

Foster Care & Education

Issue Brief

INFANTS AND TODDLERS WITH DISABILITIES IN THE CHILD WELFARE SYSTEM

Introduction

Of the 423,773 children in foster care as of September 30, 2009, 36% were under age 6 and 20% were under age 3.¹ Infants and toddlers remain in care longer and are more likely to return to care than older children. More than half of these children will experience serious medical conditions and significant developmental delays.² There is a growing body of research demonstrating that abuse, neglect, and exposure to trauma affect children's neurological development. Maltreatment changes children's brains, and in particular it affects children's development in their behavioral, social, and emotional domains.³

These infants and toddlers may well be eligible for special help from the federal Individuals with Disabilities Education Act (IDEA) program for infants and toddlers with developmental delays. Child welfare advocates need to know what help might be available for very young children in their care, how to get that help, and how to overcome the special barriers that children in care sometimes encounter. And remember – time is of the essence. The sooner children with developmental and learning difficulties get the help they need, the better their school and life outcomes will be.

¹ AFCARS Report – Preliminary FY 2009 Estimates as of July, 2010,
http://www.acf.hhs.gov/programs/cb/stats_research/afcars/tar/report17.htm.

² Sheryl Dicker, *Reversing the Odds, Improving Child Outcomes for Babies in the Child Welfare System* (2009).

³ *Promoting Social and Emotional Well-Being for Children and Youth Receiving Child Welfare Services*, U.S. Department of Human Services Administration for Children and Families, Log No: ACYF-CB-IM-12-04 (April 17, 2012),
http://www.acf.hhs.gov/programs/cb/laws_policies/policy/im/2012/im1204.pdf.



Q: How is the need for early intervention services for infants and toddlers (birth to age 3) with developmental delays addressed in the IDEA?

A: In 1986, the IDEA was amended to help states provide “early intervention” services to children with disabilities who had not yet reached school-age. The part of the IDEA that applies to children from birth to their 3rd birthday is now called “Part C.” The IDEA was again significantly changed in 2004, including some key amendments to Part C. On October 28, 2011, final regulations implementing the Part C changes went into effect.⁴

All states currently accept federal funding under Part C and thus are required to fulfill its mandates. Each state has a “lead agency” that is charged with ensuring compliance with the law. Like the school-aged and preschool parts of the IDEA (known as Part B), Part C is an “entitlement” program. That means that any child who is eligible for services has a right to receive those services. However, Part C programs can look quite different in different states. This is because the federal law gives states choices about, for example, whether the state will charge for some Part C services;⁵ whether children can remain in the Part C system (with some conditions) beyond age 3; and whether, once a child is referred, the state must conduct a comprehensive evaluation, or (subject to the parent’s right to bypass the screen), it can first screen children to determine whether they should be evaluated to determine whether they are eligible for services.

Q: Are any of the recent amendments to Part C or the new regulations specific to children in care?

A: Yes! Several important changes to Part C emphasize the urgency of reaching eligible, but un-served, infants and toddlers in foster care. Perhaps most important, the IDEA and the regulations now require that all infants and toddlers for whom abuse and neglect has been substantiated or who are identified as directly affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure be referred to the Part C system for screening and/or evaluation.⁶ In addition, Congress added “infants and toddlers in foster care” to the Act’s “purpose clause” as children who are “historically underrepresented” in the early intervention system.⁷

The state’s lead agency must ensure that the state’s “child find” system targets infants and toddlers who are “in foster care” or who are “wards of the State”⁸ and that this system is coordinated with the efforts of the “[c]hild protection and child welfare programs, including programs administered by, and services provided through, the foster care agency and the State agency responsible for administering Child Abuse Prevention and Treatment

⁴ The Part C regulations are at: <http://www.gpo.gov/fdsys/pkg/FR-2011-09-28/pdf/2011-22783.pdf>.

⁵ But child find, evaluation and assessment, service coordination, costs related to developing and reviewing service plans, and use of procedural safeguards must be free and the state must not charge families that are below the state’s standard for “inability to pay.” See, 34 C.F.R. §303.521(a)(4)(ii),(b).

⁶ 34 C.F.R. §303.303(b).

⁷ 34 C.F.R. § 303.1(d).

⁸ 34 C.F.R. § 303.302(b)(1)(ii).

Act (CAPTA).”⁹ “Public agencies and staff in the child welfare system, including child protective service and foster care,” are added as primary referral sources (*i.e.*, they are directed to refer any child who may be in need of Part C services within 7 calendar days of the time the child is identified as potentially eligible for Part C services).¹⁰ Definitions of “parent” and “ward of the State” and the rules for “surrogate parents” were added or clarified and these now closely resemble comparable rules and definitions in Part B.¹¹

Q: Which children qualify for Part C services?

A: A child under age 3 qualifies for Part C services if the child (1) is experiencing a developmental delay, as measured by appropriate diagnostic instruments and procedures or through informed clinical opinion,¹² in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social or emotional, or adaptive (self help); or (2) has a physical or mental condition that has a high probability of resulting in a developmental delay (for example, severe attachment disorders, disorders secondary to exposure to toxic substances including fetal alcohol syndrome, and chromosomal abnormalities such as Down Syndrome).

Each state sets its own standard for the level of delay that constitutes a “developmental delay” in that state (for example, Pennsylvania has set the bar at a 25% delay in any one of the developmental domains). If the child meets the state’s standard IN ANY ONE of the developmental areas, including the social or emotional domain, then the child is eligible for Part C services directed to that domain. A state has the option to include “at-risk infants and toddlers” (such as low birth weight babies and children with a history of abuse or neglect) in the program, or it can choose to monitor “at-risk” children to determine whether they experience developmental delays as they get older.

Q: What services are available under Part C?

A: A critical Part C component is called “service coordination.” Eligible children must be assigned a service coordinator who – together with the parent – participates in the team that develops the written service plan or “Individualized Family Service Plan” (IFSP). The service coordinator is the “single point of contact” who works with the family to ensure compliance with Part C. The non-exhaustive list of other Part C services includes: assistive technology devices and services, audiology services, family training, counseling, and home visits, health services, medical services (to assess the child and determine what Part C services are needed, but not on-going treatment that must be provided by a doctor), nutrition services, nursing services, occupational and physical therapy, sign language and cued speech, social work services, special instruction, psychological services, speech-language pathology, vision services, and transportation and other related costs.

⁹ 34 C.F.R. § 303.302(c)(1)(ii)(G). Each state’s child find system is charged with ensuring that “[a]ll infants and toddlers with disabilities in the State who are eligible for early intervention services under [Part C] are identified, located, and evaluated,” and that “[a]n effective method is developed and implemented to identify children who are in need of early intervention services.” 34 C.F.R. §303.302(b)(1), (2).

¹⁰ 34 C.F.R. §303.303(a)(2)(i), (c)(9).

¹¹ 34 C.F.R. §303.27; 34 C.F.R. §303.37; 34 C.F.R. §303.422.

¹² See below for more on “informed clinical opinion.”

Q: How is “parent” defined? How is “family” defined? What is the role of the “parent” and the “family” under Part C?

A: The child’s family plays an essential role in ensuring that an eligible child gets the help he or she needs. The “parent” gets notices, gives written consent to the child’s initial evaluation and for services to begin, participates in the IFSP team meeting and transition planning, and has the right to agree or disagree with, for example, the child’s proposed Part C services, and to ask for mediation or a hearing to resolve the dispute. Since participation in Part C is voluntary, the parent can decide that the child will not take part in the program at all.

In addition to the biological or adoptive parent, “parent” under Part C can include a foster parent (unless state law or contract prohibits the foster parent from serving as the Part C parent); a guardian generally authorized to act as the child’s parent or to make early intervention, educational, health or developmental decisions for the child (but not the state if the child is a ward of the State); an individual who is acting as the child’s parent (including a grandparent, a stepparent, or other relative with whom the child lives) or an individual who is legally responsible for the child’s welfare; or a “surrogate parent.”

Unless a court has decided that another person should make education decisions for a child,¹³ an engaged birth or adoptive parent is the child’s Part C decision maker. If there is no engaged birth/adoptive parent, the child’s foster parent can serve unless state law prohibits foster parents from performing this role. Under no circumstances can a Part C provider or agency that provides any services to a child or family member of that child act as the child’s Part C parent.

Part C also uses the term “family.” With the parent’s consent, when a child is determined to be eligible for Part C services, the agency must conduct a “family-directed assessment of 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 that infant or toddler.”¹⁴ With the concurrence of the “family,” the child’s IFSP must contain a statement of the results of the family assessment and the specific early intervention services needed to meet the unique needs of the child and the family. Although Part C does not define the term, it seems clear that “family” is a broader concept than “parent” and can, for example, include a sibling or other person in the family unit.

This broader concept of “family” provides a unique opportunity to have Part C services complement and enhance the services being provided through the child welfare agency to the birth and foster families. For example, when an infant or toddler child is in placement, especially for an extended period, the foster parent or other member of the foster family could qualify as a “family” – either instead of or in addition to the birth family. The foster family would then be a focus of the family assessment, and the services the foster family needs to enhance the child’s development would be included in the child’s IFSP. The IFSP could also include services that help the foster and birth parent work together with the child and service provider, which can aid in

¹³ For example, the court could have divested the birth/adoptive parent of the authority to make educational decisions for the child or could have issued an order appointing another person to perform this role. See, 34 C.F.R. §303.27(b).

¹⁴ 34 C.F.R. §303.321(a)(1)(B).

a smooth transition when the child's plan calls for reunification. A cautionary note: If the birth parent is still the Part C decision maker, treating the foster parent as part of the family would probably require the birth parent's consent.

Q: When does a child need a surrogate parent? What can judges do?

A: The state's lead agency for Part C or other Part C public agency must ensure that children's rights are protected when, after reasonable efforts, no "parent" can be located or the child is a "ward of the State" (which means that the child is in the custody of a child welfare agency and is not living with a foster parent who can serve as his "parent" for Part C purposes). In this situation, in most cases the agency must make reasonable efforts to assign a surrogate parent within 30 calendar days¹⁵. In an important new addition, the regulations state that, in implementing the surrogate parent requirements, the lead agency must "consult with the public agency that has been assigned care of the child."¹⁶

A judge who is overseeing the child's case can appoint a surrogate parent for a child who is a "ward of the State." Neither the Part C agency nor the court can assign as a surrogate parent a person who is an employee of the lead agency, a Part C public agency, or an early intervention service provider that provides early intervention services, education, care, or other services to the child or any family member of the child. The person appointed to be the child's surrogate parent cannot have a personal or professional interest that conflicts with the interest of the child he or she represents, and the person must have the knowledge and skills to ensure adequate representation of the child. Once assigned, the surrogate parent has all the rights of the birth/adoptive parent in the Part C system.¹⁷

Q: As a child welfare advocate for a young child, how do I get a child evaluated for Part C services and how long should the evaluation process take?

A: Parental consent is needed before a child can be screened or evaluated. The child welfare advocate must work closely with the birth/adoptive parent (foster parent, surrogate parent, or other authorized decision-maker) to secure that consent and to support the parent throughout the evaluation process. When the necessary parental consents are in place, the responsible Part C agency must conduct an evaluation of the child (including any necessary assessments of the child and family) and, if the child is eligible, complete the initial IFSP within 45 calendar days from the date the agency received the referral for assessment of the child.

Part C recognizes that it is hard to test very young children accurately and that there is a dearth of reliable standardized testing instruments. Part C therefore permits the evaluators to use "informed clinical opinion" to reach conclusions about whether a child has delays and needs Part C services. Since the family assessment is an important part of the evaluation process, the child welfare advocate should urge the parent and other crucial

¹⁵ 34 C.F.R. §303.422(g).

¹⁶ 34 C.F.R. §303.422(b)(2).

¹⁷ 34 C.F.R. §303.422(d),(f).

family members to participate in that assessment and to help the evaluators understand the child from the family's (which could include the foster family's) perspective.

If the state has opted to screen children to determine whether an evaluation is necessary, the screen must be completed within this 45-calendar-day time period. The parent can decide to skip the screen altogether. If the screening results in a determination that no evaluation is needed, the parent must be notified in writing of this decision; the parent can then reject that determination and an evaluation must be conducted.

Because this system depends heavily on the child having an active parent participating and making decisions, it is incumbent on child welfare advocates to ensure that all infants and toddlers in care who are referred to Part C have an active parent or someone authorized to give needed consents and to represent the child throughout the evaluation process and afterwards. Otherwise children in care will continue to be under-identified and denied services when they need them the most.

Once the IFSP is completed and parental consent has been received, services must begin as soon as possible. Some states have specific deadlines. A parent can consent to some services (which then must start) while still disagreeing about other aspects of the IFSP.

Q: How can a child welfare advocate make sure that a child's IFSP contains all needed services and that those services are delivered, whenever possible, in a setting where children without disabilities would normally spend their day?

A: Like the Individualized Education Program or IEP under Part B, for children over age 3 the IFSP is a contract between the Part C agency and the child's parents that specifies the services the child is entitled to receive, including the frequency, intensity, and method by which the services will be provided. Child welfare workers have an important role to play in supporting the family (which could include the foster family) throughout this process and making sure that all of the child's needs are identified by the IFSP team and included in the IFSP. The services must be based on pertinent data from the assessments, and, to the extent practicable, be based on peer-reviewed research. The IFSP must also include the steps needed to support the child's transition to the Part B Preschool program or other appropriate services. With the parents' consent and based on the voluntary "family assessment," the IFSP should also include the services the family needs to enhance the child's development.

Also like the IEP, the IFSP is developed at a team meeting. Team members include the child's parent (which could be the child's foster parent if that person is the child's decision maker); other family members selected by the parent; one or more persons directly involved in conducting the assessments and evaluations; appropriate persons who will be providing early intervention services to the child or family; if the parent chooses to bring one, an advocate or other person outside the family (which could be the child's caseworker, attorney, or Guardian Ad Litem (GAL)); and the service coordinator.

With the child's developmental and permanency goals in mind and the parent's consent, child welfare advocates may be able to provide additional data, evaluations, and other information that can help the IFSP team. Take, for example, a child's whose permanency goal is reunification with her birth family. In the course of its responsibility to assess the family and determine what services are needed to help it enhance the child's development, the IFSP team could include in the IFSP family training or other support services that could also

expedite reunification. Or, for a child whose goal is adoption and for whom parental rights have been terminated, the family assessment and the family services portion of the IFSP should focus on the pre-adoptive parents.

Babies and toddlers are entitled to receive Part C services, to the maximum extent appropriate, in “natural environments.” Common “natural environments” for young children include the child’s home, day care, and other settings where children of the same age without disabilities would normally spend their day. The IFSP must include a statement of the “natural environments” in which the services will be provided, including a justification for any services that will not be provided in the natural environment. The IFSP must be reviewed at least once every six months or more frequently if conditions warrant or the parent requests a review. A meeting must be convened at least annually to evaluate and, if necessary, revise the IFSP.

Q: As a child welfare advocate, how can I ensure that a young child in foster care has a smooth transition to the Part B preschool system or other appropriate services when he or she turns 3?

A: States are required to have procedures and policies in place that ensure that each child receiving Part C services who is eligible for Part B Preschool services will have a smooth and effective transition to the Part B Preschool program when Part C services stop,¹⁸ and that the child will have an IEP or IFSP (as appropriate) in place and implemented.

This is a very complex area for which the rules were expanded and clarified in the new regulations. Now states can permit children (when the parents select this option) to begin receiving a free appropriate public education (FAPE) at age 2 (otherwise limited to preschoolers and school-aged children) and can permit children, who at age 3 are eligible for Part B Preschool services, to remain in the Part C system until they are eligible for or enter kindergarten.¹⁹ Each option comes with specific parental notice and consent requirements and specific content requirements (for example, if the child remains in the Part C program after age 3 the child’s program must include a school readiness program and incorporate pre-literacy, language, and numeracy skills).

If a child may be eligible for services under the Part B Preschool program, with the family’s approval, the lead agency must convene a transition conference not fewer than 90 days and not more than 9 months before the child’s 3rd birthday. The purpose of the conference is to develop a transition plan for the child. The transition plan must include the steps the child and the family need to exit from the Part C program and any transition services that the IFSP team identifies as needed by the child or family.

The transition conference can be combined with an IFSP team meeting, but in any case must meet the IFSP team meeting requirements. Participants include the lead agency or early intervention service provider, the family, and the local education agency (LEA) where the child lives. Since it is now clear that the transition plan

¹⁸ Or other services if the child is not eligible under Part B.

¹⁹ For the rules that govern transition for children over the age of 3 still receiving Part C services when eligibility for Part C ends, see 34 C.F.R. § 303.211(b)(6).

is part of the IFSP, the child welfare advocate (who could be the caseworker, the child’s attorney, the foster parent, or others) again has an important role to play. If the foster parent is the special education decision maker, he or she is the “parent” and a mandatory member of the IFSP team that develops the transition plan. If the parent chooses to bring an advocate, that could be, for example, the caseworker or GAL.

Transition to the next stage – whether it is a Part B Preschool program or other appropriate early childhood program – is absolutely critical. There can be no gap in services when the child turns 3 during the summer months. To assist with the smooth transition, LEAs are required to convene an IEP Team meeting when a child who had previously received Part C services becomes eligible for a FAPE under Part B, and, at the request of the parents, an invitation must be sent to the service coordinator or other representative of the Part C system to attend the initial IEP meeting.²⁰

²⁰ 34 C.F.R. §300.321(f).