

A Family Perspective on the Individuals with Disabilities Education Act, Part C: Infants and Toddlers with Disabilities

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Abstract:

During the 2000-01 school year, programs under the Individuals with Disabilities Education Act (IDEA) served more than six and a half million infants, children and young adults. Amended in 1997 and up for reauthorization this year, IDEA seeks to protect disabled children's right to a free, appropriate public education designed to meet their needs. Under Part C of the 1997 amended IDEA. Congress enacted federal policy to assist states with early intervention for infants and toddlers with disabilities. Premised on the effort to minimize developmental delay and the need for special education at the K-16 level, Part C seeks to enhance families' capacity to meet their children's special needs (IDEA, 1997). This paper uses the checklist for assessing family impact originally developed by the Family Criteria (Ad Hoc) Task Force of the Consortium of Family Organizations (COFO) to examine how early intervention services for infants and toddlers may affect the strength, stability, and functioning of family life. On the one hand, the analysis reveals a policy that supports family strength, encourages family commitment, and facilitates family empowerment through providing services and involving families in program planning and implementation. On the other hand, the significant commitments involved in participating in Part C programs may prove barriers for those families already at risk.

Introduction

The 1997 amended Individuals with Disabilities Education Act (IDEA) is up for reauthorization in 2002. During the 2000-01 school year, programs under IDEA served more than six and a half million infants, children, and young adults. Originally passed as the Education for All Handicapped Children Act of 1975, IDEA is founded on the principle of "support[ing] states and localities in protecting the rights of, meeting the individual needs of, and improving the results for...infants, toddlers, children, and youth with disabilities and their families" (Office of Special Education and Rehabilitative Services, 2001).

Prior to enactment of this law, more than one-half of the population of disabled children in the United States did not receive educational services to address their special needs, and one million children with disabilities were excluded from public education altogether (Individuals with Disabilities Education Act Amendments of 1997). Public Law 94-142 and the amended IDEA of 1997 sought to change these conditions by guaranteeing all children, regardless of disability, the right to a free, appropriate public education and the opportunity to be educated alongside their non-disabled peers.

Under Part C of the 1997 amended IDEA, Congress enacted federal policy to assist states with early intervention for infants and toddlers with disabilities. Premised on the effort to minimize developmental delay and thereby the need for special education at the K-16 level, Part C explicitly mentions enhancing families' capacity to meet their children's special needs (IDEA, 1997). After 27 years of federal involvement in special education, states face increasing demands to provide and coordinate educational and transitional services for disabled children and their families. In the language of the act,

In order for States to address such demands and facilitate lasting systemic change that is of benefit to all students, including children with disabilities, States must involve local education agencies, parents, individuals with disabilities and their families, teachers and other service providers, and other interested individuals and organizations in carrying out comprehensive strategies to improve educational results for children with disabilities (IDEA, 1997, p. 101).

With the upcoming plan for reauthorization of IDEA, discussions at the local, state, and federal level regarding the act are likely to increase. Under the current administration, federal funds to states implementing IDEA have increased \$1 billion as part of the President's *No Child Left Behind* reform law. Yet legislators, researchers, policy implementers, and families of disabled children alike point to concerns about the current implementation of IDEA. Stakeholders on all sides of the issue have raised questions about the over-representation of children of color and language minority students in K-12 special education programs, and about the amount of paperwork and red tape surrounding the identification and support of disabled children. Given the timely nature of this issue, this paper seeks to provide yet another perspective on IDEA: that of its effect on families.

Research has shown that a family perspective helps to uncover both positive and negative effects of policies and programs on family functioning (Ooms and Preister, 1988). Scholars studying family impact have found that families are "the most powerful, most humane, and by far, the most economical system for building competence and character" in children and adults (Bronfenbrenner, 1986). Because Part C of IDEA mentions support for families, an analysis of the policies and programs it proscribes is particularly salient. This paper uses the checklist for assessing family impact developed by the Family Criteria (Ad Hoc) Task Force of the Consortium of Family Organizations (Ooms and Preister 1988) and revised by the Policy Institute for Family Impact Seminars (Bogenschneider, 2002) to examine how early intervention services for infants and toddlers may affect the strength, stability, and functioning of family life.

Background

Part C of IDEA is a federal grant program designed to provide, facilitate, and coordinate early intervention services for disabled infants, toddlers and their families. In 1999-2000, 205,769 infants, toddlers, and their families accessed these services, a figure representing 1.8% of all U.S. infants and toddlers according to data from the U.S. Census Bureau (United States Department of Education, 2002). In 1997, the federal Office of Special Education Programs (OSEP) commissioned a study of infants and toddlers in early intervention programs. This study, called the National Early Intervention Longitudinal Study (NEILS), collects data on a nationally representative sample of 3,338 disabled infants, toddlers, and their families who initially enrolled for intervention services between 1997

and 1998. The study will continue data collection through the time that these children enter kindergarten (OSEP, 2000).

Family Characteristics. NEILS data show that over 6 in 10 (61%) of the early intervention population were boys, and that the largest racial/ethnic group represented was white (56%), with black children making up roughly one-fifth of the population (21%), Hispanics 15%, and Asian/Pacific Islander 5% (U.S. DOE, 2001a). Although not a precise parallel, data from the 2000 U.S. Census indicate that that the racial/ethnic distribution of children under 18 was approximately 69% White, 15% Black, 17% Hispanic and 4% Asian or Pacific Islander (Annie E. Casey Foundation, 2002). While overrepresentation of children of color and language minorities is frequently cited as a cause for concern among the school-age special education population, these numbers indicate that this is not as much of a concern in the case of early intervention, with the possible exception of Black children. The reasons for children's eligibility for early intervention varied, and represented a range of conditions, delays and disabilities. The most prominent commonality was difficulty with communication or communication delay. Almost a third of the children were born with low birth weight (as compared with 7.5% of the general population), a condition often associated with developmental and medical problems (U.S. DOE, 2001a).

The overall picture of children and families served by early intervention points to a diverse population, but one with a relatively high proportion of low socioeconomic status. NEILS data on children and families in early intervention programs found family income level for almost half (41%) was less than \$25,000. Nearly a third (32%) had received welfare or food stamps in the past year (U.S. DOE, 2001a). In the general U.S. population, only 15% of families with children under 18 report household income levels under \$25,000 (Annie E. Casey Foundation, 2002). While parents of older children obviously may have had more time in the workforce, NEILS researchers found this marked difference in income levels notable (U.S. DOE, 2001a). This is particularly so given the fact that 9 out 10 fathers/male caregivers and nearly half (43%) of mothers/female caregivers were employed at least part-time (U.S. DOE, 2001a).

Children in early intervention were slightly less likely than the general population to be living in single parent households, however. According to NEILS data, 15% of disabled infants and toddlers were living in households with only one adult, compared to national data indicating that 23% of the general population of children between birth and age 4 live with only one parent (OSEP, 2002).

<u>Early intervention services</u>. What then are the services that these families and their children receive? Federal statues outline the types of services provided under Part C of IDEA. According to NEILS data, the most commonly accessed of these was 'service coordination', which was utilized by 80% of families, although families can elect to perform this function themselves. Other high incidence services related to specific treatments, such as speech, occupational, and physical therapies (U.S. DOE, 2001a). A complete list of services offered can be found in Appendix A.

One of the key elements of Part C legislation is that services should be delivered in 'natural environments' to the greatest extent possible. In the language of the policy, natural environments include the home and community settings where non-disabled children also participate (IDEA, 1997). The intention behind this effort is to allow children with disabilities

the maximum opportunity to live, play, and be educated alongside their non-disabled peers. NEILS data show that more than three quarters (78%) of infants and toddlers in early intervention programs received services in their homes. Over one-quarter (28%) received services in specialized center-based early intervention programs and/or a clinic or office (29%; U.S. DOE, 2001a). Only one in ten participated in family day care, pre-school or nursery school programs. Because families with disabled infants and toddlers may be accessing services at any or all of the above, the likelihood is that children receive interventions in multiple environments.

Legislation

Before proceeding to an analysis of the effect of Part C policy on families, it makes sense to examine the legislation itself. As of 2002, all states and eligible U.S. territories participate in programs under Part C. Participation is contingent upon each state designating a lead agency as administrator of the program and appointing an Interagency Coordinating Committee (ICC). In establishing the ICC, state governors make appointments and designate a chairperson who is not a member of the lead agency administering the program. Composition of the ICC requires that at least 20% of the members be parents or guardians of disabled infants or children under 12, and an additional 20% be public or private early intervention service providers (IDEA, 1997).

Participation requires that states fulfill a number of statues and regulations. Chief among these are:

- 1. The state must provide "appropriate early intervention services...[to] all infants and toddlers with disabilities in the State and their families" (IDEA, 1997, p. 83). These services are provided under public supervision and are at no cost except where Federal or State law provides for a payment system that includes a sliding scale. Services must be designed to meet the needs of infants and toddlers with disabilities related to cognitive, physical, social, emotional, adaptive, or communication development. Intervention services must provide for family training, counseling, and home visits, special instruction, and physical, occupational, and speech/language therapies. Families receiving early intervention are also eligible for health, social work, and psychological services, as well as medical services related to diagnosis or evaluation of disability. As mentioned above, service coordination is a key element of intervention programming, and includes "transportation and related costs" required to enable an infant or toddler and the infant's or toddler's family to receive any of these services (IDEA, 1997).
- 2. The state must also have in place a comprehensive 'child find' system to identify eligible infants and toddlers, including a public awareness program. Once identified, the state must provide for a "timely, comprehensive, multidisciplinary evaluation of the functioning of each infant or toddler with a disability in the state and a family-directed identification of the needs of each family of such an infant or toddler" (IDEA 1997, p. 84).
- 3. This evaluation should be part of the individualized family service plan that must be in place for all eligible disabled infants and toddlers in the state. This plan must include the following:

- a. A multidisciplinary assessment of the child to determine appropriate intervention services;
- b. A "family-directed" assessment of priorities, resources, and the services and supports needed by the family to meet their disabled child's needs; and
- c. A written plan detailing the above developed by a multidisciplinary team of service professionals and parents.

The individualized family service plan also provides for periodic review, and all services are subject to parental consent. Parents are given the right to examine all records relating to their child's assessment, and must receive written notice in their native language prior to any adjustment in services.

4. The program must also provide for a comprehensive system of personnel development. While not a requirement of the system, Part C indicates that this system may include personnel training in service coordination and working in rural and inner-city areas (IDEA, 1997).

Family Impact

Based on the above discussion of the background and details of Part C legislation, this section seeks to apply the six principles of family impact analysis outlined by the Family Criteria (Ad Hoc) Task Force of the Consortium of Family Organizations and revised by the Policy Institute for Family Impact Seminars (Bogenschneider, 2002; Ooms and Preister, 1988). These principles reveal the degree to which Part C policy is sensitive to and supportive of family needs.

Principle 1: Family Support and Responsibilities:

• Does the policy support and supplement parents' and other family members' ability to carry out their responsibilities?

Overall, Part C of IDEA makes efforts to both support and supplement family functioning. By families with services such as training, counseling, social work and psychological services, Part C may enhance families' capacity to attend to the needs of disabled infants or toddlers. While implementation of the policy likely varies across states and localities, the language of Part C does not seem to provide incentives for other persons to take over family functioning, except in the case of an infant or toddler whose parents or guardians cannot be found. In addition, because of both the service coordination function and allowance for costs related to accessing services, families may be able to make more effective use of early intervention. All of these are positive indications of Part C's supportiveness of family responsibilities.

On the other hand, Part C does not mention any effort to enforce absent parents' obligations to provide financial or other support for their children. Another indicator under this principle asks if the policy or program "set[s] unrealistic expectations for families to assume financial and/or care-giving responsibilities for dependent, seriously ill, or disabled family members" (Ooms and Preister, 1988). While the term 'unrealistic' will vary from family to family, the degree of responsibilities involved in early intervention should not be underestimated. Families are expected to participate in extensive evaluation procedures,

both for diagnosing and assessing their child's disability, and for determining and accessing appropriate services and care. Because family responsibility is a complex web that extends beyond caring only for a disabled child, involvement in these processes may place a heavy burden of time and commitment on family members, resulting in reduced time for other family members and family functions such as providing economic support. Family relationships may be strained by the extent of care-giving duties, particularly if counseling and support services do not target how care-giving responsibilities may interfere with other aspects of family life.

Principle 2: Family Membership and Stability

• Does the policy strengthen marital commitment or parental obligations?

Part C may serve to strengthen parental obligations and parents' willingness to have their children participate in early intervention by offering opportunities to be involved in designing and implementing service plans. The social work and family counseling services available under Part C may also assist families with caring for a disabled infant or toddler, handling the stress of caring for a special needs child, and managing the coordination of multiple services. Additionally, the focus on delivering services in the 'natural environment' of the home may serve not only as a convenience for both parents and children, but also as a way of helping parents deal with situations that arise in everyday family surroundings. By offering services in the home, not only would siblings be able to participate where appropriate, but this would also relieve the burden of finding supplementary childcare.

Principle 3: Family Involvement and Interdependence

• To what extent does the policy recognize the reciprocal influence of family needs on individual needs, and the influence of individual needs on family needs?

By offering comprehensive services under the individualized family service plan and by involving families in assessing priorities and resources, Part C policy may address the reciprocal nature of the influence of disabled infants and toddlers on their families and vice versa. The breadth of programming also appears to recognize the complexity involved in caring for disabled infants and toddlers. While the extent of families' involvement in working on plans for individualized service likely varies, there are provisions to include family input in this process.

This being said, the policy does not indicate whether extended family may take part in developing these plans, although it is not worded in such as way as to exclude extended family. This lack of clarity may cause for uneven implementation depending on service settings and personnel. For families where care-giving responsibilities are shared by extended family, access to services and planning may be essential. In the case of disabled children requiring special types of care, training for extended family members involved in care-giving may be paramount.

By including community settings in the definition of the 'natural environment' for early intervention services, the policy does make an effort to build on informal support networks. However, NEILS data indicated that only 5% of infants and toddlers in Part C programs received services in community-based programs or other settings (U.S. DOE, 2001a), which means that more could be done to develop and encourage the use of existing

community resources in supporting families of disabled infants and toddlers. Additionally, the policy does not target resources for families to develop informal support systems with other families of disabled infants and toddlers. Similarly-situated families who face like challenges may be able to offer perspective, support, and experience that professionals may be less able to provide.

As to the degree to which Part C policy assesses and balances competing needs, rights, and interests of various family members, there is little in the policy language that provides for this kind of detail. Because of the state and location-specific nature of early intervention services, programs' respect for family divisions of labor is difficult to assess. This is also the case with determining programs' efforts to ensure that the perspectives of all family members are represented.

Principle 4: Family Partnership and Empowerment

• In what specific ways does the policy encourage professionals to work in collaboration with the families of their clients, patients, or students?

A clear strength of Part C policy is its explicit efforts to encourage families' collaboration with program professionals in service delivery. Including family priorities in developing the individualized family service plan may lead to a family's enhanced sense of empowerment, capacity, and commitment to carrying out the components of the plan. In addition, parents also have the opportunity to participate in Interagency Coordinating Committee (ICC) work. By requiring that committees be made up of at least 20% parents of disabled children, the policy makes an effort to use families as a resource in policy development and planning.

This being said, it is worth considering how representative parents who participate in ICCs may be. In a recent article on enhancing family roles in early intervention programs, researcher Barbara Popper points out that parents "are not always in a position to absorb the costs of participation" (Popper, 1997). Work commitments, transportation, parking, childcare, and other responsibilities may all play a role in a parent's ability to take part in ICC work. While stipends may be available in some cases, these often do not cover all costs, nor do all parents feel comfortable or know how to inquire about reimbursement (Popper, 1997). For working parents, finding the time to participate may be a serious challenge, particularly if there is no other parent or family member to assume care-giving responsibilities, especially the specialized caregiving that some children may require.

The language of the policy appears to support family autonomy and decision-making by providing for parental consent to intervention services and offering a process for dispute management and mediation. Yet recent NEILS data raise questions about the implementation of partnerships between families and service providers. As part of the effort to assess outcomes for families, researchers found that more than one-fifth (22%) of families wanted to be more involved in decision-making processes. Fully one-quarter (25%) indicated that it took some or a lot of effort to find out where to get early intervention. What researchers found most surprising, however, was that nearly one-fifth (18%) of families were unaware of a written individualized family service plan, despite ostensibly having collaborated on it (U.S. DOE, 2001a). These data point to the need to conduct assessments to evaluate the effectiveness of service delivery to determine whether the intent of the legislation is being carried out.

Principle 5: Family Diversity

 How does the policy or program identify and respect the different values, attitudes, and behavior of families from various racial, ethnic, religious, cultural, and geographic backgrounds that are relevant to program effectiveness?

The policies outlined under Part C do not appear to discriminate against families on the basis of structure or roles. Based on the data from the NEILS study, families served by programs under Part C include single parent, two parent, and multi-adult households (U.S. DOE, 2001a). No language in the policy specifies that any particular family structure is preferred over another for service.

Nonetheless, it is difficult to ascertain to what extent programs under Part C might give rise to cultural conflicts between service providers and recipients, which is another indicator of supportiveness of family diversity. Presumably, not all families would feel comfortable with state- and federally- sponsored 'intervention' into the ways that they raise their disabled infant or toddler, or their parenting priorities may differ from the white middle class practices that often serve as the norm (Smith, 1993). Parents do have the right to mediation and litigation of disputes, yet many families may be unwilling to engage in active disagreements with state personnel or other figures of medical or service authority. Part C does make a provision that any changes to individualized family service plans must be provided in writing in the family's native language, but this provision does not specify a plan for families who may be illiterate in their native language. Conceivably, mismatched values between service providers and receivers could cause families of disabled infants and toddlers to feel stigmatized, and therefore less inclined to take advantage of available services. Conflicts in these relationships may result in power inequities that interfere with service delivery.

Principle 6: Support of Vulnerable Families

 Does the policy or program give support to families who are most vulnerable to breakdown and have the fewest resources?

While not a specific aim of Part C, the policy includes supports for economically disadvantaged families. All services supported by Part C programming must be provided to families at no cost or on a sliding fee basis. Transportation for disabled infants and toddlers and their families in order to receive services is also covered, as are assistive technology devices, such as hearing aids. The policy indicates that personnel training programs "may include...work[ing] with inner city or rural populations" (IDEA, 1997, p. 84). However, it is not clear that this would effectively target all families in need of support, and the vagueness of the language may allow this issue to fall through the cracks.

Moreover, the extensive time and other commitments involved in receiving early intervention might be a barrier for families already at risk. According to NEILS data, 70% of families with disabled infants or toddlers had more than one child at home, and 20% had another child with a disability (U.S. DOE, 2001a). For many families, the cost of child care, work responsibilities, and/or caring for other family members could easily get in the way of accessing early intervention. Indeed, NEILS data indicate that 81% of families with disabled infants and toddlers missed services at some point during the first six months of enrollment. While many of these missed appointments were due to issues related to the

child's health (58%), nearly half of the respondents (46%) had missed an appointment due to 'family circumstances' such as transportation (U.S. DOE 2001a).

Lastly, the NEILS data on the low levels of educational attainment among some parents of disabled infants and toddlers raise questions about how effectively some of these women and men will be able to navigate the educational system on behalf of their children. For parents whose own experiences with public education were not positive, there may be a reluctance to take advantage of early intervention services. Conversely, for those who do want their children in early intervention programs, there may be an unwillingness to work with program personnel due to the uneven balance of power and authority. While Part C is intended to offer services to all families of disabled infants and toddlers, it is possible that for families already struggling to balance childcare with other responsibilities, early intervention may pose as much of a challenge as it does a support.

Policy Considerations

With the re-authorization of the Individuals with Disabilities Education Act this year, there will likely be heightened conversation about how best to provide educational services to our nation's disabled children and their families. While educational policy and implementation in the United States are still in many ways state- and locally-based affairs, federal policies like IDEA can have a tremendous effect on the direction of educational access and opportunity. This family impact analysis has set out to examine IDEA's policy for infants and toddlers with disabilities in order to explore more in-depth how it does and does not address what supports families of disabled children may need.

- 1. Costs. From a state perspective, one of the key issues raised by IDEA is cost. In 1975, when P.L. 94-142 was first enacted, Congress authorized the federal share of funds at 40% of each state's "excess costs" for implementing special education programs. In other words, the federal contribution would be calculated by taking 40% of national average per pupil spending and multiplying it by the number of children served under IDEA in each state. This amount is commonly referred to as the "full funding" amount for the legislation. Despite this provision, the federal contribution to implementation costs is currently 17%, its highest level to date.
 - The scope of provisions under Part C alone points to serious budget considerations for state, district, and local level personnel. Regardless of the family-supportiveness of the law, (e.g., its efforts to include family input and to assist families with coordinating the multiple services they receive) without the funding to implement it fully, it is likely that program quality may be seriously compromised. In 2002, with many states facing severe budget deficits, federal contribution to programs like IDEA may become even important to ensuring that the goals of the policy are met.
- 2. Implementation. Implementation is another key issue related to Part C. Like many federal education policies, IDEA is administered and interpreted by state agencies. State provisions are translated and interpreted by districts, and in turn, by localities and schools. At each level, competing priorities and varying levels of capacity, resources, and will all have an effect on how programs are designed and carried out. While a national-level study of state implementation of IDEA is currently under way, it should be born in mind that compliance at every level—state, district, and local—may vary, and that this could have serious implications for the actual level of

- support provided to families, regardless of the language of the law. For example, in states or districts where adequately trained personnel are in short supply, the quality of attention and availability of services available to families may be compromised.
- 3. Outcomes. For educators, families, and policymakers alike, one of the major questions relating to early intervention is the outcome for the children and families involved. The NEILS project is in the process of collecting longitudinal data with regard to outcomes for children and families served by Part C programs (U.S. DOE, 2001a), but some consider this an issue that needs more targeted federal and state attention. Given that Part C makes no mention of outcomes-related evaluation, there may room in the re-authorized act for further consideration of this important concern. Without targeted attention to the short- and long-term effects for children and programs' effect on enhancing families' capacity, it is possible that areas for program improvement may go undetected and that program components that have been successful may unwittingly be eliminated.

Conclusion

Part C of IDEA has clearly taken steps to be inclusive of families and sensitive to their needs as they navigate the system of early intervention services for their disabled infants and toddlers. By addressing remaining questions with regard to family diversity and accessibility, Part C may become an even stronger example of what policymakers can do when they consider the effect of their efforts on families. On the other hand, if key issues of implementation go unmonitored, the comprehensive supports outlined by the policy may be seriously compromised.

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Appendix A:

Early Intervention Services Offered Under the Individuals with Disabilities Education Act, Part C. Infants and Toddlers with Disabilities.

- 1. Family training, counseling, and home visits;
- 2. Special instruction;
- 3. Speech-language pathology and audiology services;
- 4. Occupational therapy;
- 5. Physical therapy;
- 6. Psychological service;
- 7. Service coordination services;
- 8. Medical services for diagnostic or evaluation purposes;
- 9. Early identification, screening and assessment services;
- 10. Health services enable the infant or toddler to benefit from early intervention;
- 11. Social work services;
- 12. Vision services;
- 13. Assistive technology devices and assistive technology services; and
- 14. Transportation and related costs necessary to enable an infant or toddler and the infant's or toddler's family to receive services listed above.

Suggested Reference for this paper:

Gross, E. (2003). A family impact analysis of the Individuals with Disabilities Act, Part C: Infants and Toddlers with Disabilities. (Family Impact Analysis Series). Madison, WI: Policy Institute for Family Impact Seminars.

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