

RATIONALES FOR SELECTING THE INDICATORS

All of the indicators included in this report were derived by consensus at workshops (1984, 1990, 1997, and 2003) including program and data representatives from each state and the DHHS Region IV Office. The following criteria were used for selection of the indicators: 1) a clear rationale/use for the indicator in planning and assessment of perinatal programs, 2) current capability of the states to produce the indicator and 3) feasibility for future production capabilities. This report documents current production capabilities. Where indicators are missing for a particular state, considerable insights have been gained regarding production constraints. The technical newsletters and state-specific technical assistance provided during the first six years of the RNDMU project, and past and current workshops have focused on strengthening production capabilities and use of the indicators.

Each year indicators are reviewed, definitions are refined (if necessary), and at times a few indicators are deleted if they are found to be inaccurate or not useful and new indicators are added. For example, with the 2002 Databook: 1) the project switched from collecting data on the adequacy of prenatal care based on the Kessner index and now includes a related indicator based on the Kotelchuck Index and 2) the fetal mortality ratio indicator was changed to the fetal mortality rate.

Specific rationales for selecting the indicators and the use of the indicators for planning and assessment warrant review. The health status and risk factor indicators include fertility rates; pregnancy and repeat pregnancy rates; rates for selected maternal characteristics; birthweight distribution rates; rates for selected behavioral risks; infectious disease rates; and infant, chronic disease, and injury mortality rates. The health services indicators focus on prenatal care, family planning services, and a few services for women in general as well as the implementation and effectiveness of regionalized perinatal care. An algorithm describing the relationship of the indicators to infant mortality can be found in Appendix B.

The rationales and program-relevant use of the selected indicators are considered briefly within the major categories listed above.

Fertility and Pregnancy Related Rates and Rates Related to Pregnancy History and Selected Maternal Characteristics

In addition to providing information regarding populations in need of perinatal services and the impact of family planning services, these well documented sociodemographic indicators measure population levels of high risk for poor pregnancy and infant outcomes (e.g., age, race, parity, education, smoking status, previous reproductive history, and intendedness of pregnancy).

Birthweight Rates

The relationship between low birthweight (LBW) and perinatal mortality is extremely powerful. For example, LBW infants who weigh less than 2500 grams are almost 40 times more likely to die in the neonatal period than normal birthweight infants, while the relative risk of death for less than 1500 gram infants is 100 times greater [Mathews et al 2002]. With regard to postneonatal mortality, they are respectively 5 times and 20 times more likely to die than normal birthweight infants. Further, LBW is strongly associated with short term morbidity and high medical care costs as well as long term consequences, particularly neurologic and developmental handicaps. Several follow-up studies indicate that 10-15 percent of less than 1500-gram infants are severely affected and an additional 25-30 percent are mildly or moderately handicapped [Hack et al 1980; Saigal 1982; Shapiro et al 1983; McCormick 1985; McCormick 1997].

Given the high mortality, morbidity, and medical care costs of low birthweight, perinatal program emphases have shifted to strategies such as those recommended by the 1985 Institute of Medicine report on *Preventing Low Birth Weight* [IOM 1985]. Because even small improvements in low birthweight distributions affect mortality, morbidity, and costs, particularly among very low birthweight infants, a number of birthweight indicators were developed to monitor birthweight distribution trends. With the added knowledge of the causes of low birthweight and prematurity and the effectiveness of low birthweight prevention programs, it is hoped, pregnancy outcomes will improve, although a caveat must be inserted. Such programs may prolong very short gestational age pregnancies and reduce fetal death rates, while increasing the proportion of “tiny” live births and their mortality and morbidity consequences.

Behavioral Risk Factor Rates

Smoking contributes substantially to chronic disease morbidity and disability. Smoking-related illnesses cost the nation more than \$150 billion each year [CDC 2002]. Smoking during pregnancy accounts for 17-26 percent of low-birthweight babies and accounted for an additional \$1.4 billion in medical care expenditures for costs related to complicated pregnancies of smoking mothers [CDC/NCHS 2001].

In addition, physical activity has been demonstrated to be protective against several chronic conditions including coronary heart disease, some types of cancer, stroke, type 2 diabetes, and osteoporosis. Besides smoking and drinking, poor diet is one of the most significant controllable risk factors leading to preventable illness and premature death in the United States. In general today, poor diet can be defined more in terms of excesses and imbalances than undernutrition [CDC/NCHS 2001].

Infectious Disease Rates

CDC’s *Healthy People 2000 Final Review* states that although we have made progress in reducing our rates of sexually transmitted diseases (STD), also referred to as reproductive tract infections (RTI), rates remain at epidemic levels, with the U.S. having the highest rates in the industrialized world. Women, adolescents, children, and communities of color suffer a disproportionately high STD/RTI burden (CDC/NCHS 2001). Pregnant women who acquire a STD/RTI infection during pregnancy place not only themselves but also their fetuses at risk for complications including prematurity, low birth weight, long-term disability, and death. Although there is clear evidence of the benefit of screening and treatment of some diseases (e.g. syphilis, congenital gonococcal ophthalmia, congenital rubella syndrome) the evidence for other infections (e.g. B streptococcal infection) is still not clear. Infections outside the reproductive tract such as periodontal disease have also been found to be associated with higher incidences of premature birth, although again no indicator of this is included due to lack of a reliable and consistent data source across states.

There is no current cure for AIDS, although treatments are now available to extend survival among those infected with the immunodeficiency virus (HIV). From 1989-2000 the Centers for Disease Control and Prevention HIV/AIDS Annual Surveillance Reports showed a slow rise in the incidence of AIDS cases per 100,000 women from 3.5 in 1989 to a high of 15.4 in 1993, followed by a steady decline to 8.7 in 2000. In 1999, 65,550 females were living with AIDS in the U.S. [CDC 2001]. The number of women living with AIDS/HIV is growing with the use of antiviral medication while the number of live-born infants infected with HIV is declining. The incidence of perinatal acquired AIDS decreased 66 percent between 1992 and 1997 [CDC accessed August 8, 2002]. This change resulted when universal screening and antiviral medications during pregnancy became standard practice.

Perinatal Related Mortality Rates

Although these outcomes are associated with economic and socioenvironmental factors, they are influenced by women's and infants' health care. For perinatal mortality rates, more specific health care relationships can be inferred, based on the point during the perinatal period when the death occurred. For example, Neonatal (<1 day) Mortality Rate may relate most closely to intrapartum as well as to resuscitation, stabilization, transport, and NICU care. On the other hand, the Perinatal Mortality Ratio (fetal deaths plus neonatal deaths <28 days), is an indicator of the impact of many forces, including a broad range of perinatal care activities. Birthweight specific mortality rate indicators assess the impact of high-risk obstetric and newborn intensive care. More narrowly, LBW-specific neonatal mortality rates for 500-999 gram and 1000-1499 gram infants may measure most sensitively the impact of high technology NICUs. Normal birthweight specific neonatal mortality (2500-4250 gram) may relate more closely to the quality of routine obstetric and newborn care.

Chronic Disease Mortality Rates

Reduction in exposure to risk factors and access to health services can decrease the incidence and greatly improve the prospect for cure of many chronic conditions. The major modifiable risk factors associated with heart disease are high blood pressure, high blood cholesterol, tobacco use, and the lack of physical activity. It is also estimated that smoking cessation and an improved diet can reduce cancer incidence by 50 percent or more [CDC/NCHS 2001]. In addition, early detection through breast self-exam and mammography screening greatly improves the prospect of cure for breast cancer.

Injury Mortality Rate

Motor vehicle injuries are the most costly and fatal of the unintentional injuries, with an estimate of \$169 billion in lost wages, medical expenses, and administrative costs [CDC/NCHS 2001]. Improvements related to children are being made in this area with the enactment of child safety seat laws but more progress could be made with the passage and enforcement of ordinances requiring motor cycle and bicycle helmet use, seat belt use, graduated licensing, and stricter drinking and driving laws.

Prenatal Care Coverage

Evidence that prenatal care utilization is associated with improved pregnancy outcome, including low birthweight, is substantial [Gortmaker 1979; Quick et al. 1981; Peoples and Siegel 1983; Showstack et al. 1984, Krueger 2000]. Therefore, indicators of prenatal care coverage are essential for perinatal planning and assessment. Three different indicators related to prenatal care are collected and are reported for total, Black, and White live births. The Kessner Index of the adequacy of prenatal care was used to define inadequate care until 2002. Starting with the 2002 Databook, the Kotelchuck index of adequate or adequate-plus care has been used [Kotelchuck 1994]. Although not available, the same prenatal care indicators for a population "in need" would be particularly useful.

Implementation and Effectiveness of Regionalized Perinatal Care

During the past 20+ years, stimulated by the report of the Committee on Perinatal Health, *Toward Improving the Outcome of Pregnancy* [CPH 1977], through the Health Systems Agencies (HSAs), the Improved Pregnancy Outcome (IPO) projects, and other developments, states have attached high priority to implementing systems of regionalized perinatal care. The results are not only measured in morbidity and mortality figures but also in financial expense of prolonged hospitalizations, overlapping resources, and

properly trained personnel. [Sanderson et al 2000]. Fundamental to such systems is the designation of Level I, Level II, and Level III hospitals; application of high risk obstetric and high risk newborn criteria; and appropriate use of their facilities and resources. Indicators available for use by states are restricted to birthweight, hospital of delivery, and birthweight specific mortality. Using these data items, indicators were developed that attempt to measure appropriateness of hospital level in relation to place of delivery and neonatal death for 500-1499 gram and 1500-2499 gram infants. Indicators for these birthweight categories of infants assess the effectiveness of regionalized perinatal care, particularly at Level II and III hospitals.

Family Planning Services

The provision of family planning services impacts on several maternal health issues. One set of outcomes relates to the prevention of high risk and unwanted pregnancies, which can have a major impact on the reduction of infant mortality. A meta-analysis on birth spacing and risk for adverse outcomes showed that “birth to conception intervals shorter than 18 months and longer than 59 months are significantly associated with increased risk for several adverse perinatal outcomes, such as preterm birth, low birthweight (LBW), and small for gestational age (SGA).” [Conde-Agudelo et al. 2006] In addition, family planning programs impact on the diagnosis and treatment of some sexually transmitted diseases and cancers. Family planning programs also provide access to health providers who can offer important preconception counseling about modifiable health behaviors (e.g. smoking cessation, violence prevention, and folic acid intake) as well as direct attention to medical problems that may have an impact on pregnancy outcome (e.g. diabetes, hypertension).

Access to Health Services in General

Almost every day an article appears in the newspaper or the evening news covering how a lack of health insurance limits access to health care. In spite of state efforts to expand coverage of the uninsured many people are without coverage. Using data from the Behavioral Risk Factor Surveillance System for 2006, it is estimated that the following percent of women age 18-64 had no kind of health care coverage: Alabama (18.8%), Florida (24.2%), Georgia (17.4%), Kentucky (19.3%), Mississippi (24.4%), North Carolina (19.4%), South Carolina (18.0%), and Tennessee (14.9%); as compared to 15.6 percent for the U.S. [CDC/BRFSS August 15, 2007]. The American Academy of Pediatrics estimates that the following percent of children less than or equal to 18 years of age were uninsured in 2003: Alabama (9.4%), Florida (16.1%), Georgia (13.6%), Kentucky (10.9%), Mississippi (11.7%), North Carolina (12.6%), South Carolina (9.4%), and Tennessee (10.8%); as compared to 11.4 percent of children under age 18 for the U.S. [USDHHS 2005].

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