

EIFA SUMMARY STATEMENT REGARDING THE PROPOSED PART C REGUALTIONS

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 by assuring meaningful family involvement in the development of Part C policies and implementation at community, state and federal levels. EIFA is pleased to offer comment on the proposed Part C regulations and would like to thank the Department of Education for the opportunity.

In preparation of developing this response, members of EIFA have participated in one conference call hosted by the IDEA Infant Toddler Coordinators Association, one conference call hosted by the Division of Early Childhood, as well as in depth conference calls with our members to analyze and review the proposed regulations. EIFA thanks our colleagues for inclusion in these conversations that allowed us to consider the impact of all the proposed regulations. After review of the entire proposed regulations package, EIFA will be developing written testimony for submission prior to the July 23, 2007 close of the comment period.

Part C has a long-standing history of being a family-driven, family-centered program. EIFA supports many of the positive thematic language changes throughout the proposed regulations. Specifically, EIFA endorses the addition of teachers of the visually impaired to the definition of special educator as well as the language regarding transition timeline changes expressly related to children referred after age two. EIFA applauds the emphasis on at-risk populations throughout the document. We would like to note that many of the changes proposed would add increasing requirements on already stretched EIS programs. This comes during a recommended \$13 million decrease in federal funding through the President's budget request for '08.

EIFA offers the following priority comments regarding regulations that will directly impact the very nature and base of the program from a family perspective:

Commencement of 45-Day Timeline

In regards to proposed regulation 303.320(e)(1), States have made significant progress in meeting the 45-day timeline for evaluation and assessment of infants and toddlers. We are aware that the Part B timeline begins at the point of consent, however we believe there are inherent differences between Part B and Part C. When families begin to notice that their infant or toddler may have delays it may take some time for them to identify the correct avenue to access early intervention services. It is therefore important that Part C agencies feel the urgency to begin the process by obtaining consent to evaluate. We are concerned that adding an undefined period of time in front of the timeline will delay services and decrease accountability. The proposed language changes the locus of control to the provider – not the parent. This is inconsistent with the nature and intent of Part C.

Family-Directed Assessment

EIFA recognizes the importance of a family-directed assessment. Proposed 303.320 (c) refers to this voluntary assessment, which assists families in identifying and addressing their resources, priorities and concerns that can result in improved and functional outcomes. EIFA would encourage the Department to use the term "family-directed assessment" consistently. The family-directed assessment should be something done with a family and not to a family. We would encourage the Department to include the reference to include members of the extended family, as invited by the parent(s) in the regulation. EIFA supports the inclusion of the language "as determined not just through the use of an assessment tool, but through a voluntary personal interview with the family" as a positive aspect of the family-directed assessment portion of the draft regulations.

Parent Representatives on ICCs

EIFA recommends that the language in proposed 303.601(a)(1)(iii) be removed. It is counterproductive to pit families against families and imply that some parents are more valuable than others. Many parents choose to utilize the knowledge and skills they gain as a result of being involved in early intervention. Why should some be penalized, or told that their expertise as a parent is unwanted, because they also have the credentials to work for early intervention programs? An alternative could be to require that parents with diverse perspectives be appointed to an SICC, including some parents who do not work for early intervention providers or PTI's or other agencies that interact with families enrolled in EI.

Service Coordination

Service Coordination, as defined in § 303.23 (a) is an important component of the Early Intervention program for infants and toddlers with disabilities and their families. When families enter the Early Intervention program they are introduced to a new set of systems. It is important that they obtain all early intervention services they need and have assistance in gaining access to non-early intervention services that they may also need. We believe that the original language which states that families be provided with one service coordinator who must help parents to obtain services and assistance they need and to facilitate the timely delivery of services is preferred language. Gaining access may be interpreted, for example, to mean that a family is on a waiting list or is given a list of providers to hunt out on their own. EIFA requests that the Department return the current regulation's stronger language in order to ensure services are obtained and delivered.

Referral

The proposed regulations at §303.302, regarding referral procedures, removed the requirement that referrals be made no more than two working days after a child has been identified. While we appreciate the difficulties that agencies have with enforcement of this requirement it is important that primary referral sources have clear and consistent guidelines for referral procedures. EIFA is concerned that this language, combined with moving the starting point for the 45-day timeline, will result in significant delays in determining eligibility and initiating services. EIFA recommends keeping "2 working days" as the preferred practice required of lead agencies when establishing relationships with primary referral sources and when developing protocols.

Other areas of concern that are more detailed in our companion table include:

Private Insurance, Public Insurance and Benefits

EIFA is encouraged by the proposed regulations with regard to policies related to the use of insurance or public benefits, 303.520(b). We agree with the Department that families need to be informed of any, and all, costs as part of consenting to the use of private or public insurance or benefits. EIFA also recognizes the funding issues that may arise if parents choose not to provide consent for public and/or private insurance or benefits; we encourage the Department to work with stakeholders to consider means to protect confidential information while enhancing funding for Part C.

Qualified Personnel

EIFA encourages the Department to retain the current regulation, that refers to respite providers, parent-to-parent support personnel, paraprofessionals and family support personnel as qualified personnel. EIFA suggests that a solution would be to specifically add "parents of a child with a disability" to 303.119, which would address that they be appropriately trained and supervised as EI providers. In addition, EIFA recommends an addition to proposed 303.105, to read "...positive efforts to employ and advance in employment, qualified individuals with disabilities and qualified parents of individuals with disabilities in programs assisted under Part C of the Act."

Comprehensive System of Personnel Development

Proposed 303.118 (b)(3) language is weakened as the regulation now states "may include" and drops the language "in enhancing the development of their children". EIFA strongly recommends maintaining the original language in 303.360 (b). It is important that all members of the IFSP team have access to training to support them in their role to identify functional outcomes and develop an IFSP, which enhances the development of an infant or toddler with a disability.

Challenging Parent's when they decline initial evaluation

While this language appears to be an attempt to align with Part B, there are inherent differences between Part C and Part B. EIFA recommends 303.420(c)(1) be deleted from the new regulations. Part C is a voluntary program by definition; this process does not have application in Part C procedures. The language in 303.420(c)(1) is incompatible with preceding language, as well as, the voluntary nature of Part C programs.

Natural Environments

For many families raising infants and toddlers with disabilities natural environments is a simple and common sense term. We are intimately aware that natural environments are more than a place. It is essential that the field understand this term and assist families in understanding the impact of certain decisions about where, when and how services are provided to our children. EIFA recommends keeping the original definition of Natural Environments in the new regulations. The basic intent of the language appears to be equivalent. Given this, and given the challenges that ensued for programs in initially implementing the Natural Environments requirement, we feel this may present an unnecessary interpretive hurdle for programs as they implement the new regulations. EIFA recommends that 303.344(B)(3) be changed to read "Based on the child's needs," rather

than "outcomes". Setting should be determined based on the child's circumstances, not the outcome. 'Outcomes' could be manipulated such that they could only be addressed in a non-natural setting.

Filing Complaints

EIFA recommends the deletion of proposed 303.434 (d) as this provision would be a deterrent for families to file complaints to the lead agency due to the very personal nature of EIS provider relationships. It is EIFA's experience that families pursue unofficial avenues, without resolution, prior to filing complaints. Requiring a more formal process would be an additional burden for the family and there is concern that immediate services may be compromised.

Content of IFSP

EIFA recommends adding the language in NOTE 2 of 303.344 into Proposed 303.344. While viewed as "explanatory", this note provides guidance on the manner in which an IFSP is developed. While the draft regulations provide guidance on obtaining parent consent, there is no other section that provides a working description of the role of parents in the development and implementation of their IFSP.

Resolution of complaints

It is the sentiment of EIFA that further guidance should be provided in regards to "reasonable effort". Clarification is needed in Section 303.442 (b) (4) which references obtaining parent participation in the resolution process. Examples of clarifying "reasonable effort" include adding a numerical factor, describing different types of contact or activities, or setting a specified amount of time.

Nutrition Services

EIFA is concerned that nutritional services have been removed from the regulations. We are further confused as to why the term Registered Dietician is included in 303.13(c) if nutrition services have been removed. EIFA would encourage the Department to retain nutritional services.

The following are areas that EIFA would like to see addressed with increased clarification of language and stronger equitability for families. Please see the companion grid for more details:

- Central Directory (303.117)
- Compensation for ICC parents

- Cultural Competency (303.227)
- Health Services (303.16)
- Screening (303.303)
- Resources (303.207)
- Transportation (303.12)

In addition to the above statement regarding f reasonable effort, states also must report their performance on the 45-day timeline indicator and completion of the 90-day transition meeting. In both of those instances, states are able to exclude those situations that were out of compliance due to parent reason. Presently there are no specific regulations that address this exclusion of "parent reason" in the data collection process. EIFA is concerned that without clarification of "reasonable effort" that parent reason will become the scapegoat for program non-compliance.

EIFA is neutral on the issue of the three to five provision. However, we concur with the Department that it is essential that families be provided with an annual notice that includes a description of the rights of parents to elect to receive early intervention services under Part C or preschool services under Part B, an explanation of the differences between early intervention services and preschool services, the types and locations at which the services are provided, the procedural safeguards that apply and possible costs, if any.

Again, thank you for the opportunity to comment on the proposed Part C regulations. As EIFA and our colleagues continue to analyze and review the possible implications of the package, we will continue to submit responses through the written testimony process. EIFA is committed to improving outcomes for infants and toddlers with disabilities and their families.