

Low Birth Weight Babies and Disability

MORBIDITY AND MORTALITY

1. **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 small for gestational age.**

- Survivability has increased among preterm newborns over the past two decades. However, increased survivability at earlier gestational ages results in increased short- and long-term morbidities and functional limitations that may require lifelong intervention.
- Among infants born preterm, the risk of long-term impairments and secondary health conditions that adversely affect functioning is more strongly associated with gestational age than with birth weight.
- Children born preterm or low birth weight (LBW) may experience a wide range of health conditions, including motor disorders (e.g., cerebral palsy, developmental coordination disorder), sensory disorders (e.g., vision loss, hearing loss), cognitive disorders (e.g., attention-deficit/hyperactivity disorder, intellectual developmental disorder), social-emotional behavioral disorders (e.g., anxiety, depression), and communication disorders (e.g., autism spectrum disorder).

- With continued improvement in neonatal care, more children will survive at younger gestational ages, and the population of those with morbidities will increase.

DEVELOPMENTAL TRAJECTORIES

2. **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.**

- Development occurs across multiple domains (i.e., motor, cognition, communication, social-emotional, adaptive).
- Anything that interferes with an environment (internal or external) conducive to optimal development can negatively affect a child's development, potentially resulting in functional limitations or ongoing health conditions.
- Increasing medical and psychosocial risk factors may have an additive effect on development and function, resulting in increased complexity in the care and intervention needed.
- Infants who are preterm often require intensive and/or extended hospitalization, which

significantly limits their ability to function normally in a family unit, impeding normal developmental and altering growth trajectories.

- Social determinants of health are among the environmental factors that can affect children's development positively (opportunities) or negatively (barriers).

sustained a developmental or educational intervention is, the greater will be its long-term impact on growth, development, and functioning for LBW infants.

- The foundation of development and the acquisition of developmental and functional skills is an active interplay between physiological and anatomical maturation and environmental experience, including parental and family interaction.
- In the past two decades, medical and nonmedical advances in neonatal care have focused on improving outcomes for children born preterm, while maintaining or improving survival.
- Guidelines and systems for identifying children in need of intervention have evolved over the past 20 years to include the expectation of routine universal developmental surveillance and screening, referral, and interventions for developmental delays and health conditions, such as hearing loss.
- Barriers to accessing screenings, evaluations, and interventions (e.g., living in underresourced areas, insufficient numbers and distribution of professionals, fragmentation of services, lack of coordination across service sectors) significantly impact outcomes for children born preterm or LBW.

FUNCTION AND OUTCOMES

3. 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.

- All functional domains identified in the Social Security Administration's (SSA's) disability determination process for children may be affected by the impairments and health conditions associated with preterm birth and LBW.
- The occurrence of multiple medical comorbidities has a negative additive effect on functional outcomes.
- Some developmental problems associated with LBW, particularly those involving higher-order, or advanced, cognitive skills, may not be identified until a later age, when those skills are typically expected to appear.
- Social determinants of health, including socioeconomic status, structural racism, and access to resources, directly influence all outcomes across all medical and neurodevelopmental domains.

SOCIAL DETERMINANTS OF HEALTH

5. 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.

TREATMENT AND SERVICES

4. 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

- The prevalence of preterm birth and LBW, as well as rates of survival and health and developmental outcomes for these infants, may be negatively affected by social determinants

of health, including but not limited to unstable and inadequate housing, food insecurity, unsafe neighborhoods, and structural racism.

- Targeted policy interventions, such as cash and food transfers, expanded access to health insurance, and paid family leave, can enhance child and family resiliency and improve outcomes.

SSA'S DISABILITY CRITERIA AND LOW BIRTH WEIGHT

6. 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 small for gestational age neonates. Criteria based on birth weight do not take into account that gestational age is a better predictor of short- and long-term outcomes among infants born preterm.

- Among preterm infants, gestational age is a better predictor than birth weight of both short- and long-term outcomes.

- A birth weight of less than 1,500 grams is considered very LBW and is close to the 50th percentile for weight at 32 weeks gestation. A birth weight of 1,500 grams better corresponds to a gestational age of 32 weeks, after which the risk of severe impairments decreases.
- Infants born small for gestational age (SGA) (i.e., below the 10th percentile for gestational age) are at increased risk of having medical morbidities and developmental delays associated with poor growth of the brain and body. SGA is an important category of LBW infants born after 32 weeks of gestation because their physiology and outcomes are comparable to those of appropriate weight who are born earlier.
- Persistent medical and neurodevelopmental conditions associated with LBW can provide alternative diagnoses or listings by which infants allowed disability benefits under the LBW listing may continue to qualify for benefits following a Continuing Disability Review.

FOR MORE INFORMATION

To read the full report, visit <http://www.nationalacademies.org/low-birth-weight-babies>.

Health and Medicine Division

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