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Statewide Parent Advocacy Network, Inc.

Family Voices-NJ comments on Proposed IDEA Part C Regulations for Early Intervention

7/20/07

We are writing concerning the proposed Part C Regulations for Early Intervention under IDEA. Family Voices is a national network on behalf of children with special healthcare needs and our NJ Chapter is housed at the Statewide Parent Advocacy Network, NJ's federally funded Parent Training and Information Center. In addition, SPAN is the Family-to-Family Health Information Center for the state as well as home for NJ Parent-to-Parent and a chapter of the Federation of Families for Children's Mental Health.

Subpart A

303.1 Purpose of the early intervention program for infants and toddlers with disabilities (e) "...expand opportunities for children...who would be at risk of having substantial developmental delay..." This is a good addition as premature infants weighing less than 750 grams are the most at risk for needing early intervention and gives states flexibility.

303.501 Permissive use of funds by the lead agency (a) "direct early intervention services...that are not otherwise funded through other public or private sources" There needs to be clarification on this and an explanation on implementation.

(c) ..."continue to provide early intervention services...in lieu of FAPE" This is not a good concept in states that have family cost share for early intervention services and/or are using private insurance affecting the lifetime cap, as children ages 3 and older are entitled to a *free*, appropriate public education (FAPE) under Part B of IDEA.

(e) "expanding, or improving collaborative efforts related to at-risk..." and (3) "conducting periodic follow-up" Again, there is the opportunity to serve more premature infants who are at risk of need early intervention services. Follow-up is important and often age-adjustment temporarily obscures developmental delays for this population.

303.13 Early intervention services (12) (iv) "Provision of sign language, cued language, and auditory/oral language services" This is a good addition, clarifying the need for alternate means of communication. Research has shown that sign language is useful for speech delays, not just for children with hearing impairment.

(14) (c) (13) “vision specialists, including ophthalmologists and optometrists” This was another good addition and clarification of needed early intervention services.

The original language in 303.12 (7) nutrition services needs to be retained. Nutrition services affects other services such as PT, OT, and speech, especially as feeding problems relate to failure to thrive resulting in the child’s size compromising their relative muscle strength.

Music therapy should be listed and defined in this section as the U.S. Dept. of Education has clarified it as a related service under IDEA (OSEP [Letter to Farbman 2000](#)).

303.17 Homeless children The focus on child find for homeless children is a good addition and clarification on needed services for a traditionally underserved population.

303.21 Infant or toddler with a disability (a) (2) (c) (1) “school readiness and incorporates pre-literacy, language, and numeracy skills” It is good to add a focus on literacy skills due to recent research on best outcomes. However, this should not outweigh EI’s longstanding focus on overall child development, including social-emotional development, and family education and support.

Subpart B

303.203 Statewide system and description of services (b) “use of public insurance or benefits, private insurance, or family costs or fees” see additional comments subpart F. Please note that the process for family cost share must follow the state’s Administrative Procedures Act rather than bypassing the process by using the state budget or other legislation in order to ensure public hearings etc. States must also inform families of their rights to FAPE, and information regarding access to insurance resulting in appeals or affecting lifetime caps.

303.208 Public participation policies and procedures (a) (1) “lead agency holds public hearings, gives adequate notice...” Again, states must follow their Administrative Procedures Act to ensure adequate public input.

303.204 (a) Application’s definition of at-risk infants and toddlers and description of services “state’s definition of at-risk infants” States need to look closely at what proportion of their premature infants end up later in early intervention and develop presumptive eligibility criteria, and the regulations should encourage this.

303.209 Transition to preschool and other programs (a) (1) “smooth transition...” and (i) “...to preschool” There is no mention of transition to the least restrictive environment (LRE). IDEA requires that first consideration must be given to the school the child would have attended if they didn’t have a disability and the general education class. Alternative placement only occurs if supports and services are not successful.

(d) (2) "...establish transition plan" Again, no mention is made of LRE. Parents entering the educational system will not be aware of their children's rights and are most often referred to preschool disabled classes or even more restrictive settings for disabilities such as autism.

303.211 State option to make services under this part available to children ages three and older (a) (1) "...enter kindergarten or elementary school" Again, in states where there is family cost share and/or insurance access affecting lifetime caps, children are entitled to FAPE at age 3 and there should be strong protections for families in the regulations, including the requirement for very clear information about parental choices and the opportunity to opt out of continued EI services and into FAPE preschool services at any time at parental discretion.

(3) "will not affect the right of any child served pursuant to this section to receive FAPE" This needs to be clarified and an explanation on implementation is needed.

(7) "substantiated case of trauma due to exposure to family violence" CAPTA is a good starting point due to the high percentage of children in need of early intervention services in this population, however cross training is needed for EI eligibility.

303.111 State definition of developmental delay "state's rigorous definition of developmental delay" State guidelines can be somewhat nebulous and there needs to be some standardization of developmental delay across the board.

Subpart C no comments

Subpart D

303.300 Public Awareness Programs (a) (1) (ii) "Dissemination to all primary referral sources...including especially parents with premature infants" This is a good addition, particularly with the emphasis on premature infants at risk and giving information to parents who may not otherwise be aware of early intervention services.

303.302 Referral procedures The previous language "two working days" must be retained rather than "referring the child as soon as possible" to ensure incentives and accountability for timely services.

303.303 Screening procedures If screening is to be considered, options for evaluation must remain and timelines must be enforced. Current policy requires evaluation, not screening, for eligibility. Since the state must identify, evaluate and provide services to all eligible infants, toddlers, and families, any provision for screening must be limited. Support the language allowing parents to request an evaluation at any time and requiring states to conduct such evaluation regardless of screening determinations.

303.320 Evaluation and assessment of the child and family and assessment of service needs (a) (1) (i) "A timely, comprehensive, multidisciplinary evaluation" This will be further delayed if the 45 day timeline is changed from date of referral to the date of written consent. The window of opportunity for EI is already very short.

303.118 **Comprehensive system of personnel development** (b)(2) “training personnel in the emotional and social development of young children” This is a good addition due to rise in autism and children with mental health issues, but all training should be required and the new language says “may include”. Further, training must include assisting parents in the IFSP process and in fulfilling their role in the IFSP process and in their child’s life.

Subpart E

303.25 **Native Language** (b) “such as sign language, Braille, or oral communication” This is a good addition in alternative forms of communication. We are somewhat concerned regarding the apparent assumption that infants and toddlers could have a language that is different from their parents; further, to ensure that families can participate fully in evaluation and in service delivery, evaluations and services must be conducted in the family’s primary language.

303.403 **Definitions** (9) “Education records includes all early intervention records required to be collected” This appears to allow the release of confidential information to the school district. As early intervention is a voluntary program, parents should be required to be informed of their FERPA rights and states should not be able to share records with schools without parental notice and consent. Both EI and preschool are voluntary systems and thus no decisions should be made without parental consent.

303.405 **Access Rights** (c) “An agency shall presume that the parent has the authority to inspect and review records...unless the agency has been provided documentation that the parent does not have the authority under applicable State law governing such matters as custody, foster care, guardianship, separation, and divorce” This is an excellent safeguard as the focus on the child is often lost in these situations.

303.420 **Parental consent and ability to decline service** (a) (1) “administering screening procedures...” Although it is a good idea to have parental consent, current regulations require a complete evaluation, not screening, to determine eligibility. If screening is to be considered, options for evaluation must remain and timelines must be enforced as mentioned above.

(4) “public or private insurance is used...” Again, parents must be informed that they may be responsible for appeals of denials and the child’s lifetime cap may be affected.

303.431 **Mediation** (b) (2) (ii) “The lead agency must select mediators in a random, rotational, or other impartial basis.” This is a good addition to improve neutrality. We also support the language requiring mediators to be knowledgeable both in the law and in mediation strategies.

(6) “A written, signed mediation agreement under this paragraph is enforceable” This is a good addition to enforce the mediation decision.

303.411 **Due Process** (6) “A proposed resolution of the problem...” In general, this will make it easier for parties to reach an agreement.

(d) “Sufficiency of complaint” This will deter families from filing and given the low rate of complaints currently filed in early intervention, there is no need to deter families to any greater extent than is currently the case.

303.440 **Filing a due process complaint** Hearings should not be allowed to override parental consent, as early invention is a voluntary system and lead agencies and/or EI providers could use this provision to bully or intimidate families – particularly immigrant, limited English-speaking, low-income, low-literacy, or otherwise traditionally underserved families – to consent to an evaluation they do not want when they will not have to consent to EI services so such an evaluation would merely be a waste of time.

303.442 **Resolution process** If done in good faith, the resolution process may avoid due process. However, it may be used to cause time delays of an additional 30 days. Given the fact that there are so few EI due process requests, it is clear that parents are not using the due process procedures recklessly. The short window of opportunity for early intervention mitigates against insertion of an additional time period for a “resolution process” into the EI due process procedures.

Subpart F

303.721 **Annual report of children served report requirement** (a) (2) “stopped receiving early intervention services...” There needs to be data tracking of premature infants who end up in early intervention later and could have been served earlier under presumptive eligibility as well as tracking families declining services due to cost share.

303.520 **Policies related to use of insurance or public benefits for payment of services** (a) (2) “the required use of private insurance as the primary...” Information must be provided that most insurers do not cover habilitative services for children as developmental or educational in nature resulting in multiple appeals and it would count against the child’s lifetime cap.

(b) “private insurance...only if the parent provides consent” Again, parents needs to be informed of the consequences such as multiple appeals and lifetime caps as mentioned above.

(2) “parental consent requirements...do not apply if the State has enacted a Sate statute regarding private health insurances coverage for the early intervention services under Part C of the Act that insures that the use of private health insurance to pay for Part C services cannot.—(i) Count towards the lifetime coverage” It appears to imply then that no consent is needed. If insurance is accessed without consent and claims are denied by the carrier, there needs to be a mechanism to determine who is responsible for appeals, and if denied, early intervention services costs. In addition, if insurance is accessed without consent, approximately half of our state plans are exempt from state regulations due to ERISA, so again there needs to be a mechanism to determine who would be responsible for appeals and early intervention services costs if denied.

303.521 **System of payments and fees** (a) (6) “However for a parent determined unable to pay...must use Part C or other funds” This needs to be clarified and must have an explanation on implementation.

Subpart G no comments

Thank you for the opportunity to comment on the proposed IDEA Part C regulations for early intervention.

Sincerely,

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Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.