DEC Position Statement on Low Birth Weight (LBW), Prematurity and Early Intervention

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 Early Intervention (EI) services of children born low birth weight (LBW) and preterm in the United States. A child's birthweight is measured immediately after birth and low birth weight (LBW) is defined as ≤ 2500 grams or 5.5 pounds (Centers for Disease Control, 2014). Preterm birth is defined as ≤ 37 weeks gestation of a 40-week pregnancy (Centers for Disease Control, 2017).

The majority of infants born LBW are also preterm, though this is not true for all infants born LBW. Preterm births declined between 2007 and 2014, with researchers citing a decline 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 9.2% (Martin, Hamilton, & Osterman, 2016). The prevalence of LBW also increased in 2015 to 8.07% (Hamilton, Martin, & Osterman, 2016).

Over the past several decades, we have witnessed better survival rates for LBW infants born at smaller and smaller birthweights and earlier and earlier in gestation (Mathews, MacDorman, & Thoma, 2015). Infants born between 20 0/7 and 25 6/7 are termed periviable gestation. 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 intensive care units. This care might include the use of antenatal steroid, neonatal resuscitations and procedures within the Neonatal Intensive Care Unit (NICU) (Raju, Mercer, Burchfield, & Joseph, 2014).

In a study of 4,458 infants who were born between 22 and 24 weeks, researchers studied neurodevelopmental outcomes at a corrected age of 18 to 22 months. Outcomes for the infants were examined using the Bayley II and the Bayley III across three time periods, Epoch 1 (2000-2003), Epoch 2 (2004-2007) and Epoch 3 (2008-2011). The percentage of infants without neurodevelopmental impairment increased from 30% (Epoch 1) to 36% (Epoch 3). However the rate of infants who did have impairments also increased over time indicating that these children are very high risk for further neurodevelopmental concerns.

How DEC Recommended Practices Influence this Population

DEC recognizes and supports the importance of serving children who are at-risk for developmental delays or disabilities and their families. DEC Recommended Practices believes that:

> …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).

It is important that practitioners increase their knowledge and skills about children born LBW/preterm and their families. The use of inconsistent practices and policies as well as gaps in collaboration between health care and EI professionals can cause complications in identifying and referring infants who are at risk for developmental delay and disabilities.

Developmental Delays Associated with LBW and Preterm Birth

Major medical conditions such as cerebral palsy and disabilities ranging from developmental delay, learning disability, and autism spectrum disorder are associated with LBW and preterm births (Schieve et al., 2016; Boyle et al., 2011). It also has been

well established that the smallest LBW infants and those born extremely preterm have the poorest outcomes, especially if they have severe respiratory illness in the neonatal period (Ambalavanan et al., 2012). Longitudinal research indicates that even for infants who experience no major disabilities, lasting cognitive and behavioral impairments often exist (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 prematurity on children's development most often comes from retrospective studies conducted on school-aged children (Anderson & Doyle, 2004; Vohr, Wright, Poole, & McDonald, 2005). Children born LBW and preterm make up a large subgroup of children who are often more at risk for developmental delay and subsequent academic challenges. For instance, based on retrospective school age studies (Anderson & Boyle, 2004; Vohr, Wright, Poole, & McDonald, 2005), many children later diagnosed with learning disabilities (LD) and/or Attention Deficit Hyperactivity Disorder (ADHD) (Center for Disease Control, 2008) were born LBW or preterm.

Although most states have a list of the specific established conditions (medical or health conditions) that qualify a child for eligibility for early intervention services, there is no consensus on LBW and/or prematurity as an established condition conferring eligibility. In addition, the criteria used to define LBW as a condition for eligibility varies greatly from state to state. For example, in Missouri, the criterion for LBW eligibility is ≤1500 grams and in Oregon the criterion is ≤1200 grams. While across the US, nearly 10% of infants are born preterm, only 7 states include prematurity as a diagnosed condition to be considered for automatic early intervention eligibility (Squires, 2012).

These variations results in some LBW children who are high risk for developmental delays being excluded from early intervention services until they demonstrate observable developmental delays. 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.

Rosenberg, Robinson, Shaw, & Ellison (2013) studied eligibility based on state definitions of developmental delay. They used the Early Childhood Longitudinal Survey - Birth Cohort (ECLS –B) to examine eligibility criteria across states and estimated the proportion of children that would be eligible based on the states definition of developmental delay. The estimated proportion was compared to the actual number of infants and toddlers receiving services based on the 2012 Child Count tables, required annual reporting under Part C of IDEA. Since a state definition of developmental delay typically does not include preterm birth, preterm was not specifically part of the comparison. However, the study highlighted the wide variability across state definitions of developmental delay and actual number of infants and toddlers that are served under Part C. Currently, the national percentage of infants and toddlers with disabilities (birth through 2 years of age), based on the 2015 Child Count data, is 3.0% with states ranging from 1.72% to 9.05% (U. S. Department of Education, 2017).

DEC joins our partners in advocating for national guidelines to establish eligibility criteria related to preterm and LBW births that can be used consistently across all states. In doing so, we acknowledge the issue of limited resources and the challenges states face in serving all at risk children under Part C.

Language Development in Children Born Low Birth Weight

Difficulties and delays in language acquisition and functioning in LBW children are well documented. A meta-analysis of studies investigating language outcomes of children born very low birth weight (i.e., VLBW, ≤ 1,500 grams) found they performed below their full-term peers on receptive and expressive language measures, as well as semantic tasks (Barre, Morgan, Doyle, & Anderson, 2011). Differences in language development were still present when studies looking at only school-aged children were included, indicating persistent language challenges. There is some research to suggest that language delays/differences in children born VLBW may become more apparent as the child ages (Sansavini et al., 2010).

In addition to delays in vocabulary acquisition, children born VLBW often demonstrate subtle but persistent differences in language processing, including slower language processing speed, grammatical differences, and phonological working memory challenges (Ramon-Casas, Bosch, Iriondo, & 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 and functioning (Foster-Cohen, Edgin, Champion, & Woodward, 2007).

Given that language challenges are well-documented in children born LBW and include differences in pre-verbal social communication skills evident in the first year of life, it is critical that early intervention (EI) programs identify and serve children born

LBW and preterm as soon as possible, rather than waiting for them to manifest documented developmental delays (Barre et al., 2011; Schuymer et al., 2011).

Finally, practitioners acknowledge the cultural and linguistic background of the family especially when the child is a dual language learner. According to DEC Recommended Practices "practitioners provide the family of a young child who has or is at risk for developmental delay/disability, and who is a dual language learner, with information about the benefits of learning in multiple languages for the child's growth and development" (DEC, RP F8).

Cognitive Development and Executive Function in Children Born Low Birth Weight

Delays in cognitive development and later school achievement such as in reading and math, grade retention, and placement in special education among LBW children also 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, such as periventricular hemorrhage and diffuse white matter injury (Rose, Feldman, Jankowski, & Van Rossem, 2011). Studies that have examined white matter injury and executive function (EF) skills in preschoolers born early found correlations via structural magnetic resonance imaging (MRIs) (Edgin et al., 2008; Woodward, Clark, Pritchard, Anderson, & Inder, 2011). Therefore, it is important to have intervention focusing on EF activities for young children in order to reduce functional limitations, improve developmental and lifelong learning outcomes, and provide family support.

EF refers to a wide range of central control processes in the brain that link and categorize information that is discernible in the cognitive, motor, and behavioral responses of young children (Diamond, 2006) and that motivate goal-directed behavior (Best & Miller, 2010). Paying attention to EF early in life is important because EF is associated with important functional outcomes, including social competence and academic achievement in both typically developing and preterm children (Zelazo, Blair, & Willoughby, 2016). EF encompasses cognitive abilities that are used to direct goal-oriented behavior, such as inhibitory control (i.e., resisting an automatic or reflexive response in order to do what is requested or needed); working memory (i.e., holding information in mind); cognitive flexibility (i.e., adjusting to changed demands or switching between rules); and organization, sequencing, and planning.

Early childhood is a critical period for laying the foundation for well-developed EF skills. Kindergarten teachers rate difficulties with following directions and controlling attention as the main cause of children's lack of ability to succeed in school (Blair & Razza, 2007). As described above, children who are LBW and preterm are at high risk for EF deficits as well as other developmental delays and behavioral difficulties. Therefore, there is a critical need for early intervention aimed at prevention or amelioration of identified developmental problems including EF and developmental delays and behavioral difficulties associated with LBW and prematurity prior to entering kindergarten.

Social-Emotional Development in Children Born Low Birth Weight

Vulnerability to delays in social-emotional development and/or behavioral challenges is well documented for children born very (VLBW; < 1500 grams) and

extremely low birth weight (ELBW; <1000 grams). At school age, researchers report children exhibit increased prevalence of: (a) issues with attentional control, (b) Attention Deficit Hyperactivity Disorder (ADHD), (c) social interaction problems, (d) problems with peer relationships/establishing friendships, (e) delays in social competence and behavior unrelated to IQ, (f) conduct disorders, (g) aggression, and (i) disruptive behaviors (Bhutta, Cleves, Casey, Cradock, & Anand, 2002; Mathewson, Chow, Dobson, Pope, Schmidt, & Lieshout, 2017; Msall & Park, 2008; Institute of Medicine, 2007; National Research Council and Institute of Medicine, 2000). Furthermore, there is evidence that these psychological and mental health challenges evident in early childhood persist throughout childhood and into adulthood (Mathewson et al., 2016; Saigal & Doyle, 2008). Additionally, the most extremely LBW children have the most persistent behavior problems (Taylor, Margevicius, Schluchter, Andreias, & Hack, 2015).

What causes social interaction difficulties, exactly how preterm birth and LBW status influences social and emotional development and behavior, and the magnitude of effect in children at school age and beyond are not known (Bhutta et al., 2002; Msall & Park, 2008). Hence, attention has increasingly focused on early identification of social-emotional difficulties and behavior problems (Boyd, Msall, O'Shea, Allred, Hounshell, & Leviton, 2013; Jones, Champion & Woodward, 2013; Spittle, Treyvaud, Doyle, Roberts, Lee, Inder, et al., 2009: Treyvaud, Doyle, Lee, Roberts, Lim, Inder & Anderson, 2012). For infants born very and extremely premature, researchers report the presence of social-emotional delays and behavior problems as early as the toddler years. For instance, in a large prospective study, Boyd et al. (2013) identified delays specific to engagement (e.g., exploration, initiative) and emotional regulation (e.g., persistence, frustration,

cooperation) in more than 25% of infants born extremely preterm (<28 weeks) during developmental assessments conducted at 2 years of age. Spittle and colleagues (2009) found decreased social-emotional competence (e.g., imitation/play, empathy, prosocial behaviors) as well as increased internalizing (e.g., peer aggression, defiance, increased activity) and dysregulation (e.g., sleep/eating, sensory responsiveness, negative emotionality) behaviors in children born very preterm (< 30 weeks or <1,250 grams) at 2 years of age.

Difficulties in social-emotional development identified at 2 years of age have also been found to be predictive of later social-emotional problems (i.e., 5 years of age) in very preterm infants (< 30 weeks or <1250 grams) (Treyvaud et al., 2012). Controlling for cognitive, developmental, and social risk factors, Treyvaud and colleagues (2012) found: (a) internalizing problems (e.g., withdrawal, anxiety) predicted emotional symptoms, (b) externalizing problems (e.g., aggression, impulsivity) predicted conduct problems and hyperactivity/inattention, and (c) social-emotional competence (e.g., compliance, attention) predicted problems with peer relationships and social competence.

Other studies of LBW preschoolers found that social-emotional and behavioral difficulties are common. At 4 years of age, Jones and colleagues (2013) reported increased risk (i.e., almost double) for emotional and behavioral adjustment problems as well as emotional dysregulation **a**nd interpersonal relationship problems in comparison to full-term peers. Very preterm infants (≤32 weeks) exhibited: (a) higher levels of hyperactivity/inattention and emotional problems, (b) poorer inhibitory control, (c) higher levels of emotional dysregulation, (d) increased self-regulatory difficulties at home, (e) more emotional dysregulation and interpersonal relationship problems with parents and

peers, and (f) being less likely to experience positive interactions with peers during play activities.

Early identification of delays in social-emotional development and behavioral difficulties is not exclusive to infants born very or extremely premature. Johnson et al. (2015) reported the risk of delayed social competence was significantly increased for infants born late (34 – 36 weeks) and moderately (32- 33 weeks) preterm (LMPT) at 2 years of age. During the preschool years, higher rates of behavioral and emotional problems were identified in infants born moderately preterm (32 – 35 weeks) (Potijk, de Winter, Bos, Kerstjens, & Reijneveld, 2011). At school age, results of a statewide study of infants born late preterm (34 – 36 weeks) reported higher risk for suspension (or retention) in kindergarten. While typically considered a 'low-risk' population of preterm infants, evidence describing increased risk for subtle neurodevelopmental disabilities (e.g., social-emotional delays, behavior problems) is accumulating for infants born late and moderately preterm.

The potential to identify social-emotional difficulties at a young age, especially those predictive of problems at school age, has important implications for assessment and intervention for infants born extremely, very, moderately, and/or late preterm. Boyd and colleagues (2013) advocated for the assessment of social-emotional development with high-risk preterm infants even when they do not present with motor or cognitive development concerns to facilitate early identification of social emotional delays. The rationale supporting this recommendation was the finding that ≥15% of the 2 year olds who exhibited questionable or non-optimal social-emotional or behavior scores actually scored within the normal range for cognitive and motor functioning. Additionally,

researchers advocated for the provision of early intervention to facilitate long-term social, emotional, and behavioral outcomes of preterm infants and support families given: (a) the impact of the social-emotional developmental domain on learning, EF, and social competence (Boyd et al., 2013), (b) the ability to modify risks and improve outcomes related to learning, behavior, and social competency at school age (Jones et al., 2013; Morse et al., 2009; Msall & Park, 2008; Spittle et al. 2009; Treyvaud et al., 2012), and (c) families may want and/or need support as they nurture and promote social-emotional development in infants and young children who were born premature (Jones et al., 2013; Maupin & Fine, 2014; National Research Council and Institute of Medicine, 2000).

Factors Associated with LBW and Optimal High Risk Outcomes

A great deal of research has looked at risk factors for LBW, VLBW, and ELBW including 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 as yet, but a number of important factors need further research. These include increases in opioid use, childhood poverty, and poor maternal health prenatally due to lack of or uncertain access to health care. Recent research is beginning to look at factors such as increased gestational exposure to particulate matter (Godfrey et al., 2017; Bbisu, Berman, & Bell, 2016) and increased neonatal abstinence syndrome as a result of the rise in opioid usage (Smith & Lipari, 2017). Of particular recent interest is neonatal abstinence syndrome (NAS) which is a clinical diagnostic terminology for a group of problems 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 Centers for Disease Control and Prevention (CDC) indicate that the incidence of NAS in the United States has significantly increased over the last ten years (Patrick et al., 2012; Patrick, Davis, Lehman, & Cooper, 2015). The most recent data on state trends in NAS incidence were collected under the State Inpatient Databases of the Healthcare Cost and Utilization Project (HCUP) during 1999-2013. According to the publicly available data, NAS incidence increased 300%, from 1.5 per 1,000 hospital births in 1999, to 6.0 per 1,000 hospital births in 2013 (Ko, et al., 2016). In addition to aforementioned signs and symptoms, NAS increases the risk of LBW and newborn intensive care unit (NICU) admission (March of Dimes, 2017).

Beginning with a landmark study in the early 1980's (Escalona, 1982), it has been well documented that LBW infants from low-income families and households with lower maternal education have the poorest health and developmental outcomes among all LBW children. Recent longitudinal follow-up studies that have considered socioeconomic status (SES) show that very LBW infants (< 1500 grams) in low SES households fared 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). But earlier longitudinal follow-up studies had already consistently been documenting this association with LBW infants born in the 1990s (Taylor, Klein, Minich, & Hack, 2000), with follow up into adulthood finding that LBW children in low SES

families fare worse into adulthood compared to LBW peers from higher SES families (Hack, 2009).

Evidence for Benefits of EI for LBW Infants

Several recent research reviews suggested that early intervention programs for LBW and preterm infants could lead to improved cognitive outcomes (Orton, Spittle, Doyle, Anderson & Boyd, 2009). While to our knowledge there are no studies specifically examining the effects of Part C early intervention 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).

The IHDP was unique in that it was the first multi-site randomized clinical trial (RCT) 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 preterm (IHDP, 1990). Infants were randomized into the comprehensive intervention group or a follow-up only group beginning immediately after hospital discharge and continuing until age 3. The comprehensive intervention included weekly home visits during the first year of life, followed by monthly home visits and a full-time center-based educational program and family support services during the second and third years of life. Infants in both groups received periodic follow-up clinic visits with multiple health, developmental, and family assessments. The sample of 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.

As summarized by Mallik and Spiker (2016), the IHDP findings demonstrated positive early intervention impacts with the children who received the intervention experiencing, at 36 months: (a) significantly higher IQ scores; (b) significantly lower behavior problems; and (c) a small but significant increase in maternally reported minor morbidity (defined as the presence or absence of health conditions), but with no evidence of an increase in serious health problems. Subject retention was high in both treatment and follow-up groups (93%) which is an important characteristic of this RCT that makes these findings strong evidence for the benefits of early intervention for LBW infants.

The largest treatment effect was that the intervention group achieved significantly higher cognitive scores relative to the follow-up group at the corrected age (CA) of 36 months. Birth weight had a main effect on the level of IQ scores, with a greater effect on the heavier LBW infants. The heavier intervention infants scored 13.2 IQ points higher than their follow-up counterparts, and the treatment group difference was 6.6 IQ points for the lighter infants which are strong effect sizes for an RCT. The positive effects on IQ scores were also seen at seven of the eight study sites, and the children from low SES families benefitted the most from the intervention (Ramey & Ramey, 1998).

Follow up of the IHDP sample after the intervention ended at age 3 showed that at age five overall, there were no significant differences between the intervention group 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 g) had higher full-scale IQ scores and higher verbal IQ scores. No such differences were noted in the lighter LBW

group. At age eight, modest intervention-related differences in the cognitive and academic skills of heavier LBW children only were found. However, a comparison of intervention children who received the highest amount of the intervention with a matched group of follow up children found positive intervention effects for cognitive and verbal skills for both the lighter and heavier intervention 8-year olds (Hill, Brooks-Gunn, & Waldfogel, 2003).

Some other IHDP findings showed that family environment was an important contributor to child outcomes and that risk for poor outcomes continues in LBW children. For example, family income and poverty status were significant predictors of IQ scores at age 5, even after accounting for maternal education, family structure, ethnicity and other differences between low- and high-income families. Additionally, based on a cohort study that did not compare intervention and control, IHDP children with behavior problems at age 3 continued to show problematic behaviors at age 5 and 8, (Gary, Indurkhya, & McCormick, 2004), suggesting a need for continuing interventions beyond the first 3 years of life.

A long-term prospective follow-up of the IHDP sample was conducted when the subjects were 18 years of age (McCormick et al., 2006). Results showed that after adjusting for cohort attrition there were positive effects favoring the intervention group on vocabulary, math achievement, and risky behavior problems for the heavier LBW group only. 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 children (< 1000 grams) (Taylor, et al., 2015). Again, these finding indicate a continuing need for interventions in this population.

Conclusion and Recommendations

As this review of research on outcomes for children born LBW clearly shows, there is abundant evidence that this is a population at risk for poor outcomes and the origins of their poor outcomes begin prenatally and in infancy. This is a global issue but our current statement is aimed at the US. In the only study of Part C early intervention with a nationally representative sample, the National Early Intervention Longitudinal Study (NEILS) reported that about one-third of infants enrolled in EI were LBW (Scarborough et al., 2004). But these NEILS national data also showed that many of the LBW infants were enrolled in the second and third years of life after documented developmental delays were apparent even among the extremely LBW group (< 1000 grams) (Hebbeler et al., 2007). The costs of the poor health, learning, behaviors, school achievement, and long-term life outcomes of LBW are substantial (Petrou, Sach, & Davidson, 2001), and support calls for identifying and providing EI services early on to reduce the long-term costs and poor outcomes.

DEC recommends that LBW should be considered an established condition 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 $\leq$ 1500 grams are high risk for delays, and this weight should be the definition for the national standard for automatic EI eligibility. Some states may want to expand their eligibility criterion to include the full range of LBW ($\leq$ 2500 grams) because the full range of LBW clearly confers risk status as well, particularly for LBW children from low income families and who have cognitive and/or behavioral concerns that do not

manifest until school-age (e.g. ADHD, LD, etc.). However, DEC and its partners support setting LBW $\leq$ 1500 grams as a national standard for EI eligibility.

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