantaged communities. The extent to which early discharge programs can be implemented to reduce Medicaid expenditures is entirely doubtful given overwhelmed and limited community resources. The only way to evaluate possible savings would be through clinical trials or demonstration projects.

Post-Discharge Survival

Generally, infants weighing less than 1,500 grams account for about 5 to 20 percent of post-neonatal deaths (Shapiro et al., 1980; Buehler et al., 1987; Goldenberg et al., 1985; and Zdeb, 1982) and postneonatal death rates in this birthweight range are about 55 per 1,000 live births (Buehler et al., 1987). NICU graduates make-up almost all of these deaths, since almost all infants in this birthweight range receive NICU care. However, it would be difficult without more specific information to (1) estimate the proportion of infants of heavier birth-weights who die following discharge from a NICU, and (2) what proportion of post-neonatal deaths among very LBW infants occurred prior to versus after discharge. Reports from two units (Hack et al., 1980 and Sills et al., 1983) suggest that most post-neonatal deaths occur prior to discharge with only two to four percent of post-neonatal deaths among very LBW children occurring after discharge.

The extent to which these post-discharge, post-neonatal deaths can be prevented is not well examined. To the extent they represent post-neonatal survival of severe congenital malformations, improvement is unlikely. In general populations, this rate is about 2 per 1,000 postneonatal deaths (Pharoah and Morris, 1979). The heavy contribution of socio-economic disadvantage to other causes of postneonatal mortality, including SIDS, suggests that rates could be reduced by a combination of good primary care and home visiting programs. However, there is no information as to possible difference in post-discharge, post-neonatal mortality rates between Medicaid-covered and privately-insured infants.

There are three sources of data to estimate post-discharge survival rates: vital statistics, reports of NICU follow-up programs, and the NMIHS Longitudinal Followup. With matched birth/infant death records, age at death can provide some estimate of post-discharge deaths. The difficulty in using vital statistics is that it is not possible to unequivocally establish that an infant had been admitted to and discharged from a NICU. Furthermore, differences in the hospital of birth and hospital of death could reflect neonatal transfer, not a post-discharge death. On the other hand, similarity in the hospital of birth and death does not preclude the possibility that an infant was discharged and readmitted. However, post-neonatal deaths after the average length of stay for a very LBW infant (for example, more than 4 months) generally represent true post-discharge deaths. Another disadvantage of using vital statistics is the inability to identify payer source. Again, these shortcomings could be overcome by linking vital statistics data with state-wide hospital discharge data or Medicaid and private-insurance claims data. The advantages of using vital statistics include the population-based estimates independent of individual NICU practices and the ability to study within hospital variations.

The second type of data comes from NICU follow-up programs. The quality of these data would depend on the individual unit both in terms of content and completeness. Recent reviews have raised major questions about the current published studies on NICU outcomes with regard to the failure to specify the selection criteria for study subjects and losses to the cohort due to death and other reasons. Given the limited number of NICU programs which report results, the variability in timing of such reports and the concerns above, the magnitude and causes of variations across NICUs cannot be assessed (Aylward et al., 1989 and Escobar, Littenberg, and Pettiti, 1991).

A special subset of the follow-up literature consists of follow-up in multi-site studies which might provide some of the comparisons desired. To date, such studies have not reported NICU-specific post-discharge deaths; however, secondary analyses could be performed.

The third data source is the NMIHS Longitudinal Followup. Beginning in January 1991, the National Center for health Statistics will re-interview the 10,000 mothers of live births who were initially interviewed as part of NMIHS. The followup period will cover from 25 to 42 months after the births. Although the sample will include approximately 1,500 births less than 1,500 gram and 1,500 births between 1,500 and 2,499 grams, the sample size may be inadequate to make Medicaid versus non-Medicaid comparisons.

Prevalence of Disability and Long-Term Service Needs

Generally, five to fifteen percent of very LBW NICU survivors will have severe neurodevelopmental handicap defined as mental retardation (IQ less than 70), severe cerebral palsy, severe seizure disorders or hydrocephalus (Office of Technology Assessment, 1987; Aylward et al., 1989; and Escobar, Littenberg, and Pettiti, 1991). These infants often have other severe congenital malformations, and (Shapiro et al., 1980) the percentages of severely affected infants persist into early school age (McCormick, 1989).

In terms of less severe problems, the percentages are higher. Current estimates of school problems or need for special education range from a third to a half of very LBW children (McCormick, 1989 and McCormick, Gortmaker, and Sobol, 1990). In some data still being analyzed, about half of extremely LBW children are limited in at least one activity of daily living. They also experience higher rates of asthma as well as neurodevelopmental problems.

Variations in the prevalence of disability by NICU and variations by health insurance status are unknown. The source and quality of the data to address these issues are, for the most part, that of the NICU follow-up studies noted above -- with all the same criticisms. While an increasing number of reports reflect geographically-based populations, none represent comparisons on institutions. The latter is further complicated by differences in definitions of what constitutes adverse outcomes. These sources have recently been critiqued (Aylward et al., 1989, and Escobar, Littenberg, and Pettiti, 1991). Again, almost all the data reflect neurodevelopmental problems. Other health problems and variation by unit are not described.

Alternate sources of information are the Child Health Supplements to the National Health Interview Survey and the NMIHS Longitudinal Followup. The data from the Child Health Supplements have been used to examine birth-weight specific morbidity rates (McCormick, Gortmaker, and Sobol, 1990 and Overpeck et al., 1989). However, even with the large samples in these supplements, the number of very LBW survivors is small (68 in the 1981 supplement ranging from 4 to 20 years of age). Such small numbers preclude subgroup analyses. The NMIHS Longitudinal Followup will have a much larger sample size, but the children's ages at the time of the followup survey will range only from two to three and a half years.

VII. CONCLUSION

The purpose of this study was to identify important research and policy issues pertaining to Medicaid and NICUs. Based on an extensive review of the clinical, cost-effectiveness and health policy literature on NICUs, we provided an **overview** of neonatal intensive care technology and delivery systems. We identified what is known and what is not known with respect to Medicaid policy issues, and we reviewed data sources and research strategies to fill the knowledge gaps.

Some of these knowledge gaps are as follows:

- There is almost no information on national Medicaid expenditures for infants who require neonatal intensive care, and the available estimates predate the recent Medicaid expansions. Future studies will require new data collection.

- The overall impact of the Medicaid expansions on Medicaid expenditures for neonatal intensive care cannot be predicted since the impact will depend on two changes. First, Medicaid expenditures for NICUs will rise as more infants are covered. However, the provision of prenatal care and other health services may reduce the incidence of the conditions that lead to NICU admission. The net effect of these two factors cannot be determined from available data.

- National estimates of the annual number of infants prenatally exposed to drugs range from **100,000** exposed to cocaine to 375,000 exposed to illicit drugs, in general. There are no good estimates of what percentage of drug-exposed infants are covered by Medicaid or require neonatal intensive care. Furthermore, the studies to date have not clearly defined the long-term effects and health care costs of prenatal drug exposure; although the cost of caring for drug-exposed infants are substantially higher than the cost of caring for normal infants.

- Anecdotal and some preliminary evidence suggests that in general Medicaid reimbursement rates do not cover hospitals' costs of caring for Medicaid patients, but there are no current or large scale studies that focus specifically on NICU reimbursements. There is also no literature examining whether Medicaid-covered infants are more expensive to treat than privately-insured or uninsured infants.

- It is unknown whether short falls between Medicaid reimbursements and hospitals' costs of caring for LBW infants limits the access Medicaid-covered infants have to neonatal intensive care or the quality of their neonatal intensive care. One possible irony is that stringent Medicaid reimbursement policies may increase the likelihood that Medicaid-covered infants are born premature or LBW (because of reduced access to prenatal care), but may increase the likelihood that these infants will be born in or transferred to a hospital with a NICU.

- Medicare DRGs and even PM-DRGs do not account for systematic variations in resource use across types of hospitals or regions. It is not known what impact the unexplained systematic variation will have on LBW newborns' access to care, transfer patterns, and quality of care. Will Level II hospitals respond to the financial incentives to "skim off" the less severely ill LBW newborns and transfer the more severely ill newborns to Level III hospitals?

- There appears to be substantial variation in mortality and morbidity among NICUs, even among Level III NICUs. A principal issue for Medicaid policy is whether Medicaid-covered newborns are disproportionately likely to be treated in NICUs with characteristically poorer outcomes or treated by lower quality physicians. At this time there are no studies of this issue; furthermore, very little is known about the magnitude and the causes of variations in quality of care across facilities.

- Finally, intermediate and long-term health and developmental problems for NICU survivors have uncertain implications for Medicaid expenditures.

As part of this study we identified data needs, data sources, and strategies to address these information gaps. We have grouped data needs into four categories: infant, hospital, cost/charge, and reimbursement. Items from one or more of these data categories are necessary to address each of the information gaps identified in this study. Data needs about infants include measures of newborn health status, sociodemographic indicators, health-insurance coverage, identification of the hospital of birth, and cause of death. The hospital data category includes the NICU level, teaching status and geographic location. Cost and charge data consist of patient-level hospital charges, hospitals' cost-to-charge ratios, and measures of hospital inputs. Reimbursement measures include patient-level hospital and physician reimbursements, plus source of payment. Table VII.1 summarizes these data needs and the data sources where they can be found. No single data source covers all data needs; therefore, it will be necessary to combine two or more data sources to address most of the research questions covered in this report.

In this report, we have reviewed ten sources of data. The data sources and some of their important characteristics are listed in Table VII.2. The characteristics included are the sample population, sample design, sample size, timeliness and cost. For the sample population, we denote whether each data source contains observations for Medicaid-covered infants and non-Medicaid-covered infants. Under sample design, we indicate whether the data sources (1) contain aggregate or individual-level information, (2) are representative of the populations and hospitals in the sample frame, (3) are based on a cross-section of hospitals, (4) contain longitudinal data on health utilization after a newborn is discharged from a NICU, and (5) include information from all newborn hospital stays (multiple hospitals). Finally, we used a scale of "good", "fair" or "poor" to evaluate the adequacy of the sample size, and the timeliness and cost of the data sources.

In this report, we have also recommended alternative research strategies to address each of the information gaps listed above. Each alternative strategy requires using one or more of the ten data sources. Table VII.3 summarizes these recommendations.

TABLE VII. 1

DATA NEEDS BY DATA SOURCE

	MMIS[a]	Survey of Medicaid Programs	Private Insurance Claims	Hospital Discharge Data: State-Wide	Hospital Discharge Data: Abstracting Services	NMIHS[b]	Vital Statistics	Hospital Billing Data	Hospital Medical Records	AHA Surveys[c]	NICU Follow-Up Programs
Infant Data											
Birth Weight	e			f		+	+		+		+
Gestational Age						+	+		+		+
Apgar Score						+	+		+		+
Complications of Labor and Delivery	+		+	+	+	+	+	+	+		+
Abnormal Conditions of Newborns	+		+	+	+	+	+	+	+		+
Diagnosis Codes	+		+	+	+	+		+	+		+
Congenital Anomalies	+		+	+	+	+	+	+	+		+
Procedure Codes	+		+	+	+	+		+	+		+
Maternal Characteristics											
So&demographic						+					
Prenatal care	-		-			+	+				
Risk factors for pregnancy						+	+				
Payer	+		+	+	+	+	+	+	+		+
Inborn/Outborn	+		+			+					
Birth Hospital	+		+			+	+		+		+
Discharge Status	+		+	+	+	+					
Date/Age of Death						+	+				+
Place of Death						+	+				+
Cause of Death						+	+				+
Hospital Data											
NICU Level						+					
NICU Size						+					
NICU Occupancy Rate						+					
Teaching Status						+					
Urban/Rural						+					

TABLE VII.1 (continued)

	MMIS[a]	Survey of Medicaid Programs	Private Insurance Claims	Hospital Discharge Data		NMIHS[b]	Vital Statistics	Hospital Billing Data	Hospital Medical Records	AHA Surveys[c]	NICU Follow-Up Programs
				State-Wide	Abstracting Services						
Cost/Charge Data[d]											
Hospital Charges											
Total	+/-		+	f	+			+			
Cost Center	-/e		+					+			
Hospital Input Measures											
Physician Charges											
Total	+/-		+						+		
Procedure	-/e		+								
Reimbursements											
Source											
Medicaid	+	+	+	+	+			+			
Private Insurance				+	+			+			
Other				+	+			+			
Hospital Reimbursement											
Total	+	+	+					+			
Cost Center	e	e	+								
Physician Reimbursement											
Total	+	+	+								
Procedure			+								

[a] Medicaid Management Information Systems (MMIS).

[b] National Maternal and Infant Health Survey (NMIHS) and the NMIHS Follow-Up.

[c] American Hospital Association's Annual Hospital Survey and the 1989 Survey of Obstetric and Newborn Services

[d] Cost-to-charge ratios are not listed here, but they can be obtained from either Medicaid or state-mandated cost reports.

[e] Not reported by all Medicaid programs.

[f] Not included by all states with state-wide discharge data.

+ Available

- Limited availability

TABLE VII.2

DATA SOURCES BY DATA CHARACTERISTIC

	Population		Sample Design					Sample Size				
	Medicaid	Non-Medicaid	Aggregate/ Individual	Representativeness	Cross-Section	Longitudinal	Multiple Hospitals	Infants	Within State	NICU	Timeliness	Cost
Data Sources												
MMIS	Yes	No	Individual	+	Yes	Yes	Yes	+	+	+	+	0
Survey of Medicaid Programs	Yes	No	Aggregate	+	Yes	No	Yes	+	n/a	+	+	+
Private Insurance Claims	No	Yes	Individual	+	Yes	Yes	Yes	+	+/0	+	+	0
Hospital Discharge Data												
State-wide	Yes	Yes	Individual	+	Yes	No	No	+	+	+	+/0	0
Abstracting services	Yes	Yes	Individual	0	Yes	No	No	+	0/-	+/0	+	0
NMIHS	Yes	Yes	Individual	+	Yes	Yes	Yes	+	0/-	+	0	+
Vital Statistics	Yes	Yes	Individual	+	Yes	No	No	+	+	+	+	+
Hospital Billing Data	Yes	Yes	Individual	0/-	Yes	No	No	0	0/-	0/-	+	
Hospital Medical Records	Yes	Yes	Individual	0/-	Yes	No	No	0	0/-	0/-	+	
AHA Surveys	n/a	n/a	n/a	+	Yes	n/a	n/a	n/a	+	+	+	+
NICU Follow-Up Programs	Yes	Yes	Individual	0/-	Yes	Yes	No	0	-		0	+

\+ Good

0 Fair

\- Poor

n/a Not Applicable

TABLE VII.3

DATA SOURCES BY RESEARCH AREA

	Cost of NIC			Access to Care				Variation in Outcome		
	Medicaid Expenditures	Medicaid	Non-Medicaid	Hospital of Birth	Transfer Patterns	Resuscitation	Termination of Care	Mortality	Post-Discharge Survival	Disability/Long Term Service Needs
Data Sources										
MMIS	+	+/0		b	p			s	s	
Survey of Medicaid Programs	+/0									
Private Insurance Claims			+/0	b	p					
Hospital Discharge Data								s	s	
State-wide	+/-	+/0	+/0	h				m	m	
Abstracting services	0/-	0	0							
NMIHS	0/-			+	+				0/-	
Vital Statistics	u	u		h, b	p			m,s	m,s	
Hospital Billing Data		+	+							
Hospital Medical Records		c	c			+	+	+/0		
AHA Surveys	u	u	u	u	u					
NICU Follow-Up Programs									+	

+ Good

0 Fair

Poor

u The data source provides useful information, but cannot support an analysis by itself. The data source must be merged with other applicable data sources in the column.

c Medical records, in combination with direct observation, are a key data source for direct measures of resource use.

h Birth certificates state-wide hospital discharge data must be used in combination.

b,p A database of Medicaid (b) and private insurance (p) claims linked to birth certificates.

m Linked birth-death certificates must be linked to state-wide hospital discharge.

s A database of Medicaid and private insurance claims merged with linked birthdeath certificates.

For studies of Medicaid expenditures, we identified four main sources of data: (1) the Medicaid Management Information Systems, (2) state-wide hospital discharge data, (3) private sources of hospital discharge data (for example, NPIC or HKR), and (4) the NMIHS.

Two alternative methods were discussed for studying the cost of providing neonatal intensive care--using charge data deflated by cost-to-charge ratios or directly measuring resource use. In both cases, it would be important to collect data for Medicaid and non-Medicaid patients so that access and quality issues could be addressed. Sources of charge data include: (1) state-wide hospital discharge data (principally UB82 reports), (2) discharge data collected from private sources, such as NPIC and HKR, (3) primary data collection of hospital billing or UB82 data, (4) private insurance claims data; and (5) Medicaid claims data. In addition, information from hospital cost reports is necessary to calculate the cost-to-charge ratios. On the other hand, direct measures of resource use require extensive primary data collection.

A major reason for studying the costs of caring for Medicaid patients is to compare costs with reimbursements. In particular, if a hospital's costs exceed payments then hospitals may face financial incentives to limit access or reduce quality of care for Medicaid patients. Two sources for reimbursement information are claims data or hospital billing (payments-received) records.

Studies of Medicaid-covered newborns' access to care will involve comparisons between Medicaid-covered newborns and newborns who are privately insured and those who are uninsured. In this report, we discussed three measures of access: (1) hospital of birth, (2) transfer patterns and (3) decisions to resuscitate or terminate care. For studies of hospital of birth, we identified two potential data sources: the NMIHS, and state-wide hospital discharge data linked with birth certificates. In order to study transfer patterns for newborns, potential databases must contain a means of tracking infants across hospitals. Three such data sources are the NMIHS, and Medicaid and private insurance claims data. Because claims data do not contain particularly good measures of newborn severity of illness, it may be useful to link these data with birth certificates. Decisions to resuscitate newborns at the extreme limits of viability or to terminate care are complex and sensitive; therefore, studies of these decisions must be based on carefully performed medical record abstractions.

In this study, we discussed several measures of quality of care: mortality, post-discharge survival, and prevalence of disability and long-term service needs. Potential databases for studies of these outcome measures include: (1) the NHIMS, (2) linked birth and death certificates, and (3) medical record abstractions.

As this quick review of data sources indicates, several of the different research questions addressed in this report can be studied by one or more of the same data sets. Therefore, if and when a decision is made to fund NICU research, it would be advisable for HCFA to consider the versatility of the alternative data sources and the possible economies of scale in combining research questions. For example, the NMIHS data can be used to study Medicaid expenditures, hospital of birth, and transfer patterns. In addition, the NMIHS Follow-back Survey may be useful for studying intermediate-term health consequences and post discharge survival rates. State-wide hospital discharge data (from states collecting UB-82 data) linked to vital statistics is another noteworthy example. This combination could be used to study Medicaid expenditures, cost of neonatal intensive care, hospital of birth, variations in mortality, and variations in post-discharge survival rates.

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