



The Early Intervention Family Alliance (EIFA) is a national group of family leaders dedicated to improving outcomes for infants and toddlers with disabilities and their families. The EIFA represents family leaders' involved in Part C programs in states and other jurisdictions implementing the Individuals with Disabilities Education Act (IDEA) Part C for infants and toddlers with disabilities and their families.

The EIFA is ready and willing to participate and assist in the implementation of the Obama Administration's Early Childhood Initiative. We provide this transition statement in support of these efforts. First we would thank you for the 10B commitment to early childhood and specifically including Part C.

The Guiding Principles of the Early Intervention Family Alliance:

- The EIFA works to assure meaningful family involvement in the development of Part C policies and its implementation at community, state and federal levels.
- Families are essential partners in implementing family-centered practices in all levels of early intervention and are respected experts on services for their children and family.
- Families have equal access to training and technical assistance to foster meaningful involvement.
- Family diversity and voices of the underrepresented are essential to insuring quality services and implementation of policies and practices; which are family-centered, community-based and culturally competent to ensure the highest quality programs.

Background Information on Part C

Part C of IDEA was enacted in 1986 to assist states to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families. Part C is intended to enhance state capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with disabilities and their families. This law is intended to enhance the development of infants and toddlers with disabilities and to minimize their potential for delay, reduce educational costs and to minimize the likelihood of institutionalization. All states are currently participating in this important program. One of the primary goals of Part C is to enhance the capacity of families to meet the special needs of their infants or toddlers with disabilities. Another goal is that families actively participate in the decisions about their child's services and understand their child and family's rights under the law. Unfortunately at this point there is an inequity of the current funding methodology that creates a disincentive for identifying and serving more children.

Priorities identified by the EIFA

- **Permanently Authorize Part C of IDEA** - the value of Part C is born out by both outcomes data and family feedback. It should be permanently authorized in the federal budget. In addition, there is a need to:
 - Issue Part C regulations; Part C of IDEA has been operating since 1992 with no new federal regulations, which has resulted in a lack of clarity and shared understanding on issues critical to this program

- There is a critical need for statutory clarity and alignment across funding and regulatory agencies. E.g. HRSA, MCHB, DOD, BIA, CMS, etc.
- As statutory clarity and alignment is achieved, there will remain a need for federal interagency collaboration that actively involves families
- **Federal allocation** –There must be a federal commitment to funding this program commensurate with the value we know it provides; Part C programs are challenged to provide quality services with the current funding. Brain research demonstrates the critical need for early intervention for infants and toddlers with disabilities. We are concerned that infants and toddlers with disabilities and their families are losing access to these critical supports and services as funding has decreased.
 - We strongly encourage that any discussions of Universal Healthcare Reform include stakeholders from the Part C program, particularly families, and assess the impacts of proposed reforms on this system
 - As states have struggled with decreasing budgets, programs have increasingly turned to
 - Utilizing private insurance without developing, distributing and implementing appropriate protections for families States can only provide protections to families whose insurance is state regulated, unfortunately many families have self-funded or ERISA plans. Families and providers often have difficulty figuring out whether or not families are protected, when difficulties arise neither Part C programs or state insurance departments are prepared to resolve the difficulties. Families may not be aware of the impact until years after they leave the Part C program. This creates an additional hardship for families who are already facing a fragmented system
 - Family fee (*cost participation*) systems that do not consider critical factors and protections for families
 - Narrowing Part C eligibility requirements, thereby leaving out previously eligible children
- **The goal of the Part C Program is to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.**
 - Family-centered care is the cornerstone of this program
 - It is essential that the commitment to supporting families of infants and toddlers with disabilities is renewed
 - Families exiting the Part C system must have the competencies to advocate for their child and family and to capably participate in interest based negotiation
 - The impact on outcomes for families of children who enter the Part C program later, for example after the child has reached the age of 2 ½ years old must be examined
 - Families must be informed and supported on how to act on their rights
- **Renew the commitment to meaningful family involvement at all levels of the policy making arenas.**
 - Support interaction with EIFA as representatives of EI families across the country.
 - Families need the same access to information and the opportunity to participate meaningfully at all levels as all of the other stakeholders at the policy table.
 - Training, Mentoring and Support of families must be a sustained activity across all programs
 - Ensure fully appointed, active state Interagency Coordinating Councils (ICC) as originally intended in Part C of IDEA.

- **While we support efforts to improve accountability we are greatly concerned that:**
 - Data collection, rather than child and family needs drives service delivery options and implementation
 - The use of technology (e.g. electronic service plans) to increase accountability should not result in ‘cookie cutter’ supports and services, or compromise the role of the family as a member of their child’s planning team, or be used in a way that blocks the family’s access to information and their family rights with respect thereto.
 - There is a need for research and development utilizing federal funds, of new developmental assessment tools for use with Part C and other early childhood programs. The recent National Academy of Sciences report Early Childhood Assessment: Why, What, How indicates there is a need to improve the quality and validity of our early childhood developmental assessment tools, so that they are valid for use with children with disabilities and with minority populations; reflect universal design principles; and measure outcomes that are meaningful in the daily lives of young children and their families. Once developed, there must be ongoing support and education on the utilization of these tools by evaluators, practitioners and families.

- **Address critical nationwide shortages of qualified personnel and the need for accountability and monitoring of required Comprehensive System of Personnel Development (CSPD).**
 - Enhance capacity through collaboration with allied health fields (Physical Therapy, Occupational Therapy, Speech and Language Pathology, Nursing, Audiology, Developmental Specialists/Educators, Social Workers, Psychologist, Counselors, and Nutrition)
 - Support families as faculty in professional development programs (pre-service and in-service)
 - Establish higher education Loan Forgiveness opportunities for individuals earning degrees in allied health fields, if they agree to work in Part C for a designated period of time; in particular offer educational financial assistance for families interested in pursuing careers in the Part C system

- **The Federal Education Rights and Privacy Act (FERPA) regulations offer critical protections to families, but should not be used to prohibit the coordination and braiding of services that is the cornerstone of the Part C program.**
 - Families report that their access to information, resources and supports is blocked by the current interpretation of FERPA, for example, access to other parents who can offer ideas and support
 - Providers and physicians are unable to coordinate services and assess the impact of their collaborative efforts due to the severe restrictions that prevent the sharing of program data