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Consensus Study Report Highlights

Low Birth Weight Babies and Disability

Approximately 3.6 million live births occur every year in the United States. About 10 percent of these births are considered preterm, defined as delivery at less than 37 weeks gestational age. Additionally, between 8 and 9 percent of infants are born with low birth weight (LBW), defined by the medical community as less than 2,500 grams or 5.5 pounds at birth. Although "LBW" and "preterm birth" are often used interchangeably, the two terms have different definitions. Most infants born preterm or with LBW will not be affected by severe developmental impairments or major or multiple health conditions. However, research indicates that infants born preterm or with LBW often do experience elevated rates of mild to moderate chronic health conditions such as cognitive and behavioral impairments, attentiondeficit/hyperactivity disorder, autism spectrum disorder, and cerebral palsy, as well as hearing loss, vision loss, and chronic lung disease conditions that have meaningful functional impacts throughout an individual's life course. The Social Security Administration (SSA) provides means-tested benefits to individuals with disabilities through the Supplemental Security Income (SSI) program, and LBW has its own medical listing that automatically medically qualifies infants born under 1,200 grams, or at higher weights depending on their gestational age, as eligible for SSI benefits. Figure 1 depicts the current relationship between SSA disability processes and potential benefits over the life of an infant born with LBW.

LBW until age ~1 year

Continuing Disability Review and New Disability Determinations for conditions related to LBW, ages 1 to 18 years

Transition to adult SSI disability age 18+ years

Truncated SSI benefit while in NICU

Benefit level based on parental income and resources

Benefit level based on recipient's income and resources

FIGURE 1 Relationship between SSA disability processes and potential benefits over the life of an infant born with LBW.

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SSA asked the National Academies of Sciences, Engineering, and Medicine to convene an expert committee to provide an overview of the current status of the identification, treatment, and prognosis of LBW babies—including trends in survivability—in the U.S. population under age 1 year. SSA also asked the committee to provide information on the short- and long-term functional outcomes associated with and the most common conditions related to LBW, available treatments and services, and other considerations.

The resulting consensus study report, *Low Birth Weight Babies and Disability*, presents the committee's conclusions. During its deliberations, the committee developed a framework to illustrate the complex interactions between a child's health condition, functioning, and disability in the context of family, life course, and other factors (see Figure 2).

LOW BIRTH WEIGHT

Infants who are born with LBW typically fall into one of three categories: (1) those who are born preterm (i.e., less than 37 weeks gestational age); (2) those who are small for gestational age (SGA) (i.e., weighing below the 10th percentile for gestational age at birth); and (3) those who are born both preterm and SGA (see Figure 3). It is important to note that the birth weight cutoffs specified by SSA in the criteria for its LBW listing differ from the current standard criteria used by the medical community. For example, the 1,200–gram criterion for



FIGURE 2 Committee's framework for functioning and disability in children and youth. SOURCE: Adapted from the World Health Organization's International Classification of Functioning, Disability and Health: Children and Youth, Geneva, Switzerland, 2007.



FIGURE 3 Relationships among medical categories of LBW infants. NOTES: AGA = appropriate for gestational age; LGA = large for gestational age. The proportions shown in the figure represent conceptual approximations.

SSI falls between the medical criteria for extremely LBW (less than 1,000 grams) and very LBW (less than 1,500 grams). Among children who are large for gestational age, birth weight does not drop below 1,200 grams until 27 weeks gestation for girls and 26 weeks for boys. Birth during this timeframe is considered extremely preterm. Typically, infants born at earlier gestational ages (e.g., less than 32 weeks) and lower birth weights (less than 1,500 grams) are more likely to experience persistent and severe health problems and functional limitations relative to those born at later gestational ages and higher birth weights.

THE COMMITTEE'S OVERALL CONCLUSIONS

Based on a literature review, the committee formulated six overall conclusions in the following areas: (1) morbidity and mortality, (2) developmental trajectories, (3) function and outcomes, (4) treatment and services, (5) social determinants of health, and (6) SSA's disability criteria and LBW.

- 1. Morbidity and Mortality: There is an inverse relationship between gestational age and mortality and health outcomes among infants born preterm, as well as health outcomes among infants born SGA.
- 2. Developmental Trajectories: Normal development is an active process that depends on the appropriate formation of neural networks and the integrity of physiological systems, as well as a developing child's physical and

psychosocial environments, beginning in utero and continuing after birth.

- 3. Function and Outcomes: Children born preterm or LBW have increased risk for associated impairments and health conditions that can have negative sequelae affecting all body systems, with lifelong impacts across all functional domains.
- 4. Treatment and Services: Appropriate and timely screenings, evaluations, treatments, and services are expected to improve outcomes among children born LBW. There is general consensus that the earlier and more sustained a developmental or educational intervention is, the greater will be its long-term impact on growth, development, and functioning for LBW infants.
- 5. Social Determinants of Health: Numerous social determinants of health may have positive or negative effects on outcomes for LBW infants. Targeted interventions can ameliorate the negative effects of social determinants of health and improve outcomes for these infants across all domains.
- 6. SSA's Disability Criteria and LBW: The current criteria in the LBW listing in SSA's Listing of Impairments do not consistently correspond to the current and standard medical definitions of LBW, preterm birth, or SGA neonates. Criteria based on birth weight do not take into account that gestational age is a better predictor of shortand long-term outcomes among infants born preterm.

SUMMARY

Most infants born with LBW, especially those born at older gestational ages and higher birth weights, will likely not be severely impacted by developmental impairments or health conditions. Nevertheless, despite advances in treatment and survivability, LBW is associated with increased rates of mild to moderate chronic health conditions that affect physical and/or cognitive development. These conditions may impede development and limit functioning in childhood, adolescence, and into adulthood. There is established knowledge that can help improve outcomes for children born with LBW, including providing interventions during the emergence of skills early in life and implementing policy interventions known to ameliorate the negative impacts of the social determinants of health. Additionally, efficient and timely information transfer from one service system or provider to another is important so that eligibility for services that address issues associated with LBW can be determined as early as possible with the goal of improving outcomes. Finally, SSI has been shown to improve outcomes for child recipients and their families, although evidence for positive effects specific to infants eligible for SSI based on the LBW criteria is limited and mixed, indicating a need for additional research.

For more details on the committee's conclusions, see the Overall Conclusions document. For the full report, visit http://www.nationalacademies.org/low-birth-weightbabies.

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FOR MORE INFORMATION

This Consensus Study Report Highlights was prepared by National Academies' staff based on the Consensus Study Report Low Birth Weight Babies and Disability (2023).

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Health and Medicine Division



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