

## **From Science to Public Policy: Premature Infants**

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*November is Prematurity Awareness Month. In recognition of this important issue, this "From Science to Public Policy" article is devoted to the developmental issues associated with prematurity, the policy implications, and opportunities for advocacy action.*

### **Introduction**

Preterm birth, defined as a birth occurring before 37 weeks gestation, places infants at high risk of long-term hospitalization, developmental challenges, and infant death. The causes of preterm birth are not well understood. Preterm deliveries have been attributed to a variety of factors ranging from poor prenatal health care, poor nutrition, maternal health, smoking, weaknesses in the reproductive tract, viruses and infections, stress, prior history of preterm birth, multiple gestation, and many other potential factors that have not been identified. Whatever the reason, preterm delivery is the most likely cause of death unrelated to birth defects in infants under one year of age.<sup>1</sup> Preterm birth imposes a huge medical cost on society, and emotional burdens on the family. The Healthy People 2010 goals target preterm birth, with a goal to reduce preterm births from the 1998 level of 11.2% of live births to 7.6% by the year 2010. In spite of this focus, the rate of preterm births has steadily increased over the past few years to 12.5% of live births in 2004.<sup>2</sup>

While the rate of preterm births has been increasing in recent years among Caucasian families, there are clear racial differences in preterm birth rates with African American mothers being much more likely than other mothers to deliver preterm. In 2003, the rates were 11.3% of live births among Caucasian mothers, 11.9% among Hispanic mothers, and 17.8% among non-Hispanic Black mothers.<sup>3</sup>

### **Consequences of Preterm Birth**

Children born preterm are at greater risk of experiencing disabilities. Nearly half of children born preterm are also of low birth weight (less than 1,500 grams at birth).<sup>4</sup> These babies may not have matured adequately to survive without medical intervention. Respiratory and vision problems are frequently an outcome of preterm birth, as well as cognitive and neurological deficits created either by the

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<sup>1</sup> Healthy People 2010 Objective 16, Maternal, Child and Infant Health, [www.healthypeople.org](http://www.healthypeople.org). Retrieved October 15, 2006, from <http://www.healthypeople.gov/Document/tableofcontents.htm#>. Volume 2.

<sup>2</sup> National Center for Health Statistics: Preliminary births for 2004: Infant and maternal health. Retrieved on 10/17/06 from [http://www.cdc.gov/nchs/data/hestat/prelimbirths04health\\_tables.pdf](http://www.cdc.gov/nchs/data/hestat/prelimbirths04health_tables.pdf) #3.

<sup>3</sup> Compendium on Preterm Birth: Epidemiology and Biology of Preterm Birth. Retrieved October 15, 2006, from [http://www.marchofdimes.com/prematurity/EpidemiologyAndBiologyBirth\\_82506\\_ed.ppt](http://www.marchofdimes.com/prematurity/EpidemiologyAndBiologyBirth_82506_ed.ppt), #353,12, Preterm Births by Maternal Race/Ethnicity, U.S., 1993-2003.

<sup>4</sup> Ibid.

child's immaturity at the time of delivery or by the medical interventions required to support the child.

Children born preterm are much more likely to require early intervention and special education services. While the incidence of children with special needs in the general population is 2.4%, nearly half of preterm infants are identified as having special needs at some point in childhood.<sup>5</sup> Preterm infants with extremely low birthweight (under 750 grams) generally require the most services. Compared to the general population, children born preterm, and especially those who are low birth weight, are at risk of many medical and developmental problems:<sup>6</sup>

- Visual impairments due to Retinopathy of Prematurity (ROP) – incomplete maturation of the visual system
- Cerebral palsy (6-10% of preterms)
- Mental retardation (4-8% of preterms)
- Hearing loss (1-6% of preterms)
- Neurodevelopmental impairments including learning and behavioral difficulties, learning deficits in reading, spelling, math skills and language development – often not identified until the child attends school
- Impulsive behavior, attention deficit disorder and hyperactive behavior (7% of preterm children compared to 1% in research control groups )

The Individuals with Disabilities Education Act (IDEA) is the federal legislation that defines eligibility for services for children with disabilities. Part C of IDEA, the Program for Infants and Toddlers with Disabilities, allows states to define developmental delay and determine the criteria for eligibility for services. Depending on the state definition, children under the age of three years may be eligible for services if they have been diagnosed with a condition that could lead to a developmental delay or disability. States may also provide services to children “at risk” for adverse outcomes. Risk factors can include physical or mental conditions that are likely to lead to developmental delays, biological and medical risks such as low birthweight, and environmental risks such as having a parent with a developmental disability. Birth-related risk factors such as preterm delivery are considered a type of “biomedical risk,” a category that states can choose to include in their definition of eligibility for early intervention services. In spite of the risks faced by children born preterm, states vary in whether they include biomedical risk in their eligibility definition. Currently only six states (California, Hawaii, Massachusetts, New Hampshire, New Mexico, and West Virginia) and two U.S. territories (American Samoa and Guam) include biomedical risks in their eligibility

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<sup>5</sup> D’Agostino, J. and Clifford, P. Neurodevelopmental consequences associated with the premature neonate. AACN Clinical Issues: Advanced Practice in Acute and Critical Care, 1998, 9 (1).

<sup>6</sup> Ibid.

definition.<sup>7</sup> When IDEA was reauthorized in 2004, new language was added to the section on referrals, instructing physicians and hospitals to ensure that parents with premature infants, among others, are aware of early intervention services.

Preterm birth leading to hospitalization in a neonatal intensive care unit puts stress on the family. Instead of experiencing a happy life event, families face stressful decisions. The parents may grieve because they did not deliver a typically developing full-term infant. Families are challenged to bond with their new baby. They may have to travel many miles to a regional peri-natal center to be with the baby. The baby may be isolated and hooked up to monitors and life support equipment, limiting physical contact. Parents may have to negotiate a complex hospital and medical system. Once the baby is able to come home, parents face additional challenges in obtaining medical care and other services the newborn may need to continue to develop optimally.

Some of the possible causes of preterm birth – poor maternal health, maternal drug or alcohol use, lack of adequate prenatal care – may indicate that the family was under stress or lacked adequate social supports even before the child came into the picture. Thus, providing health care and social supports to the expectant family may be important in reducing both the incidence and the negative impact of preterm birth.

### **Policy Recommendations**

Prematurity at birth can lead to numerous challenges for a child and his or her family. Policy can play an important role in supporting families as they strive toward improved health and development. Some policy recommendations related to preterm birth include:

- Provide for risk-appropriate prenatal care for mothers and health care for women of childbearing age.
- Provide adequate family supports while the preterm newborn is hospitalized to reduce family stress and encourage bonding with the new infant.
- Support the transition from the hospital to home with effective case management and support services, and referral to needed services in the community.
- Ensure that children born preterm receive periodic screening for developmental delays and disabilities that may emerge long after hospital discharge.
- Include biomedical risk factors in state definitions of eligibility for early intervention (IDEA Part C) services.

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<sup>7</sup> Shackelford, J. State and jurisdictional eligibility definitions for infants and toddlers with disabilities under IDEA. National Early Childhood TA Center (NECTAC Notes, Issues No. 21, July 2006. Retrieved on 10/16/06 from <http://www.nectac.org/pubs/titlelist.asp#stateligibility>.

- Provide research funding to identify the causes of preterm birth and to develop preventive strategies.
- Educate mothers about the risk factors known to be associated with preterm birth.
- Support smoking cessation campaigns.

The U.S. Congress is currently considering issues related to preterm birth. The PREEMIE Act (Prematurity Research Expansion and Education for Mothers who deliver Infants Early Act, S. 707 and H.R. 2861) would expand and coordinate research on preterm delivery within the National Institutes of Health, increase public and health care provider education on the topic, and create an Interagency Coordinating Council on Prematurity and Low Birthweight within the Department of Health and Human Services. The bills have broad support by 92 U.S. Representatives and 42 U.S. Senators. To find the current status of these bills and a list of supporting members of Congress, visit to the [ZERO TO THREE Policy Network web site](#) (click on “Bills & Votes”).

### **Opportunities for Advocacy Action**

Infant-toddler advocates can play an important role in raising awareness about the developmental consequences of prematurity and the policy solutions that can contribute to healthy development of all infants and toddlers. Here are a few simple advocacy strategies:

- Find out about how your local hospital Neonatal Intensive Care Unit (NICU) and/or early intervention programs support families of preterm infants.
- Contact your [state child advocacy organization](#) or [state department of health](#) to find out how your state is currently supporting families of preterm infants, including your state’s definition of eligibility for early intervention services under IDEA-Part C. If there are gaps in service or gaps in eligibility for services, advocate for greater attention to these issues by proposing some of the policy recommendations listed above.
- Write a letter to the editor or opinion editorial about preterm birth, using Prematurity Awareness Month as your theme. Use this article and the [prematurity fact sheet](#) from the March of Dimes to support your letter or oped.
- Visit the [ZERO TO THREE Policy Network web site](#) to find out the current status of the PREEMIE Act and whether your members of Congress are currently co-sponsoring the bill. If they are already co-sponsors, write them a thank you letter highlighting the importance of this issue to healthy development. If your members of Congress are not currently co-sponsors, write or call them and share information about how they can contribute to the good health and development of families with young children.

## **Conclusion**

Preterm birth puts infants and their families at risk of poor developmental outcomes and creates an increasing burden on the health system. Health care professionals, family advocates and early interventionists have an opportunity to advocate for improved services to reduce the incidence and consequences of preterm birth. In spite of the challenges encountered by many preterm infants, some born preterm grow along a typical, healthy developmental path. We need to learn much more about the causes of prematurity and the factors that contribute to the resilience of preterm infants, to guide us as professionals in caring for preterm infants and their families.

## **Additional Resources**

### ***American Academy of Pediatrics***

[www.aap.org](http://www.aap.org)

Recently released policy on supporting families after NICU discharge.

### ***Healthy People 2010***

[www.healthypeople.gov](http://www.healthypeople.gov)

Provides national health goals, relevant statistics, and background on maternal and child health issues, as well as links to community plans and activities designed to address the goals.

### ***KIDS COUNT***

[www.aecf.org/kidscount/data.htm](http://www.aecf.org/kidscount/data.htm)

Statewide and local statistics on health indicators, including preterm birth.

### ***Legislative search***

[www.thomas.gov](http://www.thomas.gov)

Library of Congress search service for federal legislation.

### ***March of Dimes***

[www.marchofdimes.com](http://www.marchofdimes.com)

Prematurity Awareness Month is sponsored by the March of Dimes. Local awareness events are scheduled throughout the country. Included is information about these events, as well as general information about preterm birth, preventive and advocacy efforts.

### ***National Early Childhood TA Center - NECTAC***

[www.nectac.org](http://www.nectac.org)

Technical assistance and clearinghouse on IDEA Part C – Early Intervention programs for infants and toddlers.

***U.S. Centers for Disease Control and Prevention– National Center for  
Maternal Infant Health***

[www.cdc.gov/reproductivehealth/MaternalInfantHealth/PBP.htm](http://www.cdc.gov/reproductivehealth/MaternalInfantHealth/PBP.htm)

Recent report on rates of infant mortality related to preterm birth, which includes a downloadable podcast on recent findings on preterm birth.

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