



## **The Promise of Early Intervention for Foster Children and their Families**

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## **The Promise of Early Intervention for Foster Children and their Families**

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The foster care population has changed drastically over the past decade. More and more young children are entering foster care and these children are far more likely to have fragile health and disabilities than other poor children. The federal entitlement to Early Intervention services can address or ameliorate those problems but it is rarely being invoked for young foster children. Insuring that young foster children and their families receive needed Early Intervention services is critical not only for their healthy development but to promote reunification with biological families or recruit and retain adoptive families. New federal regulations further clarify the rights of foster children to these important services. This article will review the research about the grim health profile of foster children, provide an overview of the federal Early Intervention Program for Infants and Toddlers with Disabilities known as Part C (formerly Part H) of the Individuals with Disabilities and Education Act (IDEA) and discuss strategies to insure that foster children and their families receive Early Intervention services.

### The Profile of Young Foster Children

In 1994, the General Accounting Office (GAO) found that while the foster care population during the late 80's and early 90's had increased 50 percent, the population of children under age two entering foster care had increased over 110 percent. Almost 40 percent of the children entering foster care in New York State and in many states throughout the country are under the age of five and one-third are under age two.

The foster care population is not only very young, the children are at grave risk of poor health and disability. Study after study paints a grim health profile of young foster children. All too often, at birth these children are predisposed to poor health and disability. Studies have found that more than three-quarters of the young children entering foster care have a history of maternal substance abuse. In an Oakland study, forty percent of the children were low birth weight and/or premature. The studies further reveal that in the first year of life these children are already displaying delays: 15-20 percent of the children have growth retardation, and one-quarter of the children have significant delays in motor development, and almost one-half have delays in communication or cognitive development. By the age of three, 60 percent of the children have substantial delays. Every study shows that 50-60 percent of foster children have significant developmental delays. Studies reveal that these developmental delays may be compounded by serious medical conditions--80 percent of all foster children have at least one chronic medical condition.

### The Early Intervention Law

These grim statistics cry out for response. Fortunately, in 1986, Congress passed amendments to the Education for the Handicapped Act (EHA, now known as the Individuals with Disabilities and Education Act or IDEA, 20 U.S.C. 1431-1445 (1997);

34 C.F.R Part 303 (1999) creating an Early Intervention entitlement for infants and toddlers with disabling conditions from birth through age two. The new program for children from birth to their third birthday is premised on a large body of child development research that proved definitively that Early Intervention starting at birth can address or ameliorate development delays. The research also identified two fundamental components of successful efforts to combat long-term problems for such children. First, a range of services should be provided, including health care, education, child care and various therapies. Second, and perhaps even more important, the needs of very young children are best understood and addressed in the context of the family. Home visits, parent support groups, parent training and education are needed to enable parents to enhance their child's development.

The Early Intervention program, previously known as Part H and now known as Part C, creates an entitlement based on the research for both children and their families to Early Intervention services. Eligible children are entitled to a rich array of Early Intervention services including traditional therapies such as occupational, speech and physical therapies, as well as special instruction, social work, transportation, and assistive technology devices such as wheelchairs and hearing aides. Service coordination or case management is a mandatory and critical component of the Early Intervention entitlement. Most importantly, the law is based on the premise that parents need services to enhance their child's development and provides a rich array of services for parents including parent training, parent counseling, parent support groups, home visits, and respite care. The services for the child and the parent are enumerated in the blueprint for services- - the Individualized Family Services Plan (IFSP)- - that is developed collaboratively by the parent, evaluator and Early Intervention official.

## Operation of the Law

### Eligibility

Studies have demonstrated that over half of young foster children are eligible for these critical Early Intervention services. Three categories of children from birth until their third birthday may be eligible for this entitlement: (1.) Children who are experiencing developmental delays; (2.) Children with a diagnosed physical and mental condition that have "high probability of resulting in delays"; and (3.) Children, at a State's discretion, "who are at risk of having substantial developmental delays if Early Intervention services are not provided." States are required to serve children from birth through two who are experiencing developmental delays in one of the following areas: "cognitive development, physical development, communication development, social or emotional development or adaptive development skills." The second mandatory category includes children whose diagnosis carries a high probability of developmental delay. New regulations recently enacted by the U.S. Department of Education further clarify that this group can include not only accepted physical and mental diagnoses (such as Down Syndrome and Cerebral Palsy), but severe attachment disorders and fetal alcohol syndrome. The discretionary category of "at risk children" has been used by very few states but can include children at biological risk (e.g. low-birth weight) or children at environmental risk (e.g. children of teen parents). A note in the new federal regulations

specifically cites history of abuse and neglect as an example of a permissible “at risk” category.

### Child Find

Lead state agencies administer the Early Intervention program and are required to have a statewide child find system to identify, locate and refer eligible children. While the federal law requires coordination with every conceivable federally funded program, such as Medicaid, Head Start, SSI, and the Maternal Child Health program, it is silent on the child welfare program. Few states have made any concentrated effort to identify and locate foster children who may be eligible for Early Intervention.

### Referral

The first step in the Early Intervention program is referral. While a referral can be made by anyone, primary referral sources including physicians and social services agencies are required to make a referral of an infant or toddler suspected of having a delay within two working days after identification. Most referrals are made by parents or physicians. Foster children are less likely to be identified because of the lack of consistent medical care and parenting.

### Evaluation

Once the Early Intervention agency receives a referral, it must appoint a service coordinator to assist the family in obtaining a comprehensive, multidisciplinary evaluation of the child’s level of functioning in the following developmental areas: cognitive, physical, communication, social or emotional and adaptive. If the evaluation finds that the child is eligible for Early Intervention, a meeting to develop the IFSP must be convened within 45 days of referral. Parental consent must be obtained before conducting the evaluation and initiating the provision of Early Intervention services.

### IFSP

The IFSP meeting must be held at a setting and time convenient to the family. The IFSP meeting must include the parent(s), service coordinator, and evaluator and may include other family members, advocates or service providers. The IFSP is developed collaboratively by the family and professionals. The needs of the whole child is determined by joining the picture of the child at home and at the evaluation. As the IFSP is the blueprint for services under the Early Intervention program, it should be as specific as possible. The IFSP must include the child’s current developmental level based on accepted, objective criteria, the family strengths and needs, the expected outcomes for the child and most importantly, the services necessary to meet the needs of the child and the family. The services should be specified and enumerated by their frequency and intensity (for example, two thirty minute sessions of speech therapy each week). The location of services must be listed and services must be provided in natural settings, at home or in

community settings, such as day care centers, where infants and toddlers are typically found.

The IFSP should specify services for both the child and the family. It is imperative that families of foster children or children at risk of foster care secure all the services to which they are entitled. The IFSP also must identify the ongoing service coordinator who will play the critical case manager role. These services can strengthen the family, enabling it to better address the child's needs, thereby preventing placement or promoting reunification. Home visits are particularly critical for children who have been abused and neglected providing an important window into their development as well as an opportunity to work with their caregiver (whether foster or biological parent) to enhance the child's development. Respite care is a vital service for parents caring for a child with special needs. It is critical that parents have the opportunity to get relief from the stresses of caring for a child with a medical condition or disability. The law permits services for caregivers so a foster parent can also be eligible for services if delineated on the IFSP. Even caregivers who are not foster parents can be eligible for services. For example, New York law permits the training of day care workers as a support service under the Early Intervention program.

### The Special Hurdles for Foster Children

#### “Parent”

While the rich array of services permitted under Early Intervention could be most beneficial to foster children and their families, these services are difficult to secure. At every juncture in this process- -evaluation, interim IFSP, IFSP, and commencement of services- - the parent is required to give his or her consent. This system, based on active parent involvement, does not fit the reality of life for children in foster care. These children often are not living with a parent, or have no one in their lives who can observe their development over time, participate in the IFSP process or consent to services. To ensure that children have someone who can act on their behalf, the Early Intervention law has a very broad definition of “parent.” In addition to the legal parent (biological or adoptive parent) the definition of “parent” includes a relative such as a grandparent or an aunt with whom the child is living, a legal guardian and, in some instances, a foster parent. For the growing percentage of children in foster care living in kinship situations, their kinship relative would qualify as a “parent” under the Early Intervention law.

The foster parent provisions were added recently by the new regulations and reflect developing case law and U.S. Department of Education decisions. The new regulations allow, unless prohibited by state law, a foster parent to be a “parent” under the Early Intervention law if the foster parent has a “ongoing, long-term parental relationship with the child” and “is willing to make decisions required of parents” and has no conflict of interest. This provision, however, will only apply “if the natural parent’s authority to make the decisions required of parents under the Act has been extinguished under State law”. The term “extinguish” has never appeared in case law or agency decisions, and may be defined differently from state to state. It can be construed to include the increasing number of children whose parental rights have been terminated under the new federal Adoptions and Safe Families Act.

The law specifically excludes the State from acting as the “parent” if the child is a ward of the state.\* State laws vary in their definition of “ward of the state”. In some it is defined as any foster child and in others, only children whose parental rights have been terminated. It is prudent to exclude all state employees from this function to prevent any conflict of interest.

Although the law has a broad definition of “parent” nothing precludes the active involvement of the biological parent. Biological parents, until their rights are terminated or surrendered, will continue to have rights under the Early Intervention law. Since the vast majority of children will be returned home, participation of the biological parent in the Early Intervention program and securing services for that parent to enhance the child’s development is essential for permanency. Good practice requires a system for gathering the necessary consents from parents of all foster children under the age three. Since the data indicates that far more than half of the children under age three in foster care will be eligible for Early Intervention services, parental consent for an Early Intervention referral and evaluation should be secured at the earliest possible juncture. Early court proceedings, where all parties are present, may be a good place to secure parental consent.

### Surrogate Parent

There are instances where the parent is not able or available to consent or participate in the Early Intervention process. This includes parents whose whereabouts are unknown and parents who are unable to fully participate because they are placed in an institution or when circumstances in their lives preclude full participation. In those instances, the law provides for the appointment of a surrogate parent. The case law indicates that if the child has a “parent” as defined by the broad definition in the regulations no appointment of a surrogate parent is necessary. Several state regulations including Pennsylvania and New York specifically permit a biological parent to designate a surrogate parent. This allows the parent to remain involved but ensures that the child obtains needed services.

The lead agency determines if the child needs a surrogate parent and assigns a surrogate parent for the child. A surrogate parent must be someone who “has no interest that conflicts with the interest of the child” and “has knowledge and skills that ensure adequate representation of the child.” The person cannot be an employee of any State agency or of any agency providing Early Intervention services. Therefore, an employee of an agency providing foster care or family preservation services would be eligible to be designated as a surrogate parent. It is far better, however, to find an individual who has no potential conflict of interest and most importantly, has a personal relationship to the child such as other family members or a family friend. In some jurisdictions, parents of other children with disabilities who have knowledge and experience in the Early Intervention program have served as surrogate parents.

The best candidate for surrogate parent for many children is the foster parent. While only a small percentage of foster parents may meet the stringent “parent” definition, the foster parent is often the best person to serve as a surrogate parent. The foster parent lives with the child every day, can observe the child, and can report on the

child's strengths and needs. Thus, the foster parent is in the best position to fill the shoes of the parent and bring the missing pieces of the evaluatory picture to the IFSP table.

### Conclusion

Early Intervention services can make the difference between a child who develops to his or her fullest potential and a child who is relegated to a lifetime of poor outcomes. Early Intervention services to families can make it possible for families to stay together or be reunited or enhance the chances for recruitment and retention of adoptive parents. The Early Intervention program is the strongest entitlement to services that exists for foster children and their families. It is critical that everyone in the child welfare system ensure that children and their families receive these vital services.

### Resources:

Individuals with Disabilities Education Act, 20 U.S.C. § 1401 *et seq.* (1997).

Early Intervention Programs for Infants and Toddlers with Disabilities, 20 U.S.C. § 1431-1445 (1197); 34 C.F.R. Part 303 (1999).

S. Blatt et al., *Foster care: special children, special needs*, 14 CONTEMPORARY PEDIATRICS 109 (1997).

N. Halfon et al., *Health status of children in foster care*, 149 ARCHIVES OF PEDIATRIC AND ADOLESCENT MEDICINE 386 (1995).

L. Klee et al., *Foster care's youngest: A preliminary report*, 67 AMERICAN JOURNAL OF ORTHOPSYCHIATRY 290 (1997).

National Center on Child Abuse and Neglect (NCCAN) *CHILD MALTREATMENT 1992: REPORTS FROM THE STATES TO THE NATIONAL CENTER ON CHILD ABUSE AND NEGLECT* (U.S. Government Printing Office 1994).

YOUNG CHILDREN IN FOSTER CARE: A GUIDE FOR PROFESSIONALS (J. Silver et.al eds., Paul H. Brookes 1999).

U.S. General Accounting Office, *Foster care: Health needs of many young children are unknown and unmet* GAO/HEHS-95-114 (1995).

\* This exclusion was present in the former Early Intervention regulations and the proposed regulations but was omitted from the new final regulations. It is the author's impression, after conversations with an official of the U.S. Department of Education, that the omission was a clerical error. The author has written a letter to the Department seeking guidance on this matter.