



EITI Newsletter

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THE PROMISE OF EARLY INTERVENTION

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Early intervention (EI) programs provide critical services that can reverse the odds for infants and toddlers with developmental delays. It is the richest federal entitlement program available to young children with developmental delays from birth to their third birthday -- regardless of income or citizenship. EI can enhance the healthy development of children by providing vital health, developmental, and therapeutic services to promote early learning and strengthen crucial relationships with caregivers.

Less than 40 years ago, in New York State and nationwide, children with disabilities were excluded from school as "uneducable". Effective parent advocacy lead to passage in 1975 of the Education for All Handicapped Children's Act (originally called EHA or PL 94-142), subsequently renamed the Individuals with Disabilities Education Act (IDEA), guaranteeing the right to a free public education for school-aged children. In 1986, Congress amended this legislation to cover preschool special education, and passed the Early Intervention Program for Infants and Toddlers with Disabilities legislation (PL 99-457), also called Part H of the Education for All Handicapped Children Act of 1975 (PL 94-142). Now known as Part C of the IDEA, the new law provided financial assistance to states to maintain and implement a statewide, comprehensive, coordinated, multidisciplinary, and interagency system of programmatic interventions for infants and toddlers with disabilities and their families.

The Early Intervention Program (Part C of IDEA) allows states to provide EI services for three groups of children under age 3: children who are experiencing developmental delay, children who have a physical or mental condition that has a high probability of resulting in delay or, at state discretion, children who meet "at risk" provisions chosen by the state. The EI program is an entitlement that enables children to receive specialized assessments and services and allows their caregivers to receive services that can improve their ability to support healthy child development. The children's biological or adoptive parents, relatives, guardians, and foster parents may receive services under EI to enhance a child's development if the individualized family service plan (IFSP) -- the blueprint for services -- enumerates those services.

EARLY INTERVENTION IS NOT SPECIAL EDUCATION

As an amendment to the IDEA, EI retains that law's definitions and procedural safeguards (i.e. parents can challenge any decision concerning EI services through due process procedures). But, it is different in four key ways from special education.

EI is a Two-generation Program

First, the EI law creates an entitlement to EI based on the research demonstrating the importance of providing services to two generations -- both young children and their families. Thus, biological, adoptive, foster, kinship or relative caregivers and legal guardians can receive vital services under this law. This is very important since infants and toddlers develop best in the context of their families. For example, providing physical therapy to an infant without teaching the exercises to the parent will not result in the gains needed by the child. The child needs to practice those exercises with his or her parent. Thus, for each service provided to an infant or toddler, thought should be given to the parallel parental service such as parent training or parent counseling to enable the parent to enhance the child's development.

EI Does Not Use a Diagnostic Definition for Eligibility

Second, the EI program differs from special education in that its definition of an eligible child is not limited to a child having a specific, diagnosed, categorical disability, but is based on functional limitations. The broad functional EI eligibility definitions reflect congressional findings that EI services can address or ameliorate delay and disability and reduce the need for special education. Most children are found eligible because they are exhibiting a developmental delay. They must demonstrate a functional delay in at least one of five domains:

- Physical (includes motor skills, growth)
- cognitive (learning and thinking)
- communication (speech-language, understanding and using words)
- adaptive (self-help skills such as feeding)
- socio-emotional development (relating to others).

A multidisciplinary evaluation must identify a delay in one or more of the above domains for a child to be eligible for EI. Many states have chosen a percentage of delay for eligibility. For example, in New York, children must have a 33% delay in one domain or 25% in two domains.

Congress also identified a second category of eligible children as those with a physical or mental condition with the high probability of resulting in delay. This category of eligibility includes not only accepted physical and mental conditions, such as Down syndrome, hearing and vision impairments, or cerebral palsy, but also severe attachment disorders and fetal alcohol syndrome. These are children who may show no signs of delay at birth or even for a period thereafter but who have a medical condition that has a high likelihood in the future of blossoming into a delay. The child with Down syndrome best illustrates this category, since on the child's first days of life, he or she may show no signs of delay but it is highly probable that this child will have mental retardation (intellectual disability). Beginning EI services immediately for such children is critical if they are to reach their fullest potential. These "high probability" children can be found eligible by identification of their condition by a physician. In many states the high probability category is broad and is used routinely in neo-natal intensive care units (NICU's) to refer very low-birth weight, premature babies and infants with obvious medical conditions.

Under the EI law, states are also permitted to include infants and toddlers who are at risk for substantial developmental delays. States that choose to invoke the at-risk category use well-known biological and environmental factors, such as low birth weight or a history of abuse and neglect. Only six states provide EI services to at-risk infants and toddlers.

EI Provides a Wide Array of Services

Third, EI entitles eligible children and their families to a rich array of services including: speech, occupational, and physical therapies; psychological services; special instruction; social services, assessment and counseling; assistive technology devices, such as hearing aids; nursing and nutrition services; and transportation services.

Service coordination or case management is a mandatory service under EI providing a designated person whose sole job it is to shepherd parents (including biological, foster and kinship parents) through the EI process. The service coordinators' many tasks include explaining the program, securing needed consents, helping to obtain the necessary multidisciplinary evaluation, arranging and participating in the IFSP meeting, ensuring that all services enumerated on the IFSP are provided, tackling any changes from newly arising developmental needs, and aiding the family through transition when the child turns age 3.

Since EI is a two-generation program, in addition to the assistance of the EI service coordinator, parents may receive a host of services to enhance their child's development, including parent training, counseling, support groups, home visits, and, in some states, respite care. The latter is critical for many parents since it provides a few hours a week or a month of relief from the stress of caring for a severely disabled child.

All services for children and parents must be delineated on the Individualized Family Service Plan

(IFSP) developed collaboratively by the evaluator, EI official, and the parent. Involvement of these parties provides all views of the child's development including how the child fared on the evaluation as well as the child's development at home. Parents, while only one player, are the key player in IFSP development. They must consent to services at the outset and can appeal through due process procedures any decision of the EI program including the provision of services. The IFSP must enumerate all the services needed for both the child and the parent including their duration, frequency and intensity. Only when the IFSP is completed is placement to be determined. Unlike special education, infants and toddlers are to receive services in "natural environments" -- environments such as at home or in day care -- where infants and toddlers are typically found. The majority of infants and toddlers receive EI services at home.

EI is Administered By a State Lead Agency

Finally, in contrast to special education, the EI program is not administrated by local school districts, but by state lead agencies. The lead agency is required to administer the program statewide and to implement a Child Find system to identify, locate, and refer eligible children. In many states, the lead agency is the education department, but the majority of states have named their health, developmental disabilities, family and social services departments as their lead agency. For many parents this is an enormous advantage since in the early years of their child's life they are shielded from interacting with complex school bureaucracies and can instead work with executive agencies more focused on assisting families.

SPECIAL EI ISSUES

Securing EI for Maltreated Infants and Toddlers

Research shows that children who experience abuse or neglect are at high risk for a variety of physical, developmental, and emotional problems, including attachment disorders, social-emotional disturbances, cognitive delays, neurobiological changes in the brain, and failure to thrive. This risk is greatest for the very young. Despite their documented need and eligibility for EI services, many children who have been maltreated do not receive them. Nationwide, states report underidentification and underenrollment of children involved with the child welfare system due to failures to refer and complications of securing consent. Congress' reauthorization of CAPTA (PL 108-36) and IDEA have addressed this problem by requiring states to develop procedures for referral of young children who have been abused or neglected. The IDEA amendments help to remove the consent barrier by allowing states to permit foster parents to consent to EI services and authorize courts to make orders for appointment of surrogate parents with the power to consent and fully participate in the EI process.

Access to EI for Infants and Toddlers with Autistic Spectrum Disorders (ASD)

At the time of the passage of the Part C or the EI law in 1986, autism was considered a low-incidence disability. Indeed, the word autism does not appear in the original 1975 EHA or the 1986 amendments. It

was only added in the 1990 IDEA amendments and the follow-up regulations. Within a few years of that passage, autism grew geometrically into the second largest disability category. The Centers for Disease Control now estimate that 1 in 150 children have a disability on the autistic spectrum, known as ASD. These children constitute a major component of infants and toddlers seeking and receiving EI services.

Children with a diagnosis of autism or ASD can be eligible for EI. First, many will fit the category of children with a physical or mental disorder with a high probability of resulting in developmental delay. They also can meet the functional definitions due to delays in communication and social-emotional development. Courts have been clear that children must meet the definition in the IDEA—a definition that is different from the one contained in the *Diagnostic and Statistical Manual of Mental Disorders (DSM IV)*. The IDEA states that:

- Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
- Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance.

Thus, the physician or other evaluator must be able to diagnose a child as having ASD and meeting the IDEA definition.

Some states, including New York, have developed EI guidelines for infants and toddlers with ASD (*New York Clinical Practice Guideline*, 1999). If there is a heightened concern about possible autism, the *Guideline*, for example, recommends using a screening tool called the *Checklist for Autism in Toddlers (CHAT)*. Once a child has been identified as having an ASD, the critical question is what services should be enumerated on the IFSP and provided to the child. The *Guideline* again provides helpful guidance by emphasizing that EI programs must clearly identify and target behaviors to be remedied. The programs should focus on developing communication and language, as well as social and play skills. The frequency of programming should be at least 20 hours per week. The *Guideline* recommends that specific techniques associated with Applied Behavioral Analysis (ABA) be incorporated into the EI services. The *Guideline* cautions against using non-evidence based therapies such as music therapy, facilitated communication, touch therapy, hormone and diet therapies.

ASD has bred a firestorm of litigation as parents seek more and more services. Yet, courts have been very cautious in covering only children who meet the IDEA definition and providing services with an evidence base enumerated in the IFSP. This is an evolving field requiring the EI program to be flexible

and driven by the needs of the individual children, not by a particular philosophy or theory of intervention. These EI services for ASD children must be provided in natural settings, usually at home, and in conjunction with family supports and services.

CONCLUSION

For infants and toddlers from birth to their third birthday, EI represents the greatest hope to reverse the odds and place them on a path to healthy development. By making early referrals to this vital program, mild problems can be corrected, moderate disabilities ameliorated and long-term outcomes for the most severe disabilities can be improved. All professionals -- physicians, psychologists, social workers, nurses, occupational, physical and speech therapists, teachers -- who interact with young children must be aware of the benefits of EI. Congress has designated these professionals as primary referral sources, required to refer any child from birth to age 3 to EI if a developmental delay or disability is suspected. By seizing the opportunity to make such referrals, these professionals enable America's infants and toddlers to benefit from the nation's richest entitlement program for children and improve their chances of growing up to their full potential.

References

- Centers for Disease Control and Prevention website, <http://www.cdc.gov/ncbddd/autism> (retrieved 8/09).
- Dicker, S. (2009). *Reversing the odds: Improving outcomes for babies in the child welfare system*. Baltimore: Paul H. Brookes Publishing Co.
- Dicker, S., Gordon, E., & Knitzer, J. (2001). *Improving the odds for the healthy development of young children in foster care*. New York: National Center for Children in Poverty.
- Education for All Handicapped Children Act of 1975 (PL94-142).
- Education for All Handicapped Children Act Amendments of 1986 (PL99-457).
- Individuals in Education Improvement Act of 2004 (PL108-446).
- NECTAC (2007). *NECTAC list of part C lead agencies*. The National Early Childhood Technical Assistance Center.
- Rothman, S. & Rothman, D. (2005). *Willowbrook Wars* (Rev.Ed). Edison, NJ: Transaction Publishers.
- Robinson, C. & Rosenberg, S. (2004). Child welfare referrals to Part C. *Journal of Early Intervention*, *26* (4). 284-291.
- Silver, J., Amster, B.J., & Haecker, T. (Eds.). (1999). *Young children and foster care: A guide for professionals*. Baltimore: Paul H. Brookes Publishing Co.
- Shonkoff, J & Meisels, S.J. (Eds.). (2000). *Handbook of early childhood intervention* (2nd Ed). New York: Cambridge University Press.