

Promoting the Health, Safety and Well-Being of Young Children with Disabilities or Developmental Delays

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This document is being disseminated in draft form to elicit input. The field review period is from September 26 through October 21, 2011. Please submit written comments to the Division for Early Childhood via email at dec@dec-sped.org or fax to 406-543-0887.

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Introduction

The Division for Early Childhood (DEC) of the Council for Exceptional Children supports local, state, and federal initiatives to promote the health, safety, and well-being of young children and their families. This includes initiatives focused on the prevention of social, emotional, physical, and cognitive disabilities, efforts taken to assure that children affected by disabilities do not acquire preventable secondary disabilities or exacerbation of their impairments or disabilities, and establishment of effective systems of referral and service provision to enhance the optimal development of children with or at risk for disabilities.

The early childhood years build the foundation for a lifetime of health and development. Investing in prevention is cost-effective when effective services are provided in natural environments with collaborative efforts to establish connections with families, appropriate community-based systems, services, and personnel.

Prenatal care services for all pregnant women and their families and early universal screening
for newborns infants, toddlers and preschoolers during well child check-ups including early
and periodic screening, diagnosis, and treatment with a single point referral system. This also
includes access to evidence-based information for all families and practitioners regarding
developmental milestones, red flags and risk factors.

Prenatal care services should address preconception care, maternal chronic diseases, previous pregnancy complications, and behavioral risk factors. Preconception care includes awareness of potential risks during pregnancy that could lead to undesirable outcomes for the mother or child. These include taking folic acid for three months prior to pregnancy to protect the developing fetus from spina bifida or other neural tube defects. Adequate consumption of folic acid during pregnancy can prevent 70 percent of all neural tube defects, including cleft lip and palate (Center for Disease Control, 2008). A healthy diet and avoiding toxic substances also are known to decrease risks during pregnancy (U. S. Department of Health and Human Services, 2004).

As women postpone childbearing into their 30's and 40's, chronic diseases including hypertension, asthma, and hypothyroidism are increasing in this population (Misra, Grason, & Weisman, 2000). Unfortunately, chronic diseases are disproportionately associated with women of color and women living in poverty (U S Department of Health and Human Services, 2010). The link between

hypothyroidism caused by iodine deficiency during pregnancy and developmental disabilities has been studied for over 2 decades (Pop, et al., 2003). Other research has identified increases in complications during pregnancy such as preeclampsia, placental abruption, preterm birth and low birth weight (Gharib, Tuttle, Baskin, Fish, Singer, & McDermott, 2005). Regular prenatal care and educational information about these complications are efforts aimed at reducing and/or ameliorating risks. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA, 2004) recognized behavior risk factors for pregnant women that should be addressed including and prenatal exposure to substances (NECTAC, Vulnerable Young Children, 2008). Environmental risks do not develop in a vacuum and the infant may be exposed to other risk factors including chronic substantiated abuse or neglect, poverty, maternal depression, placement in the foster care systems, homelessness, and exposure to family violence. These risk factors often have physical and psychological impacts with lifelong implications for development and growth. If these risk factors are not addressed and minimized, children are at continued risk for school failure, unsuccessful peer relations, increased and chronic health issues, inability to complete formal education, and mental health disorders (Shonkoff & Phillips, 2000).

The developing brain is vulnerable to neurotoxins including alcohol, nicotine, and cocaine. Other agents that affect brain development include infections, drugs, radiation, environmental pollutants, and chronic illness in the mother that lead to disruptions in fetal development (Haffner, 2007). The degree to which the fetus is affected depends on the timing and intensity of contact with the teratogen, factors inherent in the mother, and genetic characteristics of the fetus. Since most organs are formed between 10 and 60 days post-conception, this is generally the most vulnerable time for the fetus (Batshaw, Pellegrino, & Roizen, 2007).

Neurotoxicants identified during prenatal development can have a negative effect on the developing central nervous system. Tobacco smoke is one of the most commonly known environmental toxins. Smoking deprives the fetus of needed oxygen and other nutrients. This state may result in low birth weight or intra-uterine growth retardation, miscarriage, stillbirth, reduced lung function and later intellectual deficits and behavioral problems (Winickoff, Van Cleave, & Oreskovic, 2010). Similarly, women who are exposed to second-hand smoke during pregnancy have a higher rate of premature births. Columbia Center for Children's Environmental Health, part of the Mailman School of Public Health at Columbia University, found that children whose mothers are exposed to second-hand smoke during pregnancy have reduced scores on tests of cognitive development at age two, when compared to children from smoke-free homes. Research studies indicated that a developing fetus exposed to second-hand smoke may have an increased risk of Sudden Infant Death Syndrome (SIDS; NIH/National Cancer Institute, 2008). In addition, teratogens are one of the leading causes for developmental disabilities, particularly cognitive impairment, hearing loss, and vision loss (Roizen & Johnson, 2008). The World Health Organization (2005) estimated that 30-40% of neurodevelopment disorders have environmental toxin involvement as a cause.

Of all neurotoxins, alcohol has the most impact on the developing brain and it is one of the leading most preventable causes of intellectual disabilities in the United States today (Center for Disease Control, 2006). The use of any illicit drug (e.g., heroin and cocaine) is dangerous to the fetus and newborn. An increasing number of adults with young children are experimenting with methamphetamine and prescription drugs. Children whose parents are abusing these drugs risk long-term exposure to chemicals that could damage their nervous system, brain, lung, kidneys, liver, eyes and skin. They are also at risk for abuse during domestic violence incidents (Virginia Department of Social Services, 2007). Unfortunately, newborns who are addicted to prescription drugs must be treated with methadone to ease the symptoms of withdrawal (Goodnough & Zezima, 2011). The long-term impact of methadone on infants is unknown.

In a policy statement, the American Academy of Pediatrics stated, "Early identification of developmental disorders is critical to the well-being of children and their families (APP, Policy Statement on Identification of Infants and Young Children, 2010). They advocated for developmental surveillance to be incorporated at every well-child preventive care visit. Any concerns raised during surveillance should be promptly addressed with standardized developmental screening tests. In addition, developmental screening tests should be administered regularly at the 9-, 18-, and 30-month visits. The National Academy for State Health Policy (ABCD III) program (2011) is charged with developing and testing sustainable models for improving care coordination between pediatric primary care providers and other providers working with young children and their families in an effort to improve the quality of care for children with or at-risk of developmental delay. Much of this work is done through strengthening referral systems, single points of contact and developing linkages between agencies (National Academy for State Health Policy, 2011). DEC strongly supports universal developmental screening and surveillance efforts to prevent and alleviate early developmental delays.

2. Culturally-responsive, developmentally appropriate yet individualized care in affordable, safe, nurturing inclusive environments using evidence-based practices by qualified early childhood practitioners (i.e. early interventionists/early childhood special educators and early childhood educators). Family-guided practices includes access to information for all families regarding positive parenting practices for all young children that takes into account varied child rearing beliefs and cultural and linguistic diversity. Family-guided, early intervention for infant and toddlers at risk for developmental delay as well as infants with high risk factors (e.g., low birth weight and prematurity) that are provided in natural settings (e.g., home, playgroups, etc.) is the foundation of early intervention services.

DEC prioritizes the promotion of health, social, emotional, and educational outcomes of young children by increasing access to high quality child care, and the prevention of developmental delays by ensuring equal and appropriate access to early intervention services for young children with or at risk for developmental delays. Professional organizations such as DEC play a key role in disseminating information to ensure families and staff understand and implement evidence-based, developmentally appropriate practices and arrange safe, nurturing and responsive environments. Dissemination efforts should be focused on ensuring that <u>all</u> families have access to safe, affordable, nurturing childcare settings which are staffed by qualified professionals who implement evidence-based, developmentally appropriate universal practices. In order to insure quality programs, efforts need to focus resources on increasing the competence of the early childhood professionals by disseminating knowledge, promoting research, and influencing policy related to evidence-based, universal practices and the essential characteristics of high-quality environments.

Developmentally-appropriate practices are suited to the child's age, strengths, interests, and developmental status; enable children to achieve functional, generative goals; include experiences that challenge children enough to promote learning and development; and are based on empirically supported principles about child development and learning. Caregivers and early childhood practitioners who employ developmentally appropriate practices are intentional and systematic in their use of approaches and strategies to support children's development and learning across domains. Universal practices to promote child well-being include strengthening and promoting nurturing relationships among staff, children, and their families. Infants, toddlers, and young children develop within the context of their caregiving relationships (Squires & Bricker, 2007), cultivating and sustaining nurturing relationships between caregivers and children is an essential component to the promotion of health, safety, and well-being of children and the prevention of or buffering of the impact of developmental disabilities. Universal practices also include arranging high-quality learning

environments. High-quality environments include responsive, physically stimulating, and developmentally appropriate materials and activities, enroll and serve children with a range of abilities and needs, and are safe and staffed by qualified, nurturing adults (Trivette, 2007). High quality environments provide ample opportunities for sustained engagement with peers and materials in meaningful activities and high-level play, which afford contextually relevant opportunities for developing critical thinking, language, social, emotional, motor, and problem solving skills. High-level play provides for positive social interactions with peers and adults, functional communication skills, expressions of empathy, and promotes the development of friendships.

DEC recognizes the importance of promoting the acceptance and respect of parenting practices across diverse cultures. Thus, information regarding positive caregiving practices should include and support the active participation of families representing cultural and linguistic diversity. Researchers indicate that when child care providers and early childhood educators acknowledge and value the family's culture (including language, parenting practices, etc.) the relationship is strengthened (Cheatham and Santos, 2009). Culture impacts developmental expectations, ways of interacting and communicating with others, and beliefs about parenting and child rearing (Carlson & Harwood, 2000). Culturally responsive and relevant strategies include practitioner self-reflection regarding dispositions towards different viewpoints about caregiving and expectations related to child development, the practices and beliefs of all families and cultures, and commitment to listening to families about their strengths, priorities, and concerns. Parenting education (including all caregivers) should be intentionally focused on relationship building and supporting families to feel more secure in the relationship with the early interventionist or teachers (Parlakian & Seibel, 2002). A goal of parenting education should be to enhance family capacity to teach and nurture their children and promote their learning and development. Parent educational supports and practices are guided by a framework to strengthen existing competencies, promote family participation, and encourage joint decision-making (Dunst & Dempsey, 2007). Practitioners focus on building rapport and strengthening the relationship with all family members through active listening about expectations, empathy, and positive, constructive feedback that promotes caregiver self-efficacy and competence (Dunst, Trivette, & Hamby, 2006). When working with families who are culturally or linguistically diverse, early interventionists may ask families to identify cultural brokers who may also act as interpreters to help facilitate the early intervention supports and services.

DEC strongly believes that early intervention for infants, toddlers and young children at risk or with established disabilities should be family-guided and provided in natural settings within daily routines and activities. Early intervention includes the identification of family and environmental risk and opportunity factors and child developmental delays or concerns. The underlying principles of early intervention are that children learn best through everyday experiences with familiar adults within familiar routines and activities and that all families can support their child's learning and development given the necessary supports and resources. As mentioned above, the goal of early intervention services should be to enhance the capacity of caregivers by using a strength-based, collaborative approach. Early interventionists should identify the family's priorities and concerns within the context of family's daily routines and activities (McWilliam, 2002). Likewise, if the child spends a good portion of the day in child care settings, service and supports should be provided in collaboration with the child care providers within the center's daily routines and activities. Early intervention should support the child and family's participation in daily routines, activities, and communities (Roggman, Boyce, & Innocenti, 2008). Effective early interventionists use evidence-based practices for gathering information and providing support to families. They collaboratively identify learning opportunities within the family's typical routines using the family's toys and materials and build on the natural caregiver-child interactions and enhance the caregivers responsive interactional style (Powell & Dunlap, 2010; Dunst & Kassow, 2008). Also, effective early intervention practitioners implement evidence-based adult learning and coaching

strategies to support caregivers capacity to embed learning opportunities throughout the day to help the child achieve identified goals and objectives (McWilliam, 2000). Practitioners support families in implementing services rather than providing direct services to the child. This ensures the child receives maximum amount of intervention and meaningful instructional opportunities throughout the day by familiar caregivers (Jung, 2003). Early intervention practitioners provide three types of support to families: emotional (e.g., positive affect, responsiveness, sensitivity), material (e.g., community resources, necessary equipment), and informational (e.g., about their child's disability, developmental expectations) (McWilliam, 2010). DEC seeks to support and sustain efforts to promote pre-service and in-service training on effective early intervention, research on evidence-based practices for working with families with young children, policies and legislation to support family-guided early intervention, and dissemination of information about best practices with children and families (Sandall, Hemmeter, McLean, & Smith, 2005).

3. Correctly administered, ethical, valid, reliable, culturally sensitive, formal and informal assessments that ensure accurate identification of the child and family's strengths, appropriate individualization of children's learning to fit each child's needs and current level of development and progress. Supporting young children through research that evaluates early intervention screening, diagnosis, and treatment aimed at minimizing risk factors and strengthening child and family capacity is essential.

To prevent social, emotional, cognitive disabilities, and promote health, safety and well being of young children with or at risk of developmental delays, DEC supports gathering of information from multiple sources using evidence-based methods by the team to determine eligibility, identify a child's current level of functioning, determine the need for additional intervention, and plan and evaluate interventions. Assessment tools and methods used must provide published information about psychometrics including validity and reliability information related to the purpose of the assessment (i.e., screening, diagnostic evaluation, program planning, and progress monitoring; Bagnato, Neisworth, & Pretti-Frontczak, 2010). A developmentally appropriate assessment should meet eight "critical" criteria: usefulness, acceptability, authenticity, collaborativenesss, equitability, sensitivity, and congruence (Neisworth & Bagnato, 2005). Given the limitations of standardized tests in early childhood (Neisworth & Bagnato, 2004), collection and use of authentic data from a variety of sources is recommended (e.g., parent report, observation, routines-based notes).

Early childhood professionals must understand the effects of culture and language on home environments, learning, and social relationships, to assess children and their families in a culturally responsive manner (Barrera, Corso, & Macpherson, 2003). Thus, assessment practices should be responsive to the family's values, communication style, and expectations, both when administering assessments and collecting information about families' concerns, priorities, and resources. Language differences and literacy levels of the families should be considered when collecting information and reporting assessment results.

DEC emphasizes family and caregiver participation in the assessment process. DEC also recognizes the importance of the family and community in each child's development and learning. Besides identifying specific concerns, family and other caregivers bring a unique perspective on children's functioning level and performance within natural environments and daily routines. Collaborative assessment methods using multiple sources of information, encouraging active parental and caregiver participation, conducted in natural settings and during routines provide authentic information about the child's strengths and needs and link directly to intervention planning.

Appropriate pre-service and in-service training including instruction related to family-centered assessment practices and opportunities to practice administering authentic assessments must be provided to early childhood professionals. Training in multidisciplinary collaboration, selection of the "right" tool for the "right" purpose to make programmatic decisions guided by evidence, and culturally sensitive assessment practices, is a key to preparing effective professionals who collect meaningful assessment information and link the assessment information to instruction and intervention. Institutions of higher education must step up to the challenge in preparing pre-service teachers to understand and practice the DEC and NAEYC guidelines for assessment. A meeting with the assessment team is the first experience a family may have with early intervention. Administrators must ensure a qualified team, guided by the eight qualities of assessment (see DEC Recommended Practices, Sandall et al., 2005), works with families to administer authentic, culturally sensitive assessments in appropriate settings.

4. High quality systems of pre-service and in-service professional development focusing on training in evidence-based, family-centered practices for working with young children and their families to minimize risk factors and strengthen child and family capacity in inclusive, natural settings. Ongoing professional development for early childhood professionals ensures better understanding of child development, provides support for reporting developmental concerns, and teaches strategies for talking with families about difficult topics.

DEC prioritizes the establishment and sustainability of high quality systems of pre-service and in-service professional development for early childhood professionals. Effective professional development should be designed and delivered based on the characteristics of the participants and content, and include relevant, high-quality learning experiences (National Professional Development Center on Inclusion, 2008). Professional development should consist of training in implementing evidence-based, developmentally appropriate, family guided practices for working with young children and their families. Professional development goals and strategies should focus on minimizing risk factors and strengthening child and family capacity and participation in inclusive, natural settings. Baker-Ericzen, Mueggenborg, and Shea (2009) found that intentional, systematic training on evidence-based practices for promoting inclusion was related to positive changes in attitudes and perceived competence toward inclusion for professionals. This study's findings demonstrate the benefits of training when professionals are already working in the field. However, effective professional development also should be provided at the preservice level, as the benefits are likely to be sustained over time when the pre-service program includes systematic coursework and field experiences in evidence based strategies for working in inclusive settings. Yet, more than 40% of early childhood, bachelor-level teacher preparation courses or practicum experiences do not provide a course or specific information on working with children with disabilities (Chang, Early, & Winton, 2005). In an in-depth study of early education care and quality, Early et. al. (2007) surveyed pre-service programs and found programs varied in quality. Their study had four important conclusions: (1) some were relatively new programs; (2) they were typically small and unfunded; (3) some changed their focus recently; (4) many experienced huge enrollment increases in many places related to degree mandates. It is imperative that early intervention/early childhood special education programs work within their state system to ensure quality early childhood placement for all children. DEC supports an increased focus on embedding evidence-based practices in inclusive settings and an emphasis on preparing professionals to work within those settings.

Programs also should include coursework and experiences related to collaboration with colleagues and families and working with families and professionals representing diverse cultures and ethnicities. The coursework should provide opportunities for understanding typical and atypical child development, learning and practicing family centered strategies, providing embedded instructional opportunities, and individualized instruction and adaptations (Chandler & Maude, 2008; Odom, et al., 2002; Sandall &

Schwartz, 2008; Trivette & Dunst, 2004; Wolery, 2005). Early professional development should include content and experiences with children and families with a variety of strengths and needs (Stayton & Miller, 2008). This ensures practitioners will be able to identify concerns as early as possible and refer children and families for early intervention when appropriate. Family-centered practices include strategies to collaborate with families and caregivers to develop goals and design instruction, strengthen family capacity to deliver instruction with routines and activities based on the family's strengths and priorities, and discuss difficult topics in a responsive, culturally relevant manner (Barrera & Corso, 2002; Dunst, 2004). Embedded instruction refers to planning and delivering contextually relevant instruction within daily routines and activities (Snyder, 2005; Wolery, 2005). Individualized instruction and adaptations are designed and delivered based on the unique goals and characteristics of individual children with and without special needs. All three of these components (i.e., family centered practices, embedded instruction, and individualized instruction and adaptations) are evidence-based practices related to positive outcomes for children and families (Chandler & Maude, 2008). Across both preservice and in-service professional development, content should be delivered in a variety of formats (e.g., readings, lectures, role play, video, discussion, practice, and coaching) representing the roles that participants will or do have within early childhood settings (Chandler & Maude, 2008). DEC supports the use of coaching and performance-based written and oral feedback within systems of professional development, as professional development without follow-up coaching or feedback is largely ineffective (Fixsen, Naoom, Blase, Friedman & Wallace 2005; Joyce & Showers, 2002; Winton & McCollum, 2008). The coaching and feedback should provide participants opportunities to discuss, engage in selfreflection, and receive performance-based feedback (Snyder & Wolfe, 2008).

5. Advocacy for public regulations and policies aimed at supporting provision of services for all young children in safe, healthy environments by qualified practitioners implementing evidence based practices. Establishing and sustaining systems of interagency collaboration is required to effectively meet the needs of children and families.

Empowering families to effectively advocate for themselves during the first few years of their child's life makes it possible for the family to make decisions and interact with different social and educational systems to best support their child's development. DEC encourages and champions advocacy efforts on an individual, local, state, and national level. DEC's Children Action Network (CAN) works to shape policy by providing feedback on current and upcoming legislation, regulations, and funding. Nationally, DEC works with other organizations such as the National Association for the Education of Young Children (NAEYC) to promote developmentally appropriate practice and provide guidance on inclusion. DEC also supports and advocates for the use of evidenced-based practices through the dissemination of DEC Recommended Practices.

DEC strives to work at the local and regional level through the CAN coordinator and state and provincial affiliate members to raise awareness and provide feedback on local policy decisions. Professionals working with young children with disabilities and children at risk for developmental delays hold a unique perspective. It is imperative that they share their experiences with policy makers (LaRocco & Bruns, 2005). The DEC Code of Ethics (2009) clearly identifies advocacy as an everyday practice to which professionals should

"...serve as advocates for children with disabilities and their families and for the professionals who serve them by supporting both policy and programmatic decisions that enhance the quality of their lives...continually be aware of issues challenging the field of early childhood special education and advocate for changes in laws, regulations, and policies leading to improved outcomes and services for young children with

disabilities and their families.... advocate for equal access to high quality services and supports for all children and families to enhance their quality of lives." (pp. 1-3)

Staying informed about key issues through newsletters and email alerts, building and maintaining relationships with policy makers, and sharing your perspective through phone calls, email, or personal visits with elected officials are three significant ways that professionals can act at a local, state, and national level. (LaRocco & Bruns, 2005). Advocacy efforts should be coordinated and aligned with the interests of other key early childhood partners involving Head Start; Early Head Start; mental health; Women, Infants, and Children (WIC) Program; developmental disabilities programs; social work; state legislators; program administrators; child protective services; pediatricians; and related specialists. Many of these early childhood partners may already be participating in their state interagency coordinating council (SICC) or local interagency coordinating council (LICC), a natural avenue for coordinating efforts.

6. Research supported through empirical research and evidenced-based. There should be substantial attention and resources devoted to prevention of social, emotional, physical and cognitive disabilities by timely and appropriate intervention in health, well being, and safety of young children and their families.

DEC Recommended Practices (Sandall, Hemmeter, Smith & McLean, 2005) were developed from three important sources of information. First, they are research-based practices that lead to high quality, effective learning experiences for young children with developmental delays and other special needs. Second and third, the practices represent the collective wisdom and values of families and providers of early intervention and early childhood special education. These practices are based on the belief that high quality caregiving environments and experiences are important for all children. DEC supports continued research efforts related to the individual and unique needs of young children with developmental delays and disabilities and their families in early childhood settings.

Within the field, many funded research projects share research syntheses on topics of importance to professionals in early childhood and early intervention/early childhood special education.

These include:

Center on the Social and Emotional Foundations for Early Learning (http://csefel.vanderbilt.edu/resources/research.html):

- 1. Infant Mental Health and Early Care and Education Providers
- 2. Research Synthesis on Screening and Assessing Social-Emotional Competence
- 3. What Works Briefs

National Professional Development Center on Inclusion (http://community.fpg.unc.edu/resources/articles/NDPCI-ResearchSynthesis-9-2007.pdf)

1. Research Synthesis Points on Early Childhood Inclusion

Technical Assistance Center for Social Emotional Interventions (http://www.challengingbehavior.org/index.htm)

- 1. Roadmaps to Effective Intervention
- 2. Issue Briefs in Evidence-based practices
- 3. Recommended practices handouts

Response and Recognition

(http://www.recognitionandresponse.org)

- 1. General Resources on Early Childhood and Pre-K.
- 2. Empirical Articles on Response to Intervention (RTI)

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This position statement is being disseminated in draft form. Your input is encouraged. The field review period is from September 26 through October 21, 2011. Please submit written comments to the Division for Early Childhood via email at dec@dec-sped.org or fax to 406-543-0887.

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