

Infants and Toddlers with Disabilities in the Child Welfare System

Q: Why is it important that child welfare advocates are knowledgeable about the Individuals with Disabilities Education Act's Early Intervention Program for Infants and Toddlers with Disabilities?

A: More than 250,000 children under age 3 have contact with a child welfare agency each year, and more than 100,000 are placed outside their home. More than half of these children will experience serious medical conditions and significant developmental delays. Moreover, infants and toddlers will remain in care longer and are more likely to return to care than older children.¹ In 2006, more than 1/3 of all children entering care were under age 3, and 16% were under age 1.² There is a growing body of research demonstrating that abuse, neglect, and exposure to trauma affect children's neurological development. That is, maltreatment changes children's brains, and in particular affects children's development in behavioral, social, and emotional domains.³

These children may well be eligible for special help from the Individuals with Disabilities Education Act's (IDEA) program for infants and toddlers with developmental delays. Child welfare advocates need to know what help might be available; how to get that help for the children in their care; and how to overcome the special barriers that children in care may encounter.

Q: What is the Part C program?

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 IDEA amendments that apply to children from birth to their 3rd birthday is now called "Part C." The IDEA was again significantly changed in 2004, including some key changes to Part C. On October 28, 2011, final regulations implementing those changes went into effect.

¹ Sheryl Dicker, *Reversing the Odds, Improving Child Outcomes for Babies in the Child Welfare System*, 8-9 (2009).

² *Id.* at 5.

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.

All states currently accept federal funding under Part C and thus are required to comply with its requirements and have a state “lead agency” that is charged with ensuring that the state complies with the Act’s requirements. Like the school-aged and pre-school parts of the IDEA (known as Part B), Part C is an “entitlement” program. But Part C give states more choices than Part B about, for example, whether the state will charge for some Part C services;⁴ 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.

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 emphasized the urgency of reaching eligible, but un-served, infants and toddlers in foster care. For example, 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.⁵ The state’s “lead agency” is directed to ensure that the state’s child find system targets infants and toddlers who are “wards of the State”⁶ 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 Act (CAPTA).”⁷ “Public agencies and staff to the child welfare system, including child protective service and foster care” are added

⁴ 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.”

⁵ 34 C.F.R. §303.1(d).

⁶ 34 C.F.R. §303.302(b)(1)(ii).

⁷ 34 C.F.R. §303.302(c)(1)(ii)(G). Each state’s child find system is charged with ensuring that “all 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 “an 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).

as primary referral sources (that is entities who are directed to refer children who may be in need of early intervention services within 7 calendar days).⁸

Definitions of “parent” and “ward of the State” and the rules for “surrogate parents” were added or clarified and these now align closely with Part B.⁹ At least one member of the State Interagency Coordinating Council must be from the state child welfare agency responsible for foster care.¹⁰

Perhaps most important, the Act and the regulations now require that all infants and toddlers for whom abuse and neglect has been substantiated or who are identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure must be referred for to the Part C system for screening and/or evaluation.¹¹

Q: Which children qualify for Part C services?

A: A child under age 3 qualifies for Part C services if the child is (1) experiencing a developmental delay, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social or emotional, or adaptive; 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).

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 the relatively low level of a 25% delay in any of the developmental domains). But if the child meets the state’s standard IN ANY ONE of the developmental areas, including the social or emotional domain, 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

⁸ 34 C.F.R. §303.303(c)(9).

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

¹⁰ 34 C.F.R. §303.601(a)(12).

¹¹ 42 U.S.C. 1437(a)(6), 34 C.F.R. §303.303(b).

neglect) in the program, or it can choose to monitor “at-risk” children to determine whether they demonstrate developmental delays as they get older. A state must provide Part C services to any eligible child within the state even if the child’s family lives elsewhere, the child is not a citizen, or is the child is in the country illegally.¹²

Q: What services are available under Part C?

A: Unlike the Part B system, eligible children must be assigned a service coordinator who – together with the parent – participates in the team that develops the 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. “Nutrition services” is another service that is available under Part C but not under Part B. The non-exhaustive list of other Part C services includes: assistive technology devices and services, audiology services, family counseling, training 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), nursing services, occupational and physical therapy, social work services, special instruction, psychological services, speech-language pathology, vision services, and transportation.

Q: In general, what are the major differences between the Part C and the Part B programs?

A: While the general overall scheme and purpose are the same, there are significant and important differences of kind and degree. As noted above, both Parts B and C are entitlement programs, and both are intended to ensure that children with qualifying disabilities get the specialized help they need to improve their functioning. Both systems start with a comprehensive evaluation, and if the child is deemed eligible a service plan is developed at a meeting at which the parent is an essential member. Both systems permit parents to resolve disputes through a hearing and appeal system and to rectify legal violations through a state complaint process.

¹² See, e.g., *Letter to Flores*, 4 ECLPR 70 (OSEP 1998); *Letter to Gould*, 26 IDELR (OSEP 1997)

A key difference is that, since they apply to children who are not of compulsory school age, the Part C (and the Part B Preschool) programs are voluntary. The Part C system is even more family-centered than Part B. Part C does not require that these very young children be labeled with a specific disability, and since there are fewer reliable testing instruments for this age group, evaluators can use “informed clinical opinion” to determine eligibility.

States have more control over the scope and cost of the Part C program. All Part B programs must be free to children and families; states can establish a sliding scale for many Part C services so long the scale does not deny services to children from families who do not have the ability to pay. States can decide whether to screen rather than evaluate children referred to the Part C system (with special notice and protections for parents). States can also opt to permit children to remain in Part C beyond their 3rd birthdays, again with special parental notice, consent, and other requirements. More detail on these matters below.

Q: What’s an Individualized Family Services Plan (IFSP) and how does it differ from an Individualized Education Program (IEP) under the Part B? What does it mean to provide services in the child’s “natural environment”?

Like the IEP, the IFSP includes pertinent data from the child’s assessments and lists the Part C services the child will receive (including the frequency, intensity, and the method by which the services will be provided). To the extent practicable, the Part C services selected must be based on peer reviewed research.

Babies and toddlers are entitled to receive Part C services, to the maximum extent appropriate, in “natural environments.” 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. 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 be spending their day. The IFSP must also include the steps needed to support the child’s transition to the Part B Preschool program or other appropriate services.

Also like the IEP, the IFSP is developed at a team meeting. The child's parent, the parent's advocate, the service coordinator, and others are members of that team. In fact, the child's family is even more integral to the process – and, with the parents' consent and based on a voluntary "family assessment" – the IFSP should include the services the family needs to enhance the child's development. The IFSP must be reviewed every six months or more frequently if conditions warrant or the parent requests a review. At least annually a meeting must be convened to evaluate and if necessary revise the IFSP.

Q: Is there anything in Part C designed to connect children in the child welfare system to the Part C system?

A: Each state must have a comprehensive "child find" system that ensures that all eligible infants and toddlers – explicitly including children who are "wards of the State" – are identified, located, and evaluated and that there is an effective method in place to determine which children are (and are not) receiving necessary services. In addition, Part C requires that all children under age 3 for whom child abuse or neglect has been substantiated or who are identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure must be referred to the Part C system. **For children in states that permit children to receive Part C services after their third birthday, children who have been traumatized by exposure to family violence must also be referred.**

Q: How quickly must the Part C system evaluate the child, develop the IFSP, and start delivering Part C services to the child? Is the rule different in a state that has opted to screen referred children to determine whether an evaluation is necessary?

If 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 that the agency receives the referral of the child. Part C recognizes that it is hard to test accurately very young children 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. Under certain circumstances services can begin before the evaluation and assessment process has been completed, and if exceptional family circumstances delay the completion of the evaluation within 45 days, the Part C agency must document the circumstances and develop an interim IFSP to the extent appropriate.

If the state has adopted the option to screen children to determine whether an evaluation is necessary, the screen must be completed within this time period. The parent can opt to skip the screen altogether. If the screening results in a determination that no evaluation is needed, the parent must be notified in writing; the parent can then reject that determination and an evaluation must be conducted.

If the child is referred to the Part C agency fewer than 45 calendar days before the child will turn 3, and that child may be eligible for Part B preschool services, the Part C agency is not required to evaluate the child. However, with parental consent the Part C agency must refer the child to the local educational agency where the child lives and the state educational agency. If the Part C agency determines the child to be eligible for EI services between 45 and 90 calendar days prior to the child’s 3rd birthday, as soon as possible after the eligibility determination has been made the Part C agency must (consistent with any opt-out policy adopted by the state) notify the LEA and SEA.

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

Q: When is parental consent required?

A: Since Part C is a voluntary program, written parental consent is essential before the Part C agency can conduct an initial screen, assessment, or evaluation of a child, before Part C services can begin, and when a child’s services are changed or even increased. Moreover, a Part C agency cannot use the procedural

safeguard system (which includes hearings and appeals) to overturn a parent's refusal to consent to an initial evaluation or for services to begin.

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

Even more than in the preschool and school-aged IDEA programs, the child's family has an essential role to play in ensuring that the child gets the help that he or she needs. As with the Part B programs, the "parent" gets notices, gives consent to the child's initial evaluation and for services to begin, participates in the IFSP meeting and transition planning, and has access to a procedural safeguard system. Since Part C is a voluntary system, the "parent" can decide that the child will not participate in the Part C system at all.

The 2004 IDEA Part C amendments and the new regulations added a definition of "ward of the State" and changed the definition of "parent." In addition to the biological or adoptive parent, "parent" under Part C can also 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 bio/adoptive parent (including a grandparent, a stepparent, or other relative), or an individual who is legally responsible for the child's welfare; or a surrogate parent.

Part C uses, but does not define, the term "family." An Individualized *Family* Service Plan is developed for each eligible child. With the "parents'" 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."¹³ 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

¹³ 34 C.F.R. §303.321(a)(1)(B).

intervention services needed to meet the unique needs of the child *and the family*.¹⁴ 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.¹⁵

Q: What are the rules relating to surrogate parents? What can judges do?

The lead agency or other 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).¹⁶ This usually means that the agency must make reasonable efforts to assign a surrogate parent within 30 calendar days. In an important new addition, the regulations require the agency to “consult with the public agency that has been assigned the care of the child.”¹⁷

For a child who is a ward of the State, a judge who is overseeing the child’s case can appoint a surrogate parent. Neither the agency nor the court can assign as a surrogate parent a person who is an employee of the lead agency, a public agency, or early intervention service provider that provides early intervention services, education, care, or other services to the child or any family member of the child.¹⁸ The person appointed by the public agency also cannot have a personal or professional interest that conflicts with the interest of the child he or she represents, and must have the knowledge and skills to ensure adequate representation of the child. Once assigned, the surrogate parent has all the rights of the bio/adoptive parent in the Part C system.¹⁹

¹⁴ 34 C.F.R. §303.344(b), (c), (d).

¹⁵ For example, the Comments to the new Part C regulations state that, unless it is clearly not feasible to do so, family assessments must be conducted in the native language of the family member being assessed, but that there may be instances when this is not feasible for “the child, parent, or family member” being assessed. 76 Fed. Reg. 60196 (Sept. 28, 2011).

¹⁶ 34 C.F.R. §303.37.

¹⁷ 34 C.F.R. §303.422(b)(2).

¹⁸ 34 C.F.R. §303.422(d)(2)(i).

¹⁹ 34 C.F.R. §303.422(d)(2)(ii), (iii).

Q: Can states screen (rather than evaluate) infants and toddlers who may be eligible for Part C services, and what special challenges do the new screening rules present for children in care?

States can now adopt procedures to screen children under age 3 who have been referred to the Part C program to decide whether they should be evaluated to determine their eligibility for Part C services. The lead or local early intervention agency must give the child's "parent" written notice that it intends to screen the child, and must get the parent's consent. The parent can bypass the screen and request – and get—an evaluation for the child. If the agency determines that the child is suspected of having a disability, it must – again with the parent's consent – conduct a full evaluation of the child. If the agency determines that the child is not suspected of having a disability, the agency must ensure that notice of that determination is given to the child's parent, and that the notice explains that he parent can still ask for – and get – an evaluation of the child. The "45 day from referral to IFSP" deadline applies to children who are screened, so screening should not result in any service delays.

Since these rules depend heavily on the parent, they present a special challenge for children in care who do not live with their bio/adoptive parents. It is the "parent" who receives the notices, gives consent, and can bypass the screen or a determination that the child should not be evaluated. Because of these concerns, commenters to the proposed rules suggested that information be given to the caregiver and the agency responsible for the child. The U.S. Department of Education expressly rejected this suggestion, opining that the broad definition of "parent" in Part C and the surrogate parent requirements are sufficient to protect children in care.²⁰ This makes it even more essential to ensure that all infants and toddlers who are referred to Part C have designated and authorized "parents" to represent them. Otherwise children in care will continue to be under-identified and will be denied services when they need them most.

Q: How does Part C ensure that children who turn 3 will transition smoothly to the Part B preschool system or other appropriate services?

²⁰ 76 Fed. Reg. 60195 (Sept. 28, 2011).

Each state is required to have procedures and policies in place that ensure that each child receiving Part C services who is eligible will have a smooth and effective transition to the Part B Preschool program (or other services if the child is not eligible under Part B) when Part C services stop, 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 at age 2 to begin receiving FAPE (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 entering kindergarten.²¹ 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 the child's program must still include a school readiness program and incorporate pre-literacy, language, and numeracy skills). Moreover, Part C lead agencies that are SEAs must also enter into intra- agency, and other lead agencies inter-agency agreements to facilitate transition.²²

The overall scheme is that, if a child with a disability may be eligible for services under the Part B Preschool program, and with the family's approval, not fewer than 90 days and not more than 9 months before the child's 3rd birthday the lead agency must convene a transition conference to develop a transition plan for the child as part of the IFSP to support the child's smooth transition to the Part B preschool program or other appropriate services. 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 meeting, but in any case must meet the same requirements. Participants include the lead agency or early intervention service provider, the family, and the local education agency where the child lives (LEA). 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

²¹ For the transition 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).

²² For details, see 34 C.F.R. §303.209(b).

convene an IEP team meeting when an 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.²³

²³ 34 C.F.R. §300.321(f).