



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 or at risk for developmental delays and disabilities and their families.

The EIFA is excited that the American Recovery and Reinvestment Act includes monies dedicated to stabilizing and stimulating job growth in this important program. However, we are concerned by some trends we have observed.

The intent of Congress in enacting Part H of P.L. 99-457 in 1986 was to assist states in developing a statewide, comprehensive, coordinated early intervention system to support infants and toddlers with disabilities and their families. This law has enabled millions of infants and toddlers to access needed services and supports since its passage. It has also reduced the number of children with disabilities needing institutionalization or group home services, saved educational dollars by improving outcomes for these children when they enter kindergarten and has assisted families to better care for their children with disabilities and delays.

Each year, states are asked to increase the number of children they serve, and improve compliance with the provisions of IDEA. Yet for years, Congress has made cuts to the Part C funding, has refused to permanently authorize IDEA, and has failed to set a floor for eligibility for these critical services and supports.

As the number of infants and toddlers served has increased exponentially from those early years, many states and localities have expressed concern over the continued growth in the number of children served and the attendant state and local costs. Many states report that they are having extreme difficulty meeting their budgets, despite the designated funding for Part C in the recovery act. To address increasing shortfalls in revenue, states are requiring fees of families for early intervention services, restricting eligibility, limiting access to services or eliminating early intervention services altogether. As you are no doubt aware, during times of economic hardship, families caring for a child or adult family member with a disability experience stress at increased levels compared to typical families. At this time, both families and state programs need additional support, not less, as well as clear guidance from OSEP and Congress

While IDEA Part C guidance on the recovery act dollars will be available shortly, the guidance has been delayed as compared to the information put forth regarding other parts of IDEA. This is a pattern that we also see with IDEA rules and regulations, an issue that is of major concern to all early intervention stakeholders. While there were some technical revisions 1997, Part C has operated with the same rules since its inception. Proposed rules to implement the changes in IDEA 2004 were sent to the Office of Management and Budget for final action in October of

2008, but were withdrawn on January 16, 2009. New, accurate regulations are absolutely essential to implement changes made in the federal IDEA legislation signed into law on December 4, 2004. The Notice of Proposed Rulemaking (NPRM) for these regulations was published in May of 2007. EIFA conducted extensive review of the NPRM, prepared detailed comments on the draft and testified at all the public hearings held across the country. Our comments on the proposed regulations are attached. More than four years after the reauthorization of IDEA, we are still waiting for rules.

Finally, we believe it imperative to call your attention to the fact that IDEA Part C is intended to be an interagency program utilizing multiple funding streams. It is therefore urgent that any discussion about national or universal healthcare consider and specifically address how changes will impact infants and toddlers with disabilities and their families. Any changes to Medicaid, private insurance, Head Start or Even Start, Title V, Title XIX, Title XX and the like will have profound and lasting consequences for the young children with disabilities and their families who are served by the early intervention program. Therefore it is critical that federal agencies align their regulations and include stakeholders when discussing and developing recommendations to address the potential impacts on IDEA Part C.

The pattern of disregard for and lack of investment in Part C is a major issue. While Part C will always be smaller than Part B, the scientific and evidence-based research provides ample justification regarding the efficacy of early intervention and affirms the value to society of the services provided. IDEA Part C is an essential adjunct to IDEA Part B; in addition to reducing future special education costs, early intervention services result in young children better prepared to learn and participate alongside their typical peers in preschool, school age and special education programs. As a result of participation in Part C, parents learn how to develop partnerships with professionals, learn how to negotiate the system of services, and how to support their children's healthy development and educational progress. Part C provides a critical foundation for improving growth and development in the preschool years; we ask that you recognize its value, and take appropriate action to address the issues we have identified.

Thank you for the opportunity to share our concerns with you. We have also attached the transition document that we provided to the new Administration, outlining our priorities for the coming years. We would be happy to meet with you or your staff if you have any questions. We look forward to working with you on behalf of infants and toddlers and their families.

Sincerely,

Maureen Casey
President

Attachments:

Comments on the proposed regulations
Transition document to the new Administration