

# Position Statement on Low Birth Weight, Prematurity & Early Intervention



Division for  
Early  
Childhood

of the Council for Exceptional Children





# Low Birth Weight, Prematurity, & Early Intervention

Division for Early Childhood (DEC)

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The Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC) endorses the development of national guidelines for the identification and eligibility for Part C, states early intervention (EI) system for children born low birth weight (LBW) and/or preterm in the United States (see Table 1 below). Although not true for all infants, the majority of infants born LBW are also preterm. Preterm births declined between 2007 and 2014, with researchers citing a drop in teenage and young mother births as one possible reason. The rate of preterm births in 2015, however, increased for the first time since 2007, to 9.6%, and the prevalence of LBW also increased in 2015 to 8.07% (Martin, Hamilton, & Osterman, 2016).

Children born early typically spend their first days of life in a Neonatal Intensive Care Unit (NICU) for anywhere from 2 to 6 weeks depending on their medical status. For all families, the NICU is a time of challenge and vigilance. Families benefit from the expertise of not only medical staff but also social workers and mental health professionals. Both mothers and fathers are at risk for high levels of stress. Studies of fathers of infants born early reveals that they experience uncertainty, suffer from individual strain, and are at risk for depression due to their child's condition (Chesney, & Champion, 2008; Lou, Pedersen, & Hedegaard, 2009). Parents of infants born early may experience continuing crises, uncertainty, and powerlessness during the NICU and transition to home (O'Brien & Lynch, 2011). Professionals affiliated with NICUs, including social workers and in some instances EI practitioners, can respond to these parent concerns as well as discuss family strengths while the babies are still in the NICU.

Over the past several decades, we have witnessed better survival rates for LBW and/or preterm infants born at smaller and smaller birthweights and earlier and earlier in gestation (Mathews, MacDorman, & Thoma, 2015). The rate of neonatal survival and neurodevelopmental disabilities varies greatly in this population and is subject to the impact of obstetric and neonatal care in NICUs.

## Terminology Associated with Low Birth Weight (LBW) and Prematurity

<b>Based on Weight</b>	
Low birth weight (LBW)	Birth weight < 2,500 g
Very Low Birth Weight (VLBW)	Birth weight < 1,500 g
Extremely Low Birth Weight (ELBW)	Birth weight < 1,000 g
Macrosomia (also called large for gestational age or LGA)	Birth weight more than 9 pounds, 15 ounces (4,500 grams)
Fetal Growth Restriction (also known FGR, growth-restricted, small for gestational age, SGA, and small for dates)	Birth weight less than expected for gestational age.
<b>Based on Gestational Age</b>	
Preterm	Birth before 37 weeks of pregnancy
Moderate to late preterm	Birth between 32 - 37 weeks
Very preterm	Birth between 28 - 31 weeks
Extremely preterm	Birth < 28 weeks
Periviable	Birth between 22 - 24 weeks
<b>Common Conditions Treated in NICU</b>	
Bronchopulmonary dysplasia (BPD)	Chronic lung disease common in premature babies who have been treated for RDS (see below). Babies with RDS have immature lungs.
Hypertonicity and hypotonicity	“Hyper” refers to high tone demonstrated by stiffness or tightness. “Hypo” refers to low tone demonstrated by floppy feel or loose when handled.
Intraventricular Hemorrhage (IVH)	Bleeding in the ventricular system of the brain, most common in the smallest premature babies. Grade 3 and 4 indicate severe bleeding and often associated with later neurodevelopmental disabilities.
Periventricular Hemorrhage (PVH)	Bleeding in the white matter tissue immediately adjacent to the lateral cerebral ventricles.


Oral Aversion	Infants refusing to accept sensation in or around the mouth. Common in infants born preterm. If not treated, may result in inadequate nutrition.
Positional Plagiocephaly	Flattening of the skull, usually on one side at the back of the head. The skulls of preterm babies are softer than full term babies' and they tend to move their heads less, therefore remaining in one position.
Respiratory distress syndrome (RDS)	Serious breathing problem due to lung immaturity and inadequate respiratory gas exchange (oxygen and carbon dioxide); seen among babies born before 34 weeks.
Retinopathy of prematurity (ROP)	Damage to the immature blood vessels of the retina in the eye. It can lead to blindness if severe.
Torticollis	Tightening of the muscles in the neck on one side that causes the head to tilt down and, the baby has trouble turning his head in the opposite direction.
Ventilator	A machine that breathes for the baby.

Adapted from Centers for Disease Control (2017, June); Howson, Kinney, & Lawn (2012).

## Developmental Delays Associated with LBW and/or Preterm Birth

Major medical conditions such as cerebral palsy (CP), sensory impairments (vision, hearing) and other disabilities may be outcomes of LBW and/or preterm birth. Children born with a diagnosed physical or mental conditions associated with high probability of developmental delay may be identified during the first year of life are eligible for EI services, Part C. It has been well established that the smallest infants born LBW and those born extremely preterm have the poorest outcomes, especially if they have severe respiratory distress and/or major brain bleeds during the neonatal period (Ambalavanan et al., 2012), and they would qualify for EI services under health conditions in most states.

Longitudinal research indicates that even for infants who exhibit no major disabilities during the first three years of life, cognitive and behavioral impairments are found at later ages (Barre, Morgan, Doyle & Anderson, 2011; Chan & Quigley, 2014; Grunau, Eckstein, Whitfield, & Davis, 2002; McCormick et al., 2006; Mulder, Pitchford, Hagger, & Marlow, 2009). Research on longitudinal effects of LBW and/or preterm birth on children's development most often comes from retrospective studies conducted on school-aged children (Anderson & Doyle, 2004; Vohr, Wright, Poole, & McDonald, 2005). Based on these retrospective studies (Anderson & Boyle,



2004; Vohr et al., 2005), children later diagnosed with learning disabilities (LD) and/or Attention Deficit Hyperactivity Disorder (ADHD) were born LBW and/or preterm. Parents have reported that their child did not qualify for EI, or “graduated” out of EI, but later manifested learning difficulties at school-age (Blasco, Guy, Saxton, & Duvall, 2017). Therefore, infants born LBW and/or preterm without known disabilities make up a large subgroup that remains high risk for developmental delay and subsequent academic challenges. In a manuscript under review, Barger et al. (2018) analyzed a majority of the states and jurisdictions to determine the types of diagnosed physical or mental conditions with a high probability of developmental delay that are specifically included on state lists for eligibility. Less than 40% of the states (49 states, Washington, D. C., and 4 territories) listed prematurity or LBW as a diagnosed condition. Specifications for gestational age defining prematurity and the degree of LBW standards varied across these states as well (Barger, Rice, Wolf, & Roach). Therefore, DEC strongly recommends that states include this population in their eligibility criteria.

## Risk for Cognitive Delays

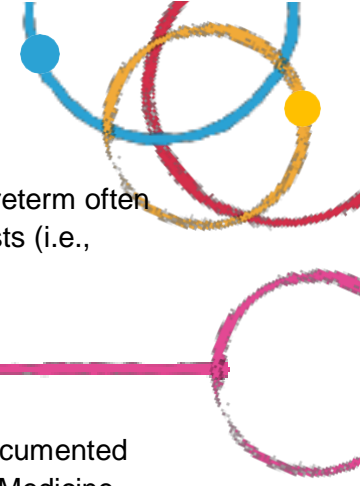


Delays in cognitive development and later school achievement such as in reading and math, grade retention, and placement in special education among children born LBW and/or preterm have been well documented for decades (Hack, Klein, & Taylor, 1995; Klebanov, Brooks-Gunn, & McCormick, 1994). Underlying these difficulties are findings showing that infants who are born early are more likely to incur brain injury during the prenatal and neonatal periods, including periventricular hemorrhage (PVH) and intraventricular hemorrhage (IVH) (Rose, Feldman, Jankowski, & Van Rossem, 2011) (See Table 1). Studies that have examined white matter injury and executive function (EF) skills in preschoolers born early found correlations via structural magnetic resonance imaging (MRI) (Edgin et al., 2008; Woodward, Clark, Pritchard, Anderson, & Inder, 2011). A meta-analysis of the research literature on children who were born very LBW and extremely preterm but without major identified disabilities, showed they are at risk for later school failure and had EF deficits (Aarnoudse-Moens, Weisglas-Kuperus, van Goudoever, & Oosterlaan, 2009).

## Risks for Communication Delays



Difficulties with language acquisition and competency in children born LBW and/or preterm are well documented, especially among those born VLBW (Barre, Morgan, Doyle, & Anderson, 2011). In addition to delays in vocabulary acquisition, children born VLBW often demonstrate persistent differences in language processing, including slower language processing speed, grammatical differences, and phonological working memory challenges (Ramon-Casas, Bosch, Iriundo, & Krauel, 2013; Sansavini et al., 2007). Furthermore, subtle differences in social engagement and responses to bids for joint attention are evident as early as 6-9 months of age, indicating the effect of preterm birth on pre-verbal communication skills may mediate language outcomes (Schuymer, De Groote, Beyers, Striano, & Roeyers, 2011). Overall, the earlier (and lighter) a child is born, the greater their challenges with language acquisition (Foster-Cohen, Edgin, Champion, & Woodward, 2007, Sansavini, 2012). However, given the subtlety of these deficits, many children born LBW and/or preterm will not meet EI eligibility for communication



supports. In addition to language services, many children who are born LBW and preterm often have feeding difficulties that require services from nutritionists and feeding specialists (i.e., speech-language pathologists and occupational therapists) combined.

## Risk for Social-Emotional Development

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Vulnerability to social-emotional delays and/or behavioral challenges is also well documented at school age (Butler & Behrman, 2007; National Research Council and Institute of Medicine, 2000). Delays, issues with attentional control and social interaction can persist into adulthood (Mathewson et al., 2017). Intervention efforts are dependent upon early identification (Boyd et al., 2013).

Delays specific to engagement (e.g., exploration, initiative), emotional regulation (e.g., persistence, frustration, competence), and social-emotional competence (e.g., imitation/play, empathy, prosocial behaviors) have been identified at 2 years of age in infants born VLBW (Boyd et al., 2013; Spittle et al., 2009). Difficulties identified in toddlers have predicted problems with social-emotional competence (e.g., compliance, attention) and peer relationships at 5 years of age for those born LBW (Treyvaud et al., 2012). In comparison to full-term peers, risk for emotional and behavioral adjustment problems is almost double for children born very preterm at preschool (i.e., 4 years of age) (Jones, Champion, & Woodward, 2013).


The potential to identify social-emotional difficulties early, especially those predictive of school age challenging behaviors, has important implications for EI. Boyd and colleagues (2013) advocated for the assessment of social-emotional development even when high-risk preterm infants do not present with obvious motor or cognitive development concerns in order to facilitate early identification of social-emotional delays. Additionally, researchers have advocated for EI to facilitate long-term social-emotional and behavioral outcomes of LBW and preterm infants and support families given: (a) the impact of social-emotional development on learning and social competence (Boyd et al., 2013), (b) the ability to modify risks and improve outcomes related to learning, behavior, and social competency prior to and at school age (Msall & Park, 2008; Spittle et al. 2009; Treyvaud et al., 2012), and (c) to provide families support as they nurture and promote social-emotional development in infants and young children who were born early (Jones et al., 2013; Maupin & Fine, 2014; National Research Council and Institute of Medicine, 2000).

## Risk for Motor Delays

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Children born ELBW are more likely to have motor delays and motor deficits such as cerebral palsy. However, due to NICU interventions, the incidence of CP has declined since 2002 (Bernardo et al., 2015). Despite medical advances, children who were born ELBW and < 28 weeks had motor concerns at age 8 as compared with children born full term based on a large scale longitudinal study (Spittle, Cameron, Doyle, & Cheong, 2018). Although gross motor delays are most likely to be detected during NICU follow-up and in Well Baby office visits, some motor delays are subtle, especially in terms of visual-motor and dexterity skills for children who are born early. In one study, children who were heavier birthweight but born 34





weeks gestational age (late preterm) had lower verbal, nonverbal, spatial, visual-motor, and dexterity scores than their full term peers at age 3 years (Baron et al. 2014).

## **Prenatal Factors Associated with LBW and/or Preterm**

Risk factors for this population include multiple births, maternal smoking, low maternal weight gain or low pre-pregnancy weight, maternal or fetal stress, infections, and violence toward the pregnant woman (Ricketts, Murray, & Schwalberg, 2005). The reasons for recent increases in the prevalence of LBW have not been fully explained in the literature, but a number of important factors need further research. These include increases in opioid use, childhood poverty, prenatal toxic exposures, and poor maternal health prenatally due to lack of access to health care (Godfrey et al., 2017; Smith & Lipari, 2017). Of particular recent interest is neonatal abstinence syndrome (NAS), which is the clinical diagnosis for a constellation of symptoms related to prenatal drug exposure. Common signs and symptoms may be seen in the first few days of life, such as hypertonia, autonomic instability, central nervous system irritability, poor sucking reflex, feeding difficulties, and impaired weight gain (Hudak & Tan, 2012; Patrick et al., 2012; Patrick, Kaplan, Passarella, Davis, & Lorch, 2014). Data from the CDC indicate that the incidence of NAS in the United States has significantly increased over the last ten years and is related to LBW and/or preterm birth (Patrick et al., 2012; Patrick, Kaplan, Passarella, Davis, & Lorch, 2014; Ko, et, al, 2016; March of Dimes, 2017).

Another risk from a societal perspective is that many infants born early have multiple risks related to poverty and low parental education. These risk factors may impact attachment as well as infant/toddler mental health (Hynan et al., 2015). Research studies have shown that infants born VLBW in low socioeconomic status SES households fare the worst on risk for chronic medical problems and neuro-sensory deficits, low IQ, poor school achievement, and need for special education at age 10-14 years (McNicholas et al., 2014). Follow up into adulthood shows that LBW children from low SES families fare worse compared to LBW peers from higher SES families (Hack et al., 2009).

There is also cultural disparity in addition to educational disparity for mothers of children born LBW and preterm. For example, in 2016, the rate of preterm birth among non-Hispanic black women was 14% that is 50 percent higher than white women (9%) (Centers for Disease Control, 2017). White women with no college background are also 29 percent more likely to give birth to a baby early and LBW than college educated women (Braveman et al., 2015).

## **Part C and Children Born LBW and/or Preterm**

As stated previously, LBW and/or preterm as conditions for EI eligibility varies greatly from state to state. For example, in one state, the criterion for LBW eligibility is  $\leq 1500$  grams and in another state the criterion is  $\leq 1200$  grams. Researchers found that 6.8% of the total population of children born LBW in one state were referred to EI within one year. Of those children birthweight  $\leq 1499$  grams predicted referral (Clements, Barfield, Kotelchuck, Lee, & Wilber, 2006). These variations result in some LBW and/or preterm children who are high risk for developmental delays being ineligible for Part C EI services until they demonstrate



observable developmental delays or disabilities. Additionally, there is the concern that when children are assessed for EI eligibility, the use of corrected age (i.e., age the child would be if they had been born on their due date) may overestimate their abilities, especially during early infancy when item density on developmental measures is low. These concerns make children born LBW and/or preterm more vulnerable to missed early learning experiences (Blasco, Guy, Saxton, & Duvall 2017). More recently, researchers have called for monitoring of development even when the child passes initial screening exams (Barger, Rice, Wolf, & Roach, 2018).

Using the most current IDEA section 618 Annual Part C Child Count data, based on the number of infants and toddlers with active IFSPs on a single day, the national percentage of infants and toddlers with disabilities (birth through 2 years of age), is 3.12%. State child count data ranged from 1.51% to 9.44% (U. S. Department of Education, 2017). Part C data are not collected by diagnosis such as LBW and preterm, only by total count. Therefore, we do not know the percentage of children who are LBW and preterm who receive Part C services.

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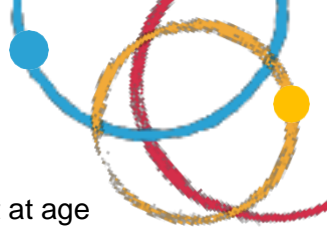
### **Informed Clinical Opinion**

Early intervention providers and professionals also must use informed clinical opinion in the evaluation and assessment process to make recommendations about initial and continuing eligibility for services under Part C. “Informed clinical opinion makes use of qualitative and quantitative information to assist in forming a determination regarding difficult-to-measure aspects of current developmental status and the potential need for early intervention” (Lucas & Shaw, 2012, pg. 1). DEC strongly supports use of informed clinical opinion to help determine eligibility and the provision of timely services to children born LBW and/or preterm and their families.

## **Evidence for Benefits of EI for Infants Born LBW and/or Preterm**

While to our knowledge there are no studies specifically examining the effects of Part C EI on the developmental outcomes of LBW infants, the benefits of intervening early with infants born LBW were clearly documented in a landmark intervention study with LBW infants that was conducted in the 1980s, the Infant Health and Development Program (IHDP) (Gross, Spiker, & Haynes, 1997; IHDP, 1990). The IHDP was unique in that it was the first multi-site randomized clinical trial designed to evaluate the efficacy of combining early childhood development and family support services with pediatric follow-up in reducing developmental, behavioral, and other health problems among infants born LBW and/or preterm (IHDP). In the study, 985 LBW infants were randomized into two birth weight groups (those infants weighing 2,001 to 2,500 grams, designated as “heavier,” and those 2,000 grams or less, designated as “lighter”) in order to look at outcomes across the full LBW range. At age 3, the study found large positive effects on development for both weight groups.





Follow up of the entire IHDP sample after the intervention ended at age 3 showed that at age five there were no significant differences between the intervention and the follow-up group (Brooks-Gunn et al., 1994; McCarton et al., 1997). However, children in the heavier LBW intervention group (2,001-2,500 grams) had higher cognitive scores. At age 8, modest intervention-related differences in the cognitive and academic skills of heavier LBW children only were found with the greatest effects for those children who received the highest dosage of the intervention (Hill, Brooks-Gunn, & Waldfogel, 2003). Finally, a long-term prospective follow-up of the IHDP sample at age 18 (McCormick et al., 2006) showed positive effects favoring the intervention group on vocabulary, math achievement, and risky behavior for the heavier LBW group. This result is particularly important because other follow up studies of samples of LBW infants into adolescence also find persistence of behavior problems especially for the ELBW group (Taylor, Margevicius, Schluchter, Andreias, & Hack., 2015). Again, these findings indicate a continuing need for interventions in this population, including for heavier LBW and for late preterm.

### Benefits of Dual Language Learning

In addressing areas of potential developmental delay in children born LBW and/or preterm, it is important to set recommendations within the context of culturally, linguistically and developmentally appropriate practices as stated in the DEC Recommended Practices.


*... when practitioners and families have the knowledge, skills, and dispositions to implement these practices as intended, children who have or are at risk for developmental delays/disabilities and their families are more likely to achieve positive outcomes, and families and practitioners are more likely to help children achieve their highest potential (DEC, 2014, p. 3).*

Interestingly, recent research also shows that bilingualism may help preterm infants (Head, Baralt, & Mahoney, 2015). Although the research is mixed, dual language acquisition may also boost EF in infants born early (Loe & Feldman, 2016). Therefore, it is important to have intervention focusing on language and EF activities for young children in order to reduce functional limitations, improve developmental and lifelong learning outcomes.

## Conclusion and Recommendations

As this position statement clearly shows, there is abundant evidence that this is a population at high risk for poor outcomes and the origins of their poor outcomes begin prenatally and in infancy. Although this is a global issue, our current statement is aimed at the United States. The costs of the poor health, learning, behavior, school achievement, and long-term life outcomes of LBW and/or preterm infants are substantial (Petrou, Sach, & Davidson, 2001), indicating the need for identifying and providing EI services early on in order to improve outcomes and reduce the long-term costs.

DEC recommends that LBW and/or preterm diagnoses should be considered diagnosed physical or mental condition that have a high probability of developmental delay to automatically



make an infant eligible to receive EI services. There is no need to wait to provide EI services until full blown delays and functional deficits are present. Across the range of LBW, there is strong research evidence to support the contention that all LBW infants born < 1500 grams are at high risk for delays, and this weight should be used as the national standard for automatic EI eligibility. In addition, children born < 37 weeks should be considered for EI services.

## DEC Call for Action/Recommendations



DEC recognizes and supports the importance of serving LBW and preterm infants who are at high risk for developmental delays or disabilities and their families. DEC supports setting a national standard of LBW  $\leq$  1500 grams and < 37 weeks for EI eligibility. DEC supports LBW and prematurity as a national recommendation for EI eligibility, with each state responsible for defining specific criteria such as birthweight and/or maximum gestational age (e.g. < 37 weeks) for which LBW can be used as criteria for EI eligibility. DEC encourages each state to review its eligibility policy and consider how their current eligibility criteria align with the current research.

Three areas for immediate action – Innovative Practice, Research, and Policy:



### 1. Innovative Practice

It is important that practitioners increase their knowledge and skills and implement practices that meet the individual needs of children born LBW/preterm and their families. Higher education faculty also play a role by providing instruction on working with this population during pre-service training. Seamless collaboration and coordination across agencies is needed to identify and refer these children and their families to EI, including monitoring referrals to safeguard that children who do not qualify continue to be tracked by EI. The American Academy of Pediatrics promotes available tools for referral, tracking and creation of feedback loops between health providers and EI so children and families do not fall through the cracks.



### 2. Research

Generate and disseminate evidenced-based research that links to practice in order to support improved outcomes for young children born early and their families. Networks of researchers who collaborate across disciplines on effective research explorations, interventions, and efficacy and measurement studies should be developed.



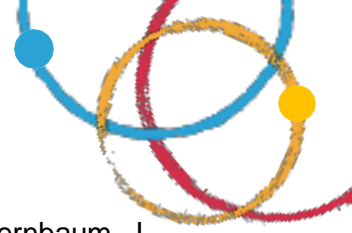
### 3. Policy

Create policy on a national level to address gaps in collaboration between health care and EI professionals that impede the identification and referral of infants born early who are at risk for developmental delay and disabilities. In doing so, we acknowledge the issue of limited resources and the challenges states face in serving all children at risk under Part C. From an EI perspective and for the purposes of policy and planning, consideration of LBW and prematurity for eligibility to services is critical in order to achieve optimal outcomes for this vulnerable population of young children.

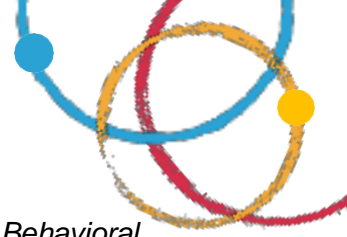
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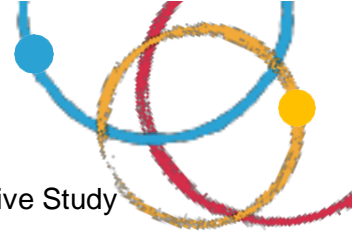
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