

III. PART C: EARLY INTERVENTION SERVICES IN NATURAL ENVIRONMENTS

In creating the Part C legislation, Congress recognized the urgent need to ensure that all infants and toddlers with disabilities and their families receive early intervention services according to their individual needs. Three of the principals on which Part C was enacted include: (1) enhancing the child's developmental potential, (2) enhancing the capacity of families to meet the needs of their infant or toddler with disabilities, and (3) improving and expanding existing early intervention services being provided to children with disabilities and their families.

To assist families in this process, Congress also requires that each family be provided with a service coordinator, to act as a single point of contact for the family. The service coordinator ensures that the rights of children and families are provided, arranges for assessments and IFSP meetings, and facilitates the provision of needed services. The service coordinator coordinates required early intervention services, as well as medical and other services the child and the child's family may need. With a single point of contact, families are relieved of the burden of searching for essential services, negotiating with multiple agencies and trying to coordinate their own service needs.

Part C requires the development and implementation of an IFSP for each eligible child. The evaluation, assessment, and IFSP process is designed to ensure that appropriate evaluation and assessments of the unique needs of the child and of the family, related to enhancing the development of their child, are conducted in a timely manner. Parents are active members of the IFSP multidisciplinary team. The team must take into consideration all the information gleaned from the evaluation and child and family assessments, in determining the appropriate services to meet the child's needs.

The IFSP must also include a statement of the natural environments in which early intervention services will be provided for the child. Children with disabilities should receive services in community settings and places where normally-developing children would be found, so that they will not be denied opportunities that all children have – to be included in all aspects of our society. Since 1991, IDEA has required that infants and toddlers with disabilities receive early intervention services in natural environments. This requirement was further reinforced by the addition of a new requirement in 1997 that early intervention can occur in a setting other than a natural environment only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment. In the event that early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment, the IFSP must include a justification of the extent, if any, to which their services will not be provided in a natural environment.

Validation Planning and Data Collection

The majority of the issues that emerged from both the State's Self-Assessment and the public forums require systemic changes in resource allocation for provision of services, recruitment and training of staff to meet the needs of children with autism, hearing impairments or vision impairments, IFSP team procedures, and training for and recruitment of service coordinators.

The Self-Assessment Report and public forum participants articulated that: (1) high caseloads of service coordinators inhibit their ability to carry out the duties required under Part C; (2) IFSPs are not developed based on individualized needs of infants, toddlers and families; (3) improved interagency collaboration is needed in order to ensure all needs and services are addressed in the IFSP process; and (4) the State has insufficient bilingual staff.

During interviews with service providers and administrators, OSEP learned that administrators in Camden County are employing creative mechanisms to retain qualified personnel. The administrator awards bonus points and monetary awards for staff to use for personal and professional development. The program generates funds for these awards by sponsoring training seminars conducted by nationally known experts that attract large audiences from many States.

A. AREAS OF NONCOMPLIANCE

1. Failure to Implement Service Coordination Responsibilities

Under 34 CFR §303.23(a) and (b), service coordinators are required to assist families in obtaining needed early intervention services, facilitate the timely delivery of available services, link the family to other available resources and continuously review and seek out appropriate services to benefit the development of each child.

DHSS has not ensured that service coordinators are performing their duties as set forth in 34 CFR §303.23 such that children and families receive the early intervention services in a timely manner in order to enhance the child's development. The lack of ongoing service coordination has resulted in lack of identification and provision of all needed services for children and families and lack of effective transition activities.

The Stakeholder Task Force and the Steering Committee reported that changes in the service coordination system, including lowering caseloads and providing training, must occur in order to ensure that all appropriate services are identified and received by eligible children and their families.

Families in all three Regions reported the service coordinators do not have adequate knowledge about the full range of services, nor the time to go out and learn about the resources that might be available. One family reported, "I don't know what my service coordinator's job is. She gives me pamphlets." Another family reported, "I have a couple of contacts per year." One service coordinator reported, "Families can, and do fall through the cracks. I would like to do more." In one Region, the service coordinators will call the providers to check on the status of the child rather than communicating directly with the family "because families are busy." One service coordinator administrator, whom also carries a caseload, reported that families do not have the support they need.

All three Regions reported that excessive service coordinator caseloads prevent service coordinators from carrying out their responsibilities under Part C. Service coordinators in two counties reported caseloads exceeding 100. One service provider stated that "service coordinators are always on the run." Families also reported that service coordinators have

caseloads that are too high. It is the therapists from whom families reported receiving support. Many families reported to OSEP that "therapists" do not have the time to be the service coordinator also.

The administrators in all three Regions agreed there are not enough service coordinators to carry out the responsibilities under Part C. Data OSEP reviewed from two Regions showed long-term vacancies in case management units. One DHSS monitoring report stated that one case management unit had had vacancies for one year. DHSS Special Child Health Services Case Management Unit supervisors reported that recruitment is hampered because of the competitive job market, salary levels and travel and flexible schedule-requirements in the State's early intervention system. In some cases, agency-hiring practices appeared to hamper recruitment because these agencies restricted hiring to certain disciplines even though State Part C policies did not have these restrictions. In the three Regions, administrators reported that the quality of service coordination units vary across the State.

The service coordinators in the three Regions reported that lack of training and State policies are barriers to active, effective service coordination. Although State policies and procedures and guidelines do not place limitations on the amount of time a service coordinator interacts with families, service coordinators reported that contact with families is driven by their interpretation of State guidelines that only require service coordinators to meet with families two times per year; at six month and annual IFSP reviews.

2. All Needed IFSP Services Are Not Identified and Provided

34 CFR §303.344(d) requires that the IFSP include a statement of specific early intervention services necessary to meet the unique needs of the child and family to achieve the outcomes listed in the IFSP, including the frequency and intensity of delivering the service. Frequency and intensity are defined as the number of days or sessions that a service will be provided during each session, the length of time the service will be provided, and whether the service is provided on an individual basis or group basis. 34 CFR §303.344(d)(2)(i). The development of an IFSP is a planning process to assist the IFSP team, including parents, in making decisions about services, frequency, intensity, and duration of services on an individual basis to meet the child's and family's unique needs.

OSEP found that IFSP teams are not making individual decisions for IFSP services for all infants and toddlers with disabilities, based on the unique needs of each child and family. DHSS and Regional staff reported that they are concerned that individualized IFSPs are not being developed and that most children receive 2 hours per week of services at public expense regardless of whether they need more or fewer hours. State policy provides that a child and family are eligible for up to two hours of services per week at public expense. If a child or family needs services beyond the 2 hours at public expense, a fee may be charged for those services based on State financial eligibility determination procedures.

OSEP reviewed 34 records from three Regions around the State. All IFSPs indicated that services would be provided from 1-2 hours per week, total for all services. Regardless of the

severity or need, 2 hours per week was the maximum provided. None of the IFSPs provided for additional services paid for by parent fees.

The Steering Committee reported that "misunderstanding or misapplication" of the guideline that services based on need are identified on the IFSP results in "needed services not being included on the IFSP, inadequate investigation of other potential funding sources (such as private insurance), and/or denial of intensive services when needed."

OSEP found inconsistencies regarding the families' view of the IFSP process and State policy. In three of the four locations visited, families reported that infants and toddlers are eligible for only 2 hours of services per week under the Part C system in New Jersey. One parent indicated that her child was in need of additional speech therapy, but would not receive it because they "already receive 2 hours of services." In one service area, 8 out of 9 parents reported that the service coordinator informed them to contact their insurance companies for additional services, but the service coordinator did not assist in this activity as required under Part C. Only in one location did the families report that infants and toddlers receive the services that are needed, although the IFSPs that were reviewed indicate they receive 1 to 2 hours of services per week.

Service Coordinators, service providers and local program administrators from all three Regions reported that almost all infants and toddlers eligible under Part C receive 2 hours per week at no cost to families, regardless of the severity of their disability and/or identified needs. Service providers report that it is difficult to explain to a family that they will only receive 2 hours of therapy a week at no cost, when they know the child would benefit from more. Administrators are in agreement that "all IFSPs seem to look alike." Administrators in one Region reported that they are aware that service coordinators and providers are reluctant to "change the cookie cutter approach to frequency and duration for financial fears - who would pay?"

Another factor that appears to limit the identification of all needed services by IFSP teams is lack of adequate personnel. One Regional Early Intervention Collaborative reported that 90% of the intervention administrators indicated difficulty with recruiting and retaining early intervention staff. Occupational, physical and speech therapy positions were the most difficult to fill. Respondents also indicated having difficulty locating providers who have experience working in early intervention. These administrators attributed recruitment and retention problems to low salaries, lack of a qualified pool of candidates, and travel requirements to ensure children are served in natural environments.

The Stakeholders Service Delivery Task Force reported that throughout the State there is a lack of trained interventionists who are skilled in working with children diagnosed with autism. Procedural Safeguards reports and parental contacts with OSEP corroborate that IFSP teams are not developing individualized IFSPs based on extensive needs of children with autism due to lack of staff experienced in working with children with autism. Staff shortages for children with hearing or visual impairments are occurring in certain areas of the State as reported by a State Task Force. OSEP has received telephone calls from advocates and parents of children with autism because they believed their children were not receiving the services they needed.

Regional staff reported to OSEP that they are trying to obtain back-up personnel from university internships to fill a temporary need. Another Region is in the process of developing a regional consulting pool to address personnel needs. DHSS has accepted the Service Delivery Task Force recommendations to address personnel shortages and inservice training. See related information under "State Supervision Methods Not Resulting in Corrections of Noncompliant Practices" in Section I of this report.

DHSS staff reported that it has provided numerous training and technical assistance opportunities for service providers, service coordinators, and administrators on the process for developing IFSPs. The State has also instituted a variety of strategies to ensure that teams are writing individualized IFSPs, such as asking teams to submit IFSPs for Regional review. However, at the time of OSEP's visit to the State, DHSS had not developed an effective means to address this statewide problem. Subsequent to OSEP's visit, DHSS held meetings in the four Regions to provide additional training on the appropriate procedures for developing IFSPs and distributed written guidance as well.

B. SUGGESTIONS FOR IMPROVED RESULTS FOR INFANTS, TODDLERS, AND THEIR FAMILIES

1. Addressing Ongoing Financial Support for the System

A Funding Task Force has convened as a result of the Stakeholder process. This 25 member group, comprised of parents, advocates, a university-based economist, and representatives from Medicaid, the State Treasury, State Administration and Management, Department of Human Services, and DHSS, is to provide recommendations about 1) disbursement of early intervention funds through competitive contractual arrangements, 2) methods to bill third party sources and 3) revising the current sliding fee scale in such a way as to place a cap on total family liability for payment of early intervention services. This workgroup is charged with developing recommendations by the end of 2001.

OSEP suggests that due to the pervasive and uncorrected issue of lack of individualized services on IFSPs that DHSS may need to develop interim plans for funding direct services based on child and family needs sooner, or provide more guidance and technical assistance to ensure children and families receive the services they need.

2. System of Child Evaluation and Assessment, Including Informed Clinical Opinion

DHSS is in the process of establishing regional evaluation teams to bring consistency to the eligibility and evaluation process throughout the State.

OSEP observed two aspects of the current evaluation process that might need additional guidance and attention during the piloting of the new system. These are: (1) Evaluation of a child's vision and hearing prior to the IFSP meeting was not being consistently carried out across the State. (2) Multidisciplinary evaluation teams in two counties reported that they did not think that clinical opinion could be used as a separate basis for establishing eligibility in addition to tests and protocols. The use of informed clinical opinion is extremely important for identifying

infants and toddlers who have atypical developmental patterns and who might need early intervention services. One evaluation team reported that many children referred by the Visiting Nurse Association are initially found ineligible but are subsequently determined eligible for early intervention services at a later date in follow-up testing. The team stated that approximately 75% of the returning children are determined eligible for early intervention. A team in another area reported that approximately 5 out of every 50 referred children are determined eligible for early intervention in follow-up evaluations. However, because they do not have a formal tracking system, they could not report how many children did not return for follow-up evaluations. This area of the State has a highly diverse population and is home to many immigrant families who might not return for follow-up evaluations for a variety of reasons. The State Part C staff stated that they had provided guidance about the use of clinical opinion as a separate criterion in the past and told OSEP they would follow up in this matter so that the evaluation teams understood the State policy.

3. System to Support Language-Minority Families

OSEP reviewed many IFSPs and evaluations that were translated into Spanish. However, New Jersey has a highly diverse population of language minority citizens who speak Chinese, Japanese, Egyptian, Hindi/other Indian dialects, Russian, Hebrew/Yiddish and Portuguese. State data indicate that between 10-17% of the families enrolled in the system at any one time do not speak or understand English.

DHSS requires contractors to have staff or consultants who speak languages represented in their respective communities. OSEP observed that children's records did not document whether or not an interpreter was present during the child's evaluation or IFSP meeting even though families needed this service according to the information in the child's record. Evaluations and IFSP meetings must be conducted in the native language of the family, unless it is clearly not feasible to do so. 34 §§CFR 303.323(a), and 303.342(d)(1)(ii).

The State is undertaking measures to analyze the gaps, if any, between available staff and the language or mode of communication of families who require interpreter services for the duration of early intervention services. OSEP learned that in Hudson County, the DHSS Special Child Health Services Case Management Unit in Hudson County has recruited service coordinators who speak Spanish, Tagalong, Ibo, Yoruba, Hindi, Urdu, and Projabr. OSEP encourages DHSS to pursue analysis and ongoing monitoring to ensure that no community is excluded from access to the early intervention system.

4. Year-Round Services

During a 12-month period, fifteen of 44 early intervention provider agencies are closed between ten and twenty-two working days in addition to the 10 State holidays. The majority of remaining provider agencies [29] closed for only a few days, primarily during the recognized State holidays, if then. State contracts specify that providers are allowed to only close one week at a time and that provider closings cannot impact on the 45-day requirements for completion of evaluations and IFSP meetings. Case management units where service coordinators are housed are open 52 weeks per year.

DHSS needs to place a special emphasis in its monitoring activities to ensure that continuous services are provided to all children and families in all geographic areas throughout the State based on the individualized needs on IFSPs.

5. Assistive Technology

Early intervention providers in one Region reported that they are not aware of any funding for purchase of assistive technology support or devices. If a child and family need a communication board, the providers construct them. Families can also borrow positioning equipment. New Jersey data in the 2000 "Annual Report to Congress" reports that .85% of infants and toddlers enrolled in early intervention received assistive technology services in accordance with their IFSPs. Motor and communication delays were the most commonly reported special needs of children enrolled in New Jersey's early intervention program [according to the State's longitudinal study]. Because children with severe motor and communication delays might require assistive technology support, OSEP suggests that DHSS provide technical assistance for IFSP teams to ensure they are knowledgeable about State policies to access assistive technology support for children enrolled in early intervention. This is an area in which interagency collaboration is important to ensure sharing of costs and resources among appropriate State agencies.