Early Intervention and Early Childhood Programs:
Essential Tools for Child Welfare Advocacy

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The Permanent Judicial Commission on Justice for Children

Published in Clearinghouse Review
Journal of Poverty and Law Policy
March-April 2001
Early Intervention and Early Childhood Programs: Essential Tools for Child Welfare Advocacy

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The face of foster care in America has changed drastically over the past decade. Children who are very young and have fragile health and disabilities now comprise the foster care population disproportionately. In 1997 Congress passed the Adoption and Safe Families Act of 1997, which further changed the foster care system by requiring tightened time frames for the court and child welfare systems to achieve safety, permanency, and well-being for children in foster care. This new reality of foster care requires that all attorneys and advocates master the early intervention entitlement and other early childhood programs to ensure that young children in foster care grow up healthy in permanent homes.

To assist attorneys and other advocates in this effort, we describe in this article the Early Intervention Program and Head Start. In part I we describe the fragile health and disabilities of children in foster care and how early intervention and early childhood programs can address their needs. In part II we give an overview of the early intervention law and highlight the special challenges in accessing the program for children in foster care. In part III we describe the benefits of early childhood education programs for young children in foster care and their families. In Part IV we offer practice strategies and models for attorneys and advocates to ensure that young children in foster care and their families receive services to enhance their development and prospects for permanency.

I. The Case for Health and Developmental Services for Children in Foster Care

Children in foster care are often very young and frequently have disproportionate risks to their health and development. Early intervention and early childhood programs address these children's needs, ameliorate developmental delays, and strengthen families.

A. Very Young and At-Risk Children in Foster Care

Children under 5 comprise the largest segment of the foster care population—40 percent of all children entering care are under 5, 25 percent are under 2, and 20 percent are under 1. These children have very different experiences and needs from those of other young children living in poverty. They are twice as likely as older children to enter foster care and are more likely to have mothers with substance-


2 Fred Wulczyn et al., The Placement of Infants in Foster Care (2000) (on file with the authors and available at the Chapin Hall Center for Children, University of Chicago).
abuse histories. Children under 3 represent over one-third of all substantiated neglect reports and more than half of all substantiated medical neglect reports. Children under 1 remain the longest in foster care. Perhaps, most disturbing, one-third of the very youngest children, those under 1 year of age, reenter the child welfare system after discharge from foster care. The incidence of reentry is highest for those infants whom the social services agency or the court return home to their biological parent.

These young children enter the child welfare system with disproportionate risks to their health and development compared to other young children in low-income families:

- Nearly 80 percent face prenatal exposure to maternal substance abuse.
- Forty percent are born low birth weight or premature.
- Eighty percent have at least one chronic health condition, and 25 percent have three or more chronic problems—three to seven times the rate found among other children living in poverty.

- One-third to one-half have dental decay.
- Over half have developmental delays including motor development problems, hearing and vision problems, growth retardation and speech and language delays—four to five times the rate found among all other children.
- Ten to 25 percent have growth retardation, defined as height below the fifth percentile—twice the expected rate found among the general pediatric population.

The trauma of removal from their homes, as well as experiences of multiple caregivers and inconsistent and unresponsive parenting, heightens these children’s risk of emotional and behavioral problems such as attachment disorders, anxiety, and depression. Indeed, research confirms that over half of young children in foster care have mental health needs that warrant immediate clinical intervention.

Despite their obvious need, these children often do not receive even basic medical care and assessments for developmental delays and other health-related conditions. A 1995 study by the U.S.


6 Wulcyn et al., supra note 2.


6 Halfon et al., supra note 5.


9 See Young Children in Foster Care, supra note 5; see also Trudy Festinger & R. Duckman, Seeing and Hearing: Vision and Audiology Status of Foster Children in New York City (2000) (on file with authors); J. Takayama et al., Relationship Between Reason for Placement and Medical Findings Among Children in Foster Care, 101 Pediatrics 201 (1998); N.J. Hochstadt et al., The Medical and Psychosocial Needs of Children Entering Foster Care, 11 Child Abuse & Neglect 53 (1987).

10 D. Wyatt et al., Widespread Growth Retardation and Variable Growth Recovery in Foster Children in the First Year After Initial Placement, 151 Archives of Pediatrics & Adolescent Med. 813 (1997); see also Young Children in Foster Care, supra note 5.

11 J.A. Morrison et al., Emotional Development and Disorders in Young Children in the Child Welfare System, in Young Children in Foster Care, supra note 5; Alvin Rosenfeld, Foster Care: An Update, 36 J. Am. Acad. Child & Adolescent Psychol. 448 (1997).
General Accounting Office of children under 3 in three urban areas serving half of all young children in foster care found that:

- 12 percent received no routine health care;
- 34 percent received no immunizations;
- 32 percent continued to have at least one unmet need after placement;
- 78 percent were at high risk for HIV (human immunodeficiency virus), but only 9 percent had received tests; and
- less than 10 percent received services for developmental delays.12

Studies nationwide reveal that caseworkers and caregivers identify very few children in foster care as having developmental delays. One study in California found that caseworkers or foster parents identified only one-third of the children as having delays. Subsequent assessments found that 84 percent had significant developmental problems requiring referral for services.13

B. Connection to Permanency

New understanding of early brain development confirms decades of research that highlights the importance of intervening in the first months and years of a child's life. Brain research also has yielded new insights into the power of the parent-child relationship to facilitate children's healthy development.14 Clearly now early intervention and early childhood education services can reduce the risk of health problems and address or ameliorate the developmental delays found among young children in foster care. These same services can help families manage the stress of parenting and make a real difference in their ability to help their children develop to their potential.

For children in foster care, health, early intervention, and early childhood education services can promote reunification with biological families or enhance the recruitment and retention of foster and adoptive families. Yet, if health and developmental needs are severe enough, or if left unaddressed, they can lead to disruptions in placement and undermine permanency efforts. The recent case of the Kelso family exemplifies this problem.15

In December 1999 the Kelso's drove their 10-year-old son, who had severe cerebral palsy, to a Delaware children's hospital and left him there with food, clothing, toys, instructions for his care, and a note stating that they could no longer care for their child. The authorities arrested the Kelso's, charged them with abandonment, and placed their son in foster care, even though the Kelso's were wealthy and well connected. The mother was an advisor to Pennsylvania's Developmental Disabilities Council, and the father the chief executive officer of a multimillion-dollar company. The family was able to afford and receive round-the-clock in-home services for their son.

The stress associated with caring for a child with a disability strained even this well-resourced family and resulted in a child's placement in foster care. Unlike the Kelso's, the families of most children placed in foster care have limited resources and supports and often struggle daily with poverty, substance abuse, or mental illness.

II. The Early Intervention Program

In most states, children in foster care are eligible for Medicaid.16 All children who are under 21 and enrolled in Medicaid

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13 Halton et al., supra note 5.
15 Andrew Jacobs, Pennsylvania Couple Accused of Abandoning Disabled Son, N.Y. TIMES, Dec. 29, 1999, at A22; see also Dateline: Lost Boy: Kelso Family Abandons Disabled Son Claiming They Can No Longer Care for Him (NBC television broadcast, Jan. 7, 2000).
may receive periodic comprehensive health assessments, screens, and follow-up diagnosis and treatment under Medicaid’s Early and Periodic Screening, Diagnosis and Treatment (EPSDT) requirements. In addition to EPSDT, the Early Intervention Program is the strongest entitlement to services for many young children in foster care.

A. Overview of Early Intervention Law

The early intervention law provides an entitlement for children who are under 3 and are experiencing developmental delays or who have a physical or mental condition with a high probability of resulting in delay—eligibility requirements that perhaps more than half of all young children in foster care can meet. The Early Intervention Program is an entitlement for both child and parent; it enables children to receive specialized assessments and services and allows their caregivers to receive services that can improve their ability to enhance their child’s development. The child’s legal parents (biological and adoptive) and foster parents may receive services under the Early Intervention Program to enhance a child’s development if the individualized family service plan—the blueprint for services under the Early Intervention Program—enumerates those services. In some jurisdictions, other caregivers such as day care providers also may receive parent support services.

In 1986 Congress passed the Part H amendment to the Education for All Handicapped Children Act of 1975, now known as the Individuals with Disabilities Education Act. Part H provided financial assistance to states to maintain and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention for infants and toddlers with disabilities and their families. By the early 1990s all states had chosen to participate in the Part H program. In some states, litigation on behalf of infants and toddlers eligible to receive early intervention services sought to ensure full compliance with the statewide system of early intervention that the law required.

In 1997 Congress reauthorized the Individuals with Disabilities Education Act and revised the Part H program with a few significant changes to enhance the capacity of families to meet the special needs of their children and strengthen the capacity of the state and local agencies to identify, evaluate, and serve historically

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17 See 42 U.S.C. §§ 1396a(a)(10), (43), 1396d(a)(4)(B), (c); see also Early and Periodic Screening, Diagnosis, and Treatment of Individuals Under Age 21, 42 C.F.R. §§ 441.50–62 (2000).
18 See, e.g., AMERICAN BAR ASSOCIATION, YOUNG CHILDREN IN FOSTER CARE, supra note 5.
19 See 20 U.S.C. § 1431 (2000); 34 C.F.R. pt. 305 (2000). Research nationwide confirms that over half of children in foster care have developmental delay or disabilities that would entitle them to Early Intervention Program services.
21 See, e.g., Barbara J. Smith & Patti McKenna, Early Intervention Public Policy Past, Present, and Future, in MEETING EARLY INTERVENTION CHALLENGES 259 (Lawrence J. Johnson et al. eds., 1994).
underrepresented populations. In 1999 the U.S. Department of Education issued new regulations for Part H, renamed Part C, which included several revisions particularly significant for children in foster care, their parents, and their caregivers. The revisions

- clarified eligibility requirements to help states ensure that the Early Intervention Program identify and serve all children, including those at risk of developmental delay;
- revised the definition of parent to include a natural or adoptive parent and a person acting in the place of a parent, such as a stepparent or grandparent, and, in some cases, a foster parent; and
- strengthened the role of parents and their due process rights.

While the Early Intervention Program is an amendment to the Individuals with Disabilities Education Act, it differs from special education in several ways. First, it creates an entitlement to early intervention based on research that demonstrates the importance of providing services to both young children and their families. It entitles eligible children to a rich array of services including occupational, physical, speech, and language therapies; psychological testing; assessment and counseling; social work; special instruction; assistive technology devices, such as wheelchairs and hearing aids; audiology, nursing, and some health services that enable a child to benefit from early intervention services; nutrition services; and transportation services.

Service coordination or case management is a mandatory and critical component of the early intervention entitlement. Parents may receive services—including parent training, counseling, support groups, home visits, and special instruction—to enhance their child’s development. The regulations permit states to provide additional services such as respite care and other family support services.

The individualized family service plan that the parent, evaluator, and the early intervention official develop collaboratively enumerates the services for the child and the parent.

Second, the Early Intervention Program differs from special education in that it does not limit its definition of eligible child to a child having a specific, diagnosed categorical disability but instead a developmental delay or a condition with a high probability of resulting

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24 Early Intervention Program for Infants and Toddlers with Disabilities, 34 C.F.R. pt. 303 (2000). In 2000 the U.S. Department of Education issued proposed regulations which included the following amendments to 34 C.F.R. pt. 303: “Section 303.19 (Parent) would be amended by making a technical and conforming change to the definition of ‘parent’ (i.e., by adding, after ‘A guardian’ in paragraph (a)(2), the phrase ‘but not the State if the child is a ward of the State’). This phrase, which would conform the definition of ‘parent’ to the Part B definition, was inadvertently omitted in the March 12, 1999, final regulations for Part C of IDEA (see 64 FR 12535). . . . Section 303.321 (Comprehensive child find system) would be amended by revising paragraph (b), first, to rename the paragraph ‘Policies and procedures’ and, second, to clarify in paragraph (b)(1), that the requirement to ensure that all infants and toddlers who are eligible for services under this part are identified, located, and evaluated includes (i) traditionally underserved groups, including minority, low-income, inner-city, and rural families; and (ii) highly mobile groups (such as migrant and homeless families).” Early Intervention Program for Infants and Toddlers with Disabilities, 65 Fed. Reg. 53807 (2000), available at www.ed.gov/legislation/FedRegister/prop2000-1/090500a.html (proposed Sept. 5, 2000).
25 34 C.F.R. § 303.12(d) (2000). The Early Intervention Program does not provide services that are surgical or purely medical in nature. See also Head Start, 45 C.F.R. § 303.13(c) (2001).
26 34 C.F.R. § 303.23 (2000).
27 Id. § 303.12(d)(3).
28 Id. § 303.340.
in delay. The states’ lead agencies, not local school districts, administer the Early Intervention Program, unlike special education. The regulations require the lead agency both to administer the program statewide and to implement a “child find” system to identify, locate, and refer eligible children. In almost half the states, the lead agency is the Education Department, but states also have named their Departments of Health, Developmental Disabilities, Children and Families, and Social Services.

B. Eligibility

The early intervention law applies to children with disabilities from birth to age 3 and mandates that states with early intervention programs provide services to two categories of infants and toddlers. First, states must include children who “are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: cognitive development, physical development, communication development, social or emotional development, adaptive development.” Part C regulations require the inclusion of informed clinical opinion in determining eligibility. Second, states must provide services to children who have a “diagnosed physical or mental condition that has a high probability of resulting in developmental delay.” This category of eligibility includes not only accepted physical and mental conditions such as Down’s syndrome and cerebral palsy but also severe attachment disorders and hearing and vision impairments secondary to exposure to toxic substances, such as is the case with fetal alcohol syndrome. The regulations, in addition, permit the states to include infants and toddlers who are “at risk of having substantial developmental delays if early intervention services are not provided.” States that choose to invoke the at-risk category may use well-known biological and environmental factors including low birth weight, nutritional deprivation, and a history of abuse and neglect in determining risk. Only nine states, California, Hawaii, Indiana, Massachusetts, Nevada, New Mexico, New Hampshire, North Carolina, and West Virginia, are providing early intervention services to at-risk infants and toddlers. The regulations require states’ lead agencies to administer the Early Intervention Program statewide and to implement a comprehensive “child find” system to ensure the identification, location, and evaluation of all eligible infants and toddlers. The “child find” system must be consistent with the Individuals with Disabilities Education Act, Part B, which requires states to identify, locate, and evaluate highly mobile children with disabil-

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29 Id. § 303.16. The broad early intervention eligibility definitions reflected congressional findings that early intervention services can address or ameliorate delay and disability and reduce the need for special education. See H.R. REP. NO. 99-860 (1986), S. REP. NO. 99-315 (1986).
33 Id. § 303.16(a)(2).
34 Id. § 303.16(a)(2)(b).
35 See id. § 303.16, n. 2.
36 These states have listed biological factors such as low birth weight, chronic lung disease, and failure to thrive and environmental factors such as parental substance abuse, family and social disorganization, poverty, parental developmental disability, parental age, parental educational attainment, and child abuse and neglect. Several other states, including New York and Pennsylvania, have provisions to screen and track “at-risk” children. See Jo Shackelford, State and Jurisdictional Eligibility Definitions for Infants and Toddlers with Disabilities Under IDEA, in NECTAS Notes, Apr. 2000.
ities. We must note that, while the federal regulations require coordination between the lead agency and virtually every conceivable federally funded program including Maternal and Child Health, EPSTD, Developmental Disabilities, Head Start, and Supplemental Security Income, the regulations are silent on coordination with the state child welfare system. Few states accordingly have made a systemic effort to identify children in foster care through their “child find” system, and, as described above, very few states have specifically identified children in foster care in their eligibility definition.

C. Operation of the Early Intervention Program

After a primary referral source (described below) refers a child for the Early Intervention Program, the lead agency must evaluate the child’s level of functioning and assess the child’s family. Then, before the agency provides services, the family and professionals must develop an individualized family service plan for the child.

1. Referral

Referral is the first step in accessing the Early Intervention Program. While anyone may make a referral, states must establish a method for making referrals by primary referral sources including hospitals, physicians, day care programs, public health facilities, and other social service agencies and health care providers. Primary referral sources must refer an infant or toddler suspected of having a disability or developmental delay to the program no more than two working days after the referral source identifies the child.

2. Evaluation and Assessment

Once the lead agency receives a referral, it must appoint a service coordinator “as soon as possible,” and then, within forty-five days, assist the family in obtaining a comprehensive, multidisciplinary evaluation of the child’s level of functioning in cognitive, physical, social or emotional, and adaptive developmental areas. The law also requires a family assessment “to determine the resources, priorities and concerns of the family and the identification of the supports and services necessary to enhance the family’s capacity to meet the developmental needs of the child.”

Before conducting the evaluation and the family assessment, the lead agency must obtain a written parental consent. If a parent refuses consent, the lead agency must make reasonable efforts to ensure that the parent is “fully aware of the nature of the evaluation and assessment or the services that would be available” and that agencies may not provide services without parental consent. The lead agency may initiate procedures to challenge a parent’s refusal of consent to the initial evaluation of the child. If the lead agency’s challenge is successful, the agency may obtain an evaluation of the child.

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38 Proposed changes in Part C broaden the requirement of “child find” systems to identify, locate, and evaluate underserved, high-risk populations of children, including migrant and homeless children. The changes do not specifically list children in the child welfare system. See supra note 24.
39 34 C.F.R. § 302.21(c) (2000).
40 In response to the notice of proposed rule making amending 34 C.F.R. § 303.321 (comprehensive “child find” system), we have proposed that the categories of children for identification, location, and evaluation include “a child who is in foster care.” Letter from Sheryl Dicker to U.S. Dep’t of Educ. (Dec. 4, 2000) (on file with authors).
42 Id. § 303.21(d)(2)(ii). The federal law, however, does not contain any sanction for non-compliance. Proposed changes in Part C eliminate the two-day time line to “as soon as reasonably possible.” See supra note 24.
44 Id. § 303.322(d).
45 Id. § 303.404.
46 Id. § 303.504(b) (provisions of Part B apply to Part C).
3. The Individualized Family Service Plan

If an evaluation determines that a child is eligible for the Early Intervention Program, a program official must convene, within 45 days of referral, a meeting to develop the individualized family service plan. Held at a setting and time convenient to the family, the meeting must include the parent or parents, the service coordinator who has been working with the child and family since the initial referral, and the evaluator or evaluators. The meeting may include other family members, advocates, and service providers. The family and the professionals collaboratively develop the individualized family service plan, which serves as a blueprint for services under the Early Intervention Program. By joining information about the child obtained by the evaluation with the parents’ knowledge and observations, the individualized family service plan addresses the needs of the whole child. The plan must include the child’s current level of physical, cognitive, communication, social or emotional, and adaptive development based on accepted, objective criteria; family strengths and needs; the expected outcomes for the child and family; and, most important, the specific services necessary to meet the needs of the child and family. The plan should enumerate the services according to frequency and intensity (i.e., speech therapy twice a week for thirty minutes) and location (i.e., home, community, or clinic based). The plan must list the location of services, which must take place in natural settings at home or in community settings such as day care centers, typically where infants and toddlers are. Unlike services under Part B, Part C early intervention services are not necessarily all free.

Most important, the individualized family service plan identifies the service coordinator, who acts as case manager. The service coordinator assists the child and the child’s family in obtaining the evaluation, gaining access to the early intervention services, coordinating all services, including medical services for purposes other than diagnosis and evaluation, across agency lines, facilitating the timely delivery of services, and continuously reviewing the services for the duration of the child’s eligibility.

The Early Intervention Program official, working closely with the child’s case worker, must obtain parental consent before service providers commence services. With the individualized family service plan developed and parental consent obtained, the child and family must receive the services that the plan enumerates. The regulations require a six-month review of the plan and an annual meeting to evaluate and, when appropriate, revise it. The law recognizes that the needs of young children can change and permits reevaluations and more frequent reviews of the plan as conditions warrant. The family and the professionals may develop an interim plan so that agencies may provide services at once if the child has an immediate need for them even before evaluation, as when, for example, a referring physician recommends that a child with a diagnosed disability receive physical therapy.

D. Special Challenges for Children in Foster Care

At every juncture in early intervention—evaluation, development of the individualized family service plan, and provision of services—the regulations require the child’s parent to give consent. Indeed, active parental involvement is the premise of the entire early intervention law, and the 1997 Individuals with Disabilities Education Act Amendments significantly enhanced the role of parents in

47 Id. §§ 303.167(c)(2), 308.18.
48 States can develop sliding fee scales or tap private insurance to fund services. However, in most states, children in foster care receive Medicaid, and states must ensure early intervention services despite parents’ inability to pay. See Letter to Howell, 30 INDIVIDUALS WITH DISABILITIES EDUC. L. REP. 610 (1998).
49 34 C.F.R. § 303.23 (2000).
50 Id. § 303.342, notes.
51 Id. § 303.345.
the early intervention and special education process. The Act uses the word “par-
tent” over 100 times; the word appears at least another 100 times in each state’s
early intervention and special education laws.\textsuperscript{52} Yet this emphasis on parent
involvement does not fit the reality of life for many children in foster care. Few of
these children reside with a biological parent, and many lack an adult who can
observe their development over time, consent to necessary services, or participate
actively in treatment plans. Parents, even those who have placed their children in
foster care, may refuse an evaluation, may accept or decline any early intervention
service, and may revoke their consent at any time.\textsuperscript{53} The lead agency may chal-
gen only a parent’s refusal to consent to the initial evaluation.\textsuperscript{54} The law does
not provide for a procedure for the state agency to challenge a parent’s refusal to
consent to the provision of early intervention services. If the parents refuse or
even withdraw consent, agencies may not provide the services.\textsuperscript{55}

A parent’s right to refuse consent for services under early intervention law dif-
fers dramatically in case law related to parental decision making in the areas of medical care and education. While federal and state law has long rec-
ognized the fundamental liberty interest of parents in the care, custody, and man-
agement of their children, parental deci-
sion-making authority is not unlimited.\textsuperscript{56} Generally a parent or guardian may not
refuse a surgical or medical procedure that appears to be reasonably necessary
to save a child’s life or to avoid serious bodily injury.\textsuperscript{57} Several states also have
enacted child protection statutes and regu-
lations that recognize medical care as a
necessity for children despite a parent’s refusal of consent.\textsuperscript{58} In some states, the
law allows the waiver of parental consent
to medical treatment when refusal of consent might compromise the child’s

\textsuperscript{52} Nancy Hubley, \textit{Children Without Parents: The IDEA’s Surrogate Parent Mandate}, 17
\textsuperscript{54} Id. § 303.404.
\textsuperscript{55} Id. § 303.342(c).
v. Dept of Soc. Servs., 452 U.S. 18 (1981); Wisconsin v. Yoder, 406 U.S. 205 (1972);
Fierce v. Soc’y of Sisters, 268 U.S. 510 (1925); Meyer v. Nebraska, 262 U.S. 390 (1923)
(Clearinghouse No. 25,118).
\textsuperscript{57} See generally Parents United for Better Schs. Inc. v. Sch. Dist. of Phila. Bd. of Educ., 978
F. Supp. 197 (E.D. Pa. 1997), aff’d, 148 F.3d 260 (1998); In re Petra B., 265 Cal. Rptr. 342
(1989); Custody of Minor, 379 N.E.2d 1053 (Mass. 1978) (Clearinghouse No. 26,832); In
re Fardah W., 579 N.Y.S.2d 377 (1st Dept’r 1992); In re Cicero, 421 N.Y.S.2d 965 (1979)
(Clearinghouse No. 28,227); In re Sampson, 317 N.Y.S.2d 641 (1970). But see In re
McCauley, 565 N.E.2d 411 (Mass. 1991); In re Willmann, 493 N.E.2d 1380 (Ohio 1986);
1983).
\textsuperscript{58} See generally 705 ILL. COMP. STAT. 405/2-3 (West 2000); MONT. CODE ANN. § 41-3-102
(2000); N.Y. FAM. CT. ACT § 1012(20)(A) (McKinney 2000). See also Walter Waldrington,
\textit{Medical Decision Making for and by Children: Tensions Between Parent, State, and
health; the law allows states to intervene to protect children in need of medical care. Many state child protection laws allow the local commissioner of social services or health to give consent to medical, dental, and hospital services for children whom a court found to have suffered abuse and neglect or who are in the commissioner's custody. In contrast, parents who have been able to remove their children from their care and custody retain the right under early intervention law to refuse consent to services that address their child's developmental delay or disability.

While the Supreme Court has given parents autonomy in choosing the proper place and manner in which to educate their children, that autonomy also has restrictions. A significant number of states list educational neglect as grounds for child protective intervention. A parent's failure to consent and plan for a child's special education services may be a basis for action under educational neglect law.

To ensure that all children have someone who knows them well and can advocate on their behalf without a conflict of interest, federal early intervention and special education laws define "parent" broadly. The definition of "parent" under early intervention law includes the legal parent (biological or adoptive), the legal guardian, and "a person acting in the place of a parent" such as a grandparent or other relative with whom the child lives. For the growing number of children in foster care living in kinship situations, their kinship relative would qualify as a parent under the early intervention law. Yet early intervention and special education laws specifically exclude state officials from acting as a "parent" in these proceedings.

Thus, while a commissioner may consent to medical treatment for a child in foster care, the commissioner may not consent at the various junctures for early intervention.

The newly enacted federal early intervention regulations specifically add foster parents to the definition of parent, but only if the foster parent meets strict criteria. States may permit a foster parent to act as a "parent" under Part C if they have the natural parents' authority to make the decisions required of parents under the Act; however, they have extinguished under State law; and the foster parent has an ongoing, long-term parental relationship with the child, is willing to make the decisions required of parents under the Act; and has no interest that will conflict with the interests of the child.

Thus the law ensures the participation of foster parents who have established a long-term, stable relationship with the child in instances where courts have extinguished parents' authority to make educational decisions. The term "extinguish" has never appeared in case law or agency decisions, and states may define it differently. The states may construe it to include the increasing number of children whose parental rights the courts have terminated as a result of the Adoption and Safe Families Act. The new foster parent provisions in the early intervention regulations reflect developing case law and U.S. Department of Education decisions that recognize the importance of an effective advocate for a foster child in the early

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59 The Supreme Court has observed that the "state is not without constitutional control over parental discretion in dealing with children when their physical or mental health is jeopardized." Parham v. J.R., 442 U.S. 584, 603 (1979); see also In re Christine M., 595 N.Y.S.2d 606 (Fam. Ct. 1992).
61 Yoder, 406 U.S. at 205.
64 Id. §§ 300.206(a)(2), 303.406(d)(1)(X).
65 Id. § 303.19(b) (2000).
66 45 C.F.R. § 1356.21 (2000). The regulations require the filing of petitions for termination of parental rights for children in care for fifteen out of the most recent twenty-two months. Id. § 1356.21(d)(4)(X).
intervention and special education process. The statutory definition of “parent” under the Individuals with Disabilities Education Act also specifically excludes the state from acting as a parent if the child is a “ward of the state.”

Part C provides for the appointment of a surrogate parent if an eligible child has no “parent” as broadly defined under the law to act on the child’s behalf. Before the surrogate parent’s appointment, states must make “reasonable efforts” to identify a parent. If the child has a “parent,” as defined broadly under the Individuals with Disabilities Education Act regulations, no appointment of a surrogate parent is necessary. Several state regulations, however, specifically permit a parent to designate a surrogate parent. These regulations enable a parent whose life circumstances preclude full participation to remain involved and ensure that the child obtains needed services.

The Early Intervention Program regulations require the lead agency to determine if a child needs a surrogate parent and to assign a surrogate parent for a child where the child has no identifiable parent, the whereabouts of the parent are unknown, or the child is a ward of the state. The surrogate parent must be someone who has no conflicts with the interests of the child and who has knowledge and skills that ensure adequate representation of the child. Once again the regulations bar the state from acting in this role. The surrogate may not be “an employee of any state agency; or a person or employee of a person providing early intervention services to the child.”

The role of the surrogate parent is limited to representing the child in all matters related to the evaluation and assessment of the child for Early Intervention Program services, the development of the child’s individualized family service plan, and the ongoing provision of early intervention services to the child. Nothing in the law precludes the foster parent from serving as the surrogate parent.

III. Early Childhood Education Programs

While half of young children in foster care may be eligible for the Early Intervention Program, the remaining children are also at serious risk of poor outcomes. All of these children can benefit greatly from early childhood programs. High-quality early childhood programs provide more than respite and child care for working caregivers. They can enhance the well-being of children in foster care by linking them to vital health and entitlement programs, creating an additional opportunity for children to establish a stable relationship with a caring adult, and promoting early learning and school readiness skills. They can strengthen families by teaching parents about skills and resources to cope with their child’s individual needs. These programs also can support permanency efforts by providing a neutral, supervised setting for visitation and early intervention services. Yet, all too often, children in foster care have no connection to these programs. While some programs have ested as a matter under state law, 34 C.F.R. § 303.406(a)(3) (2000).


70 Nothing in the law requires incarcerated parents to appoint a surrogate. E.g., these parents can participate in the individualized family service plan by phone or videoconferencing.


72 Id. § 303.406(g).

73 Id. § 303.406(e).
rolled children in foster care, very few have developed targeted initiatives to identify and recruit these children. Child welfare workers, attorneys, and advocates often do not consider referrals to these programs as part of permanency planning and case review.

Head Start is a federally funded, comprehensive, multidisciplinary national program of education, health, mental health, social, nutrition, and family support services. Designed to serve children from birth to age 5 and living in low-income households, Head Start is available in all communities. Early Head Start, established by the Head Start Reauthorization Act of 1994, serves pregnant women and families with children from birth to age 3.\(^{74}\) Since its inception in 1965, Head Start has served over fifteen million children.\(^{75}\) Over 600 Early Head Start programs serve nearly 45,000 children.\(^{76}\) All Head Start regulations apply to children eligible for Early Head Start.\(^{77}\) Administered by local programs, Head Start and Early Head Start target children whose families live below the poverty line.\(^{78}\) Like the Early Intervention Program, Head Start is two generational. Head Start regulations require programs to assess the "child's unique strengths and needs" and the services appropriate to meet those needs, as well as the "resources, priorities and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of the child."\(^{79}\) Head Start programs also must assist families in accessing continuous and accessible medical, dental, and mental health services as EPSDT requires and must identify a child's developmental, sensory, and behavioral needs.\(^{80}\)

The regulations require Head Start programs to serve children with special needs—children with physical disabilities, mental retardation, emotional disturbances, and developmental delays. Head Start must allocate at least 10 percent of the spaces in the program to children with special needs.\(^{81}\) In contrast to early intervention regulations, Head Start regulations require programs to establish ongoing, collaborative partnerships with family preservation and support services and child protective agencies.\(^{82}\)

Active parental involvement is the premise of Head Start as well as the Early Intervention Program. Like that program, Head Start requires parental consent for evaluation and services. Head Start regulations define "parent" broadly as a "head start child's mother or father, other family member who is a primary caregiver, foster parent, guardian or the person with whom the child has been placed for purposes of adoption pending a final adoption decree."\(^{83}\) Programs must work with parents to identify family goals, strengths, and needed services; access community resources; and assist parents in enhancing the development of their children.\(^{84}\) They must inform parents of the need for all health and developmental screenings and services, obtain advance parental consent for all procedures, assist in securing needed services, and maintain written documentation of any refusal of consent.\(^{85}\)

\(^{75}\) See Head Start FAQ, at www.childrensdefense.org/headstart_faq.html.
\(^{76}\) U.S. DEPT OF HEALTH & HUMAN SERVS., HEAD START BULLETIN No. 69, at 1 (Oct. 2000).
\(^{77}\) 45 C.F.R. § 1304.1 (2000).
\(^{78}\) Head Start, 45 C.F.R. § 1305.2(a) (2001). Head Start Programs may serve up to 10 percent of the children above the poverty line. Id.
\(^{79}\) Id. § 1304.36(a)(1).
\(^{80}\) Id. § 1304.20.
\(^{81}\) Id. § 1305.6(c).
\(^{82}\) Id. § 1304.41(a)(2)(x)-(vi).
\(^{83}\) Id. § 1306.30(b).
\(^{84}\) Id. § 1304.40.
\(^{85}\) Id. § 1304.20(b)(1-5). Parents also have the authority to make decisions about the operations of local Head Start programs as mandated members of policy councils and committees. Id. § 1304.50(b)(3).
Some other quality early childhood programs also use the two-generation approach that Early Head Start and Head Start embrace. Throughout the country, the Child Care Resource and Referral Program comprises community coordinating and planning agencies for local child care services. This program can give information about quality early childhood programs and provide technical assistance about early childhood resources to attorneys and other child advocates. Other parent education and family support programs such as Healthy Families America and Parents as Teachers exist in many communities. An initiative known as Starting Early, Starting Smart works with health care and child care providers to develop strategies to address the emotional health needs of very high-risk children and families.86

IV. Practice Implications

The new reality of foster care—more young children with medical conditions and disabilities—coupled with new demands of the Adoption and Safe Families Act, requires major changes in child welfare practice. The Act makes clear that children's health and safety are paramount concerns in child protective proceedings. The Act's new regulations further ensure that service providers must address the well-being of children in foster care—their medical, educational, and mental health needs.87 Addressing these needs can promote children's healthy development and improve their chances of growing up in loving, permanent homes. To meet this goal for an individual child in foster care, effective lawyering and advocacy require looking beyond issues of safety to ensuring the child's access to all necessary services, including early intervention and early education services. Attorneys need to bring information about the child's health and developmental status to the attention of the court. They also need to work with early intervention and other professionals to ensure that the individualized family service plan and early childhood services reflect permanency goals. To enhance

At the earliest possible juncture, advocates should ensure that a child receives a comprehensive examination and a referral for a developmental screen.

outcomes for all children in foster care, advocates should ensure that children in foster care are on the radar screen of all other systems serving vulnerable, young children. They can work with state and local early intervention officials to target children in foster care and develop an automatic referral for all children who are in foster care and under 3 as part of their "child find" activities. They can work with Head Start programs to identify these children and their families for recruitment and to designate priority slots for enrollment.88

A. Advocates for Children

The first line of defense to assure the healthy development of foster children is their representative, who can gather information, make recommendations to the court, and monitor plans and court orders. This representative may be an attorney or a court-appointed special advocate. The representative's obligation to ask questions about a child's healthy development is clear. The American Bar Association Standards of Practice for Lawyers Who Represent Children in Abuse and Neglect Cases directs lawyers to conduct independent investigations of the child's social service, psychiatric, medical, and school records; attend case conferences concerning the child; and access entitlements including medical, mental health, and

86 For information about Starting Early, Starting Smart programs nationwide, see www.casey.org.
88 45 C.F.R. §§ 1305.3, .6 (2000). Head Start regulations require programs to conduct a community assessment every three years to identify children and families with greatest need, and prioritize them for recruitment and selection. Id.
education services. The Standards also directs that attorneys for a child with special needs ensure that the child receives appropriate services to address physical, mental, or developmental disabilities.

Nationwide research indicates that at least half of young children in foster care will need to receive early intervention services. At the earliest possible juncture, advocates should ensure that a child receives a comprehensive examination and a referral for a developmental screen. Advocates can refer every child under 3 with a suspected disability or a high probability of developmental delay to the Early Intervention Program for developmental assessment. They should work to ensure that case planning and court orders reflect information from examinations, screens, and evaluations. Children's representatives must monitor cases to ensure the actual enrollment of the children in early intervention and early childhood education programs. Advocates particularly can aid their child clients in overcoming the various legal hurdles to accessing the Early Intervention Program. They can help child welfare case workers and service coordinators in identifying a "parent," obtaining needed consents by working with parents' counsel, and, where appropriate, identifying a surrogate parent. Advocates also can bring information about the court process and permanency efforts to the development of the individualized family service plan. For example, if the goal is reunification, advocates can recommend that the plan include services for both the foster and the biological parent so that the child receives needed services while in care and so that services are continuous once the service provider returns the child home. By advocating early intervention services and early childhood programs for already adopted children or children who are awaiting adoption, attorneys can further strengthen those families and make adoption retention more likely. Attorneys also can use the Early Intervention Program provision that permits services for caregivers to ensure that foster parents and preadoptive parents receive services that the individualized family service plan specifies.

B. Agency Counsel

Counsel for state and local agencies also have a role in connecting young children in foster care to early intervention and early childhood education services. The requirements of the Adoption and Safe Families Act underscore their obligation, as the U.S. Department of Health and Human Services will monitor the states to ascertain whether they are addressing children's health, educational, and mental health needs. Since addressing those needs is interconnected with permanency, early intervention and early childhood programs can support the state's compliance with Act. Government attorneys can make sure that caseworkers ask questions about a child's health and developmental status and then share this information with the court. Attorneys also can "unstick" legal problems concerning consent to early intervention programs by collaborating with attorneys for parents. Most important, they can ensure that case plans actually reflect the child's need for these services. At the reviews required by Act, attorneys can build in oversight mechanisms that ascertain whether service providers are meeting children's needs. By focusing on children's health and children's timely receiving of appropriate services, attorneys can give the court information essential for permanency decisions.

C. Advocates for Parents

The obligation of a parent's attorney to advocate early intervention and early

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89. AMERICAN BAR ASSOCIATION STANDARDS OF PRACTICE FOR LAWYERS WHO REPRESENT CHILDREN IN ABUSE AND NEGLECT CASES CANON C-2, C-4 (1996).
90. Id. Canon C-5.
childhood services may not appear as clear as the obligations of the other attorneys involved in the case. However, the parent's attorney's obligation to advocate zealously on behalf of the attorney's client is clear. In most cases, the client wants reunification with the child. Recognizing a young child's special needs and ensuring that the child and the parent receive services to address those needs are crucial for reunification. The Early Intervention Program and Head Start can bolster reunification efforts by providing services to children and families to support parents to enhance their ability to care for the child. Attorneys must explain this child-parent connection to clients and encourage them not only to give consent but also to participate fully in the early intervention process. Practice guidelines for attorneys for parents stress the importance of counseling parents to cooperate and accept appropriate services immediately. Encourage attorneys to investigate community resources that can preserve or reunify the family, and recommend that they ensure that the court record casts parents in the most favorable light possible. To meet these standards, attorneys can recommend that early intervention or Head Start services take place in a center-based setting or during court-ordered parent visits to ensure parent participation. These visits can offer support services to enhance parents' capacity to understand and meet their children's needs.

D. Three Models

When one or more parties focus on the child's individual needs, the dynamics of child welfare practice changes. Advocates can reframe the case to bring the parties' attention to the child's well-being, not to the parent's alleged misconduct. This reframing allows new compromise solutions to emerge and improve the chances that children develop to their full potential in permanent homes. The initiatives that we describe below demonstrate how advocates can focus on the healthy development of young children in foster care and ensure that they and their families actually receive services.

1. Permanent Judicial Commission on Justice for Children

Established in 1988, the Permanent Judicial Commission on Justice for Children addresses the problems of New York State children whose lives the court system touches. Chief Judge Judith Kaye chairs the commission, whose membership includes judges, attorneys, legislators, state and local officials, and child advocates. As the nation's only children's commission based in the judiciary, it is spearheading efforts to reform the family court's handling of foster care cases to ensure improved outcomes for foster children under the federally funded Court Improvement Project. As part of its efforts under the Court Improvement Project, the commission launched a multipronged initiative to spotlight the unmet health needs of children in foster care and its connection to permanency.

To assist all those involved in the court process in focusing on the individual needs of children in foster care, the commission has developed the Checklist for the Healthy Development of Foster Children. The checklist and its accompanying booklet, Ensuring the Healthy Development of Foster Children: A Guide for Judges, Advocates and Child Welfare Professionals, asks ten questions to identify a foster child's health needs and gaps in services, reasons for asking each question, and references to expert sources. Each question is consistent with national standards for health care as the American Academy of Pediatrics, the Child Welfare


95 To receive copies of the booklet, contact the Permanent Judicial Commission on Justice for Children, 140 Grand St., Suite 404, White Plains, NY 10601.
The Permanent Judicial Commission on Justice for Children Checklist for the Healthy Development of Foster Children

- Has the child received a comprehensive health assessment since entering foster care?
- Are the child's immunizations up to date and complete for the child's age?
- Has the child received hearing and vision screening?
- Has the child received screening for lead exposure?
- Has the child received regular dental services?
- Has the child received screening for communicable diseases?
- Has the child received a developmental screening by a provider with experience in child development?
- Has the child received mental health screening?
- Is the child enrolled in an early childhood program?
- Has the adolescent child received information about healthy development?

League of America, and the EPSDT provisions of Medicaid recommend.66 Family court judges, lawyers, and court-appointed special advocates are using the checklist throughout New York State and nationwide to focus on children's needs and to ensure that permanency plans reflect their needs.

2. Court-Appointed Special Advocates

Court-appointed special advocates are specially trained community volunteers; a family court judge appoints them to assist in ensuring safe and permanent homes for children in the child welfare system. Once a judge appoints a volunteer to a child's case, the court-appointed special advocate becomes an official part of the judicial proceedings. As an appointed officer of the court, the special advocate works alongside the judge, attorneys, and social workers. Unlike attorneys and social workers, the special advocate speaks exclusively for the child's best interest, not a child's wishes. Many court jurisdictions have adopted the court-appointed special advocate program; 900 such programs are now in place nationwide.97

The commission has trained all the New York State court-appointed special advocate directors to use its healthy development checklist, and the directors have trained their local volunteers. Court-appointed special advocates throughout New York State are using the checklist at the earliest possible point, even in abandonment proceedings, to identify and address the needs of young children in foster care and to shape permanency planning. Two New York counties, Erie and Westchester, have assigned court-appointed special advocates specifically to cases of children in foster care who are under 5. The special advocates are creating a health profile of the children in their caseload, documenting barriers to services, and facilitating referrals to early intervention and early childhood programs. The special advocates' involvement has made more judges aware of children's health and developmental needs and the connection of these needs to permanency planning. In several instances, the special advocates' involvement has encouraged judges to write court orders specifying health and early intervention services for a child. Attorneys for children, parents, and agencies have reported that the special advocates' involvement has often highlighted unaddressed needs and expedited access to services.


97 For more information about court-appointed special advocates, see www.nationalcasa.org.
3. Kathryn McDonald Education Project, Juvenile Rights Division, New York City

In New York City, the Juvenile Rights Division, which represents over 90 percent of the city’s foster children, employs an attorney to address the early intervention and special education needs of its clients in child protective cases. The attorney works closely with attorneys, caseworkers, biological and foster parents, and coordinators from the New York City Early Intervention Program to ensure appropriate referrals to the program and children’s receiving timely evaluations and services. The attorney also conducts training and consults on cases in the Early Intervention Program for the interdisciplinary staff of the Legal Aid Society, New York City child welfare caseworkers, and court-appointed special advocates. This initiative draws on a model of expert consultation—long available in legal services programs—on specialized legal issues such as health, housing, and consumer law.99

Understanding the health and developmental needs of young children in foster care and connecting children and their caregivers to resources that address these needs can assist advocates in their efforts to reunify families and recruit and retain foster and adoptive parents. Indeed, programs such as EPSDT, the Early Intervention Program, and Head Start can be essential tools to meet the fundamental interest of their clients—that they grow up safe and healthy in permanent, stable homes.

Authors’ Acknowledgments:
We gratefully acknowledge the research assistance of Melissa Gamble.

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98 The attorney began as a fellow, funded through the law firm Skadden, Arps, Slate, Meagher & Flom.

99 For more information about the Kathryn McDonald Education Project, Juvenile Rights Division, contact Kathryn Locker, klocker@legal-aid.org.