Issues in Labeling Young Children with Developmental Delay: Whose Responsibility is It?

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Abstract

The Individuals with Disabilities Education Act of 1997 required states to provide comprehensive, coordinated, family-centered special education services to children from birth to age 9 after being identified as 1) being developmentally delayed, or 2) having conditions that could lead to delay, or 3) at risk for developmental delay. Within the provisions of IDEIA 2004, states have been encountering a number of obstacles including: a) wide variation in definition, b) over-identification, c) family and cultural diversity, d) appropriateness of norm-referenced tools, and e) cost involved in providing services. The purpose of this article is to highlight issues pertaining to the discrepancies in defining the term "developmental delay" and further discuss the transition process from Part C to Part B.

Key Words: Early intervention, developmental delays, early childhood education, special education.

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Introduction

Early childhood early intervention is a growing field that is developing as rapidly as the children who are receiving the services. The centerpiece of early intervention relies heavily on an appropriate identification process. The issue of labeling young children in need of early intervention services has been the focus of debates with parents, advocates, service providers, researchers, and policy makers for a number of years. As a result, our knowledge base has been expanding at a phenomenal rate over the last decade. At the U.S. policy level, this advancement would have not have been possible for individuals with disabilities without the United States federal government's involvement.

The first major federal recognition of the specific importance of early childhood special education/early intervention can be attributed to The Handicapped Children's Early Education Assistance Act of 1968 (HCEEAP). The intent of this legislation was to support model programs that would demonstrate exemplary practices. The act established HCEEAP across the nation. Over the years this law funded outreach programs such as the Technical Assistance and Development System which eventually became known as the National Early Childhood Technical Assistance Center (NECTAC; Hooper & Umansky, 2004).

Additionally prior to 1975, a number of reports to the United States Congress indicated that children with disabilities were either not identified or were not provided adequate services. Consequently, given the discrepancies in special education services across the individual states and a lack of adequate financial means in providing the necessary services, the United State Congress enacted the Education for All Handicapped Children Act (EHCA; P.L. 94-142) in 1975. This law mandated that states provide special education services for children identified and labeled with different disability categories from ages 5 to18. Currently, eligible children are served from birth through age 21 under the Individuals with Disabilities Education Improvement Act (IDEIA, 2004). Further, IDEIA requires an Individualized Education Program (IEP) or Individual Family Service Plan (IFSP) to be in place for each child eligible for special education and related services. The IEP/IFSPs are based on a multi-disciplinary assessment and include statements of the specific special education and related services to be provided for each individual child. IDEIA (2004) stated that all children with disabilities will be educated, to the extent appropriate, in the "least restrictive environment" (LRE) or in the "natural environment" (NE) along with typically developing peers. Parents were also given the right to participate in every decision related to the identification, evaluation, and placement of their child as well as due process rights. Due process rights has allowed parents to seek legal remedies should their child not be receiving appropriate services based on identified needs.

Later in 1986, EHCA was amended and reauthorized under P.L. 99-457, the Education of the Handicapped Act Amendments. The major revision of the amended law extended all provisions to preschool children ages three to five and encouraged states to serve children with disabilities from birth through age two (0-3). When the newly revised P.L.

94-142 was amended under P.L.99-457, fewer than half of the states had mandates for the education of very young children with disabilities (Howard, Williams, & Lepper, 2010). Under the provisions of P.L. 99-457, states were provided with funding and were given five years to plan the implementation of the preschool mandates.

In 1990 the EHCA (P.L. 94-142) was renamed as Individual with Disabilities Education Act (IDEA). Later in 1997 and again in 2004, IDEA was further amended. These amendments required states: (1) to provide early identification and services for infants and toddlers with developmental delays, (2) at the state's discretion, to identify children at risk for developmental delays and, (3) to establish conditions that are associated with developmental delays. States that chose not to serve the at-risk population were encouraged to track and monitor these children's development so that they could be referred in the future should they require early intervention services. Further, this law mandated that states refer children for a free, comprehensive, multidisciplinary evaluation by a team of professionals including families to decide which services were needed for the child by means of an IFSP. Furthermore, it mandated states to implement a coordinated, family-centered, and culturally competent community-based system of care and to provide early intervention services for children identified with developmental problems (IDEIA, 2004).

In addition IDEIA (2004) added corresponding language, requiring Part C referrals to be made for children under age three in circumstances such as substantiated case of child abuse/neglect, illegal substance abuse, or if a child was demonstrating withdrawal symptoms resulting from prenatal drug exposure. The latest requirements potentially could increase the likelihood of young children to receive needed services (CAPTA, 2003). In addition, the amendment to IDEIA 2004 Part C required every IFSP to include a statement of specific early intervention services based on peer-reviewed research and measurable outcomes including pre-literacy and language skills that would be developmentally appropriate for a particular child (Division for Early Childhood, 2008).

Part C and B of IDEIA

The purpose of Part C of IDEIA (2004) was to develop a system that provided early intervention services for children experiencing developmental delays and encouraged states to expand opportunities for children under the age of three years who would be at risk for developmental delay should they not receive early intervention services. Unlike IDEIA (2004) regulations for school-age children, each state was given the responsibility of determining specific eligibility guidelines for early intervention services. Under the Infants and Toddlers with Disabilities Program (Part C of IDEIA, 2004), states are required to define the term "developmental delay" in order to identify eligible children from birth through age two (0-3). Under Part B of IDEIA (2004), states were also given the freedom to define "developmental delay" as a disability category for children ages three through nine, or any subset of that age range, including ages three through five. Previously, such an option was not available and children as young as three years of age had to be given a specific label such as communication disorder, learning disability, or autism (Bowe, 2007).

Developmental Delay

Developmental delay (DD) can generally be defined as a child not reaching specific milestones in one or more of the areas of development (e.g., communication, motor, cognitive, social-emotional, or adaptive skills) as expected for typically developing children. At the same time, a child's delayed development should not be associated with a condition or a specific diagnosis (e.g. deafness). Under IDEIA (2004), children with DD may be eligible to receive early intervention and related services if they meet certain eligibility according to federal and/or state criteria. Under Part C of IDEIA (2004) each state determines the definition of "developmental delay" for children under the age of three years. A child who has an existing diagnosed physical or mental condition with a high probability of DD may also qualify for early intervention services. Other children who demonstrate a delay, as determined by each state, would also be eligible to receive early intervention services.

Currently, states are faced with many eligibility issues which influence the numbers and types of children who are in need of or receiving services, the types of services provided, and ultimately, the cost of these early intervention services. As a result, several states have revised their definitions; some have narrowed their eligibility criteria and a few have expanded them. Soon after the creation of the Early Intervention Program under IDEIA (2004), many states were interested in serving children who were at risk for DD; however, fears of greatly increased numbers of eligible children and the associated costs reduced the number of states that included children at risk in their eligibility definition. Currently, several states that are not serving at risk children have indicated that they would monitor the development of these children and would refer them for early intervention services as delays are manifested (Danaher, 2011).

Rationale for a Developmental Delay Category

Even though there are concerns about the use of the term "developmental delay" as a label, there is widespread support for the use of the DD label. The period of early childhood development typically characterized as early childhood is birth through age eight. This period of early development is considered a unique developmental period where development is characterized by a broad range of behaviors across developmental domains and is better described by developmental criteria than by academic criteria. These developmental age ranges are accepted by national organizations such as the Division of Early Childhood (DEC) of The Council for Exceptional Children (CEC) and the National Association for the Education of Young Children (NAEYC). Additionally, the reliability of standardized and norm-referenced assessments tools for identification and diagnosis of young children is problematic in these early ages, resulting in inaccurate identification/categorization and potential loss of services. Furthermore, for many children, these early years are critical for successful acculturation within the public educational system (Division for Early Childhood, 2008).

Developmental Delay and Variations among the States

Since the provisions of IDEIA (2004) charged the states with creating a definition for a DD category, a number of different definitions have been devised based on available resources in each state. Due to this variability in early identification within each state, children could become eligible for services based on clinical opinion, biological/environmental risk factors, and/or environmental risk factors. Consequently determining the percentages of children identified with DD is difficult due to varying definitions (Derrington & Lippitt, 2008).

For example, Alaska, Arizona, Oklahoma, Missouri, Montana, Nevada, North Dakota, and the District of Columbia use a 50% delay in one area of development or 20% in two areas as one of the criteria for a DD category. Alabama, Arkansas, Delaware, Florida, Indiana, Maine and Maryland use a 25% delay in one area of development as one criterion for a DD label. Yet, some other states, such as California, Colorado, Hawaii, Michigan, Ohio, Vermont and West Virginia do not use any specific percentage or standard deviation. They use significant delay in one or more areas of development as determined by a qualified multi-disciplinary team. Given the discrepancies across the states, a child could be labeled as DD in one state; and, if the child's family moves to another state, the very same child may no longer be considered DD. As a result, these kind of changes could bring confusion as well as frustration for parents of young children.

Adding to this dilemma, IDEIA (2004) added the at-risk category as an option for the states to serve young children from birth through age three who were at risk for becoming developmentally delayed later in their childhood. However, within the at-risk category, there are many discrepancies among the states. To our knowledge, only six states including California, Hawaii, Massachusetts, New Mexico, New Hampshire, and West Virginia provide services for infants and toddlers with at-risk conditions. For example, Alaska only provides services for at-risk children through infant learning programs based on availability of funding. The other 44 states have chosen not to serve infant and toddlers with at-risk conditions. California serves high-risk children identified by a multidisciplinary team who have a combination of two or more biological irregularities. In Massachusetts, a child can be eligible for up to six months of service based on clinical judgment. After six months, the child can continue to receive services based on a diagnosis, a DD label, or other risk factors.

Similarly, Part B of IDEIA (2004) allows the DD label to be used for children from age three to nine in any combination that best serves the needs of each state. Given the fact that each state is charged with creating a definition for the term DD, the end result was not only variation of how DD is defined by each state but also multiple variations in age ranges served by each state. For example, Alabama, Delaware, Kentucky, Louisiana, Hawaii, Oklahoma, Rhode Island, and Washington use age three through eight as the age range for the DD category. Other states such as Arizona, Georgia, Idaho, Illinois, and Kansas use age three through nine as the age range for the DD category. Virginia uses an age range of two to six years, while the states of Michigan, Utah, and North

Carolina use an age range of three through seven. Similarly, states such as Arkansas, Connecticut, California, Florida, Indiana, and Missouri use the age range of three through five for the DD category Danaher (2011). Given the variations in age range for a developmental delay label and disparities in eligibility criteria, families could again lose eligibility if they move from one state to another.

Issues in Using a Developmental Delay Label

The rationale behind the use of a DD label is to provide needed services without placing a stigmatizing label on a child. However, the use of a generic DD label has created a number of issues including eligibility criteria, over- or under-identification, loss of services due to placing a child in a non-specific disability category, problems inherent in the norm-referenced instruments used in the identification process, and transition from Part C (infant/toddler) to Part B (preschool).

Eligibility Criteria

Since the U.S. federal government has allowed the states to use a DD label for children up to age nine this has created considerable variability and misunderstanding across the states. To determine a child's eligibility for services, some states have chosen quantitative criteria, such as standard deviation units; while other states have used criterion-referenced tests, indicating a certain percentage of delay. Some states have used developmental age, typically specifying a 20-50% delay, and other states have used informed team consensus based upon professional judgment or informed clinical opinion. Unfortunately, at the present time there is no meaningful consistency across the states.

Over/Under Identification

Because of the aforementioned issues related to a DD label, young children may either be over or under identified. For example, a state that extended their age range for a label of DD to age eight noticed an increase in the number of children identified as a result of the age increase. At the same time, since the states have the autonomy to change their definition of DD, financial strains could force some states to narrow their definition of DD, thus reducing the number of children deemed eligible for early intervention services. These kinds of measures could result in children being under-identified (Rosenberg, Zhang, & Robinson, 2008).

Specific Disability

Even though using a DD label may be viewed as a more accepting label for a young child, it could also be inappropriate in ensuring that a child will receive needed services. For children with low incidence disabilities (such as deaf, blind, and deaf-blind), multiple disabilities, or autism, a DD label may result in loss of services, authorization of inappropriate services, or lack of access to qualified service providers. Unfortunately, this has been the case for many young children who have not received appropriate services. Aylward (1997) stressed that a DD label traditionally implied that a child will eventually catch up; however, this concept is somewhat inaccurate. More specifically, the identification of dysfunction could be related to a number of factors including maturation, neural dysfunction, or the impact of external factors. Aylward (1997) has rightfully explained that the assessment of young children is difficult due to the complexity of human development.

Transition from Infant/Toddler (Part C) to Preschool (Part B)

In-depth discussions of the issues related to the transition of young children from Part C to Part B are beyond the scope of this paper. However, it is important to highlight the impact of a DD label within the context of this paper. Under the provision of IDEIA (2004), when children with special needs turn age three, they have to formally transition from Part C to Part B. Although every state has tried to develop a smooth transition process from Part C to Part B, the transition procedure has oftentimes been problematic for both parents and administrators. One major issue in transition is due to the provisions of IDEIA (2004). Under IDEIA (2004), the US Congress designated the Department of Education as the lead agency in charge of implementation of Part B for children ages 3-21 in all fifty states. At the same time, the US Congress has charged each state with the selection of a lead agency for children ages zero to three under Part C of the law. Some states, like Minnesota, have chosen the Department of Education as the lead agency for children ages zero to three as well, but the majority of states have chosen a different state agency. Therefore, for the states which have a different lead agency, a child and his/her family have to go through a transition process from one agency to another. Further, a child who is served under Part C may not necessarily be eligible for services under Part B of IDEIA. As a result, every child has to be reassessed by the Department of Education at age three. The dilemma is that a child who was labeled as DD under Part C could be assessed by the Department of Education and may no longer be eligible for services based on their definition of DD. For example, in Alabama the definition of DD for children ages zero to three under Part C is a 25% delay in one or more areas of development. However, under Part B in Alabama, the definition of DD is two standard deviations delay in one area or 1.5 standard deviations in two areas, or a 30% delay if a criterion-referenced test is used. In Alaska, the Part C definition of the DD label for children ages zero to three is a 50% delay below the norm in one area, while the DD definition in Part B for children aged three to eight is two standard deviations delay in one area or a 1.7 standard deviation delay in two areas, or a 25% delay in one area of development or a 20% delay in two areas (Shackelford, 2006). Some states like Indiana and Oklahoma have tried to match their definitions of DD for both groups.

Variation among the states pertaining to the definition of the term DD is a source of confusion for parents who may not be knowledgeable about these discrepancies in the definition from Part B to Part C. A parent may think that their child who is not eligible for services under Part B is no longer developmentally delayed. Even if a child with special needs is determined eligible for services under Part B, a public school is not necessarily required to provide the same amount of services which were made available to the child when the child was under the age of three. This creates questions for the families concerning frequency and duration of services. For example, a particular family's child could have been receiving physical therapy twice a week under Part C; and now, under Part B, the same child could receive physical therapy once a week.

Family and Cultural Diversity

Earlier research supports the notion that culture plays a significant role in determining what behaviors are developmentally appropriate for a child at a given age. These expectations often differ greatly from Eastern European and American/Western European cultural perspectives. For example, in some Asian and Latino cultures, more emphasis is placed on interdependence, collectivism, and extended family than in American/Western European cultures (Sameroff, 1993). Similarly, in a number of non-western cultures, parents may not expect a child to feed, dress, shower, or use the toilet independently. Therefore, it is very important to take into account cultural expectations and variations when labeling a child with a DD label. According to Sameroff (1993),

> There is no logical possibility of considering development of an individual independently of the environment. Continuity cannot be explained as a characteristic of the child, because each new achievement is an amalgam of characteristics of the child and his or her experience. If continuities are found, it is because there is continuity in the relationship between the child and the environment, not because of continuities in either taken alone (p. 5).

Given the above statement from a well-known expert in the field, it would be of utmost importance to take into account the fluidity of brain development and the impact the environment can make during the early years of development. The urgency for stakeholders like parents, professionals and advocacy groups is to take immediate action to provide appropriate and timely early intervention services for young children who are at risk for delay or are considered to be developmentally delayed.

Identification Process: Norm and Criterion Referenced Instruments

Across the states, norm referenced and criterion referenced instruments have been used to label children with developmental delay. However, the use of both has been problematic. An in-depth discussion of the issues related to the use of normative and criterion referenced tests for identifying a "developmental delay" is beyond the scope of this paper; however, it is important to note that assessment or screening for DD label is complicated by the inherent nature of a developmental continuum. Although there are milestones to accomplish and concepts to master, which formally originated in Arnold Gessell's initial "developmental schedule" of 150 items (Nuttall, Nuttall-Vasquez, & Hampel, 1999), these developmental milestones can have broad expected ranges and may not always appear linear. For example, a child may demonstrate speech and language delay and then begin to speak in two-word sentences, skipping over the developmental milestone of one-word phrasing (Brassard & Boehm, 2007).

Similarly the reliability of norm referenced assessment tools for the identification and labeling of young children has been very problematic. For example, the normative samples used for standardizing a test may not always be representative of the group of children being assessed by the instrument. Adding to this dilemma is the nature of young children and the importance of maintaining strict procedure in order to preserve the standardization of an instrument. In the words of Hebbler, Barton, and Mallik (2008), "Young children are unreliable test takers because of their limited abilities to understand and follow directions of test administrators. Yet, by definition, standardized tests must be administered the same way to all test takers" (p. 53). As a result, a number of professionals in the field of early intervention have instead promoted the use of criterion referenced tests. The criterion referenced test measures the child's present levels of performance and charts a child's progress over time. Given that there is no normative sample, other than field- based samples, there is no clear way to compare a child with his/her same aged, typically developing peer. The subjective nature of some of the criterion referenced tests can also make it difficult to justify labeling a child as DD.

It is understandable that the validity and reliability of these types of tests appear to improve as the children get older, however sufficient concern for young children will continue to remain. Furthermore, the use of another measure such as "age equivalent" scores generated by these tools could also be problematic Bredekamp & Copple, (1997). Statistically, "age equivalents" are not directly comparable across domains because scores for one age group compared to another age group will not necessarily be the same. For example, if the chronological age of a child is 14 months and his or her age equivalent is 12 months that does not necessarily mean that the child is two months delayed. Further, if another child is 36 months and the age equivalent is 34 months the two months gap between the first example and the second example is not statistically equivalent. Miller (2007) stated that as a result of "current practice within school neuropsychology, including the early assessment of developmental delay, would stress the importance of everyday functioning and prescriptive recommendations, rather than diagnostic conclusions" (p. 94). Later, Dooley (2010) stated how "school neuropsychological and developmental evaluations have evolved to stressing this concept of ecological validity" (p. 333).

Given all the issues discussed, there are a variety of risk factors that play into the overall evaluation process of early childhood development. Brassard and Boehm (2007) warn of possible considerations pertaining to the child, the family, the school or childcare setting, and the community which need to be addressed when interpreting early risk. These risk factors can include low birth weight, prematurity, poor prenatal care, malnutrition, or a history of family mental illness. Family related risk factors may include exposure of the child to maltreatment, lower maternal education level, poverty, and a high degree of family mobility. Other risk factors that occur in the school or community setting may include rigid or skill-focused curriculum, decreased opportunity to interact with other children, social isolation, and violence being frequently observed by the child. Consequently, the purpose of developmental assessment is to use the available science to more fully relate established neuropsychological processes to functional behaviors.

Dilemma: What is the State of Service Delivery?

In addition to the issues related to the identification and definition of a DD label, service delivery of early intervention is another major obstacle. The prevalence of DD making children eligible for early intervention services is much higher than previously thought. In addition, a majority of children eligible for early intervention services do not receive appropriate services. Nationally, only 17% of children under the age of five who have a DD actually receive services. Studies of children younger than three years of age showed an even larger number of children who were eligible for Part C early intervention services but were not receiving services. Race, gender, poverty, and the availability of health insurance have been found to be factors in whether a child receives early intervention services or not (Rosenberg, Zhang, & Robinson, 2008). In addition agencies under Part C are given the authority to charge for services on a sliding fee scale based upon family income (IDEIA, 2004).

According to Rosenberg et al. (2008), the only study on this topic found that in Hawaii uninsured children were using early intervention Part C services less than those who had health insurance. Similarly, in Minnesota, counties with a higher percentage of African American children had lower overall rates of early intervention enrollment. However, within the national population, African-American children tend to be over- represented. The lack of conclusive data in regard to the proportion of young children who receive early intervention services creates urgency for further studies to be done in this area.

Conclusion

Labeling of young children who may require early intervention services should no longer be a major focus of debate among parents, service providers and policy makers. Most states do define a DD label as a disability category for children ranging from the ages of birth through nine. Currently, states are faced with issues such as determining the eligibility criteria which can influence the number of children who are receiving services, the types of services provided, and ultimately, the cost of these early intervention services. As a result, several states have revised their definitions; some have narrowed their eligibility criteria and a few others have expanded them. Consequently based on current practices, any child who was labeled as DD under Part C could be assessed by the Department of Education and may be found not eligible for services based on their state's definition of DD under Part B. Adding to this dilemma, IDEIA (2004) allowed individual states the option to add the at-risk category to serve young children from birth to age three who were determined to have greater likelihood of becoming developmentally delayed later in their childhood. However, just as with the DD label, the at-risk category has many variations from one state to the next. Although beyond the scope of this paper, the issue of an at-risk category needs to be addressed further.

It is understandable that the United States federal government needs a specified window of time for passing legislative provisions and allocating resources. As the current administration strongly supports public early childhood programs, it is these authors view that we have done enough exploring and the time is now to enact federal legislation aimed at better serving young children with special needs. It is our recommendation that the US federal government provides support to individual states for establishing regional centers as a clearinghouse across each state. Further research should be pursued that examines how to replicate the success of individual states such as Minnesota, where the Department of Education is the lead agency for children ages birth to three. Now is the time to endorse a more cohesive, national definition of a DD label. The issue of labeling does not recognize any borders across the nation. Our hope is that every government entity takes a more serious approach to early child development.

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