



**UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES**

Honorable Howard Peters III
Secretary
Department of Human Services
623 E. Adams
PO Box 19429
Springfield, Illinois 62794-9429

SEPTEMBER 23, 1998

Dear Secretary Peters:

During the week of March 2, 1998, the Office of Special Education Programs (OSEP) of the U.S. Department of Education conducted a targeted on-site review of the Illinois Department of Human Services' (DHS) implementation of Part C, formerly Part H, of the Individuals with Disabilities Education Act (Part C)¹. The purpose of the review was to determine whether DHS is meeting its responsibility to ensure that early intervention services for infants and toddlers with disabilities and their families are administered in a manner consistent with the requirements of Part C. OSEP focused its inquiry on specific aspects of implementation of Part C in Illinois, particularly child find and public awareness activities, provision of early intervention services to eligible children and their families in natural environments, transition from Part C to preschool or other appropriate services at age three, and DHS' administrative responsibilities for implementation of the statewide early intervention system.

The issue of whether all eligible children in the State are being served, which was the focus of litigation against the State and of Illinois' "high risk" grantee status for fiscal years (FYs) 1996 and 1997, was not investigated on this trip. However, we will be returning for a follow-up visit and will examine that and other issues at the time. In addition, we did not include in this report issues identified during the visit relating to the State's use of families' private insurance to fund Part C services, because OSEP is currently conducting rulemaking proceedings on that topic. After a final decision is made on the issues, OSEP will review Illinois' policies and practices regarding the use of insurance.

We recognize that the lead agency responsibility for Part C in Illinois changed to DHS just two months prior to OSEP's visit and that some of the problems cited in this report may well have begun during Illinois State Board of Education's (ISBE's) tenure as lead agency. OSEP decided that it was important to conduct a program review early on in DHS' tenure as the lead agency for Part C to facilitate an ongoing working relationship between DHS and OSEP. One area of particular concern and in need of immediate attention is the number of inconsistencies with Federal law (34 CFR Part 303) found in the "Early Intervention Services System Procedure Manual." OSEP was told by all Child and Family Connections (CFC) managers and initial service coordinators visited that the Manual is their primary guidance document to implement Part C. DHS must take immediate action to correct the inconsistent procedures. These issues are addressed in Enclosure A to this letter, section III.D.2. On July 7, 1998, this Office received a

¹The findings contained in this report are based on the regulatory requirements of Part H of IDEA that were in effect at the time of OSEP's monitoring visit.

600 INDEPENDENCE AVE., S.W., WASHINGTON, DC 20202

Our mission is to ensure equal access to education and to promote educational excellence throughout the Nation

copy of revisions of selected forms in the Manual. This Office will work with your staff to identify other areas of the Manual found to be inconsistent with Part C requirements and in need of correction.

OSEP's monitoring places strong emphasis on those requirements most closely associated with positive results for children with disabilities and their families. During the exit briefing at the conclusion of OSEP's on-site visit, members of the OSEP monitoring team (Dr. Bobbi Stettner-Eaton, Dr. Gregg Corr, Ms. Terese Lilly, Ms. Sarah Willis) discussed the preliminary findings with you, members of your staff (i.e., Associate Secretary Ann Patla, Deputy Division Director Connie Brooks, and Bureau Chief/Part C Coordinator Mary Miller) and Ms. Sue Walter, the representative of the Illinois Interagency Council for Early Intervention (IICEI). At the time of the briefing, we highlighted both areas that OSEP considers strengths of Illinois' early intervention system, as well as areas that continue to be a challenge.

Enclosure A of this letter sets forth OSEP's findings of non-compliance with Federal requirements. Enclosure B addresses some of the overarching systemic concerns related to the implementation of Illinois' statewide early intervention system, and is offered for technical assistance purposes only.

OSEP'S MONITORING METHODOLOGY

Pre-site Document Review

As in all States, OSEP used a multifaceted process to review the implementation of Part C in Illinois. In addition to on-site visits, this process included: review and approval of the State's Part C application which sets out the State's statute, policies and procedures, review of the State's annual performance report, and other correspondence, and telephone calls that OSEP received regarding the State's implementation from a variety of sources, including parents and advocates. Prior to its visit, OSEP also requested and reviewed additional documentation related to the State's implementation of requirements for due process hearings, complaint resolution, and monitoring procedures, as well as the child count and service reports from the twenty-four Child and Family Connections sites. During the initial planning conversations, Ms. Miller explained that Child and Family Connections is a statewide endeavor with regional points of entry into the early intervention system, that is responsible for the comprehensive, multidisciplinary evaluation of each child, birth through two, to determine eligibility, needed assessment activities related to the child and the child's family, and development and implementation of the Individualized Family Service Plan (IFSP) within the 45-day time frame.

Selection of Monitoring Issues and Providers to Visit

OSEP reviewed State documents regarding the provision of early intervention services in determining the issues that it would review in the on-site visit. In conjunction with Ms. Miller and her staff, OSEP identified five Child and Family Connections sites to visit as a sample of the statewide implementation, including one of the sites previously deemed a "demonstration" site.

On-site Data Collection and Findings

The five Child and Family Connections managers also invited service providers and other Child and Family Connections managers in proximity to their geographic area to be part of the OSEP interviews. For purposes of this report, provider areas are identified alphabetically as A, B, C, D, or E, and include both the original five Child and Family Connections Sites and the subsequently participating sites from the surrounding areas. OSEP uses these designations rather than the name of any of the Child and Family Connections or providers in Enclosure A because the findings in Enclosure A focus on the effectiveness of DHS' system for ensuring compliance, rather than compliance by any particular provider.

INTERVIEW LOCATION	CHILD AND FAMILY CONNECTIONS SITES	DESIGNATION
East St. Louis	Child and Family Connections # 21, 22, 24	Provider Area A
Effingham	Child and Family Connections # 19, 20, 23	Provider Area B
Springfield	Child and Family Connections # 17 & 18	Provider Area C
Chicagoland	Child and Family Connections # 7 - 12	Provider Area D
Bloomington	Child and Family Connections # 13 - 16	Provider Area E

During the entrance conference on March 2, 1998, Dr. Stettner-Eaton, the OSEP Part C contact, and Dr. Corr, the OSEP Associate Division Director, interviewed Ms. Patla, Ms. Miller, Ms. Brooks, and you. Two additional interviews were also held on that date; one with representative members of the Executive Committee of the Illinois Interagency Council for Early Intervention and the other with members of the Early Intervention Transition Team, which facilitated the transition of lead agency responsibility for the implementation of the statewide system of early intervention services from ISBE to DHS. In addition, relevant documentation was also reviewed.

Drs. Stettner-Eaton and Corr also visited informally with Dr. Vincent Allocco and several of his staff at El Valor to obtain information about services to predominantly Spanish-speaking families served in the immediate Chicago area. On March 3, Drs. Stettner-Eaton and Corr conducted group interviews at Child and Family Connections site #7 in Chicago with parents of children served by the Part C system, service coordinators, service providers, and Child and Family Connections managers from sites #7 through #12. On March 4, a similar process of group interviews, as identified above, was conducted at the Child and Family Connections site #16 in Bloomington, including Child and Family Connections managers from sites #13 through #16.

The other OSEP team, Ms. Lilly and Ms. Willis, visited and collected implementation data at Child and Family Connections sites in East St. Louis (Child and Family Connections sites #21, 22, 24), Effingham (Child and Family Connections sites #19, 20, 23), and Springfield (Child and

Family Connections sites #17 and 18). Again, a similar pattern of group interviews was followed as described above. Where appropriate, OSEP has included data in Enclosure A that it collected from those sites that support or clarify its findings regarding the sufficiency and effectiveness of the early intervention system for ensuring compliance with the requirements of Part C.

Involvement of Parents and Advocates:

OSEP is committed to actively involving parents and advocates as integral partners in the monitoring process. Therefore, every effort is made to include their input by soliciting their perceptions regarding various aspects of implementation of the statewide early intervention system. As previously stated, OSEP conducted small group parent interviews at each of the five Child and Family Connections sites where interviews were conducted. These meetings provided OSEP with parents' views of the effectiveness of the early intervention services provided for infants, toddlers and their families, as well as the challenges.

Parents and advocates were also involved in a stakeholders' meeting that was convened by DHS at the conclusion of OSEP's monitoring visit. Prior to the on-site visit, OSEP worked closely with DHS to identify the representative constituencies needed at the stakeholders' meeting. Stakeholder representation included individuals from two different parent training and information centers, advocates, parents, including a parent representative from the Illinois Interagency Council on Early Intervention, members of the State Early Intervention Transition Team, a legislative staff representative, a representative from ISBE, and DHS staff. Ms. Jo Schackleford, from the National Early Childhood Technical Assistance System (NEC*TAS), which is Federally-funded by OSEP to provide technical assistance to States in the implementation of Part C and the Preschool Program, facilitated the stakeholders' meeting.

During the stakeholders' meeting, OSEP presented its initial findings from the monitoring visit and DHS provided its observations, reactions, and responses to the issues raised by OSEP. In many cases, DHS confirmed OSEP's initial impressions. These discussions were followed by break-out sessions in which the stakeholders identified strategies and activities that could be utilized to address the identified areas of deficiencies, including approximate timelines, resources, and tentative identification of responsible persons.

The outcome of the stakeholders' meeting was the development of a draft improvement action plan, which DHS will revise for completeness after reviewing the findings identified in Enclosure A. In order to support the development of a mutually agreeable improvement action plan that will correct the findings and improve results for young children with disabilities and their families, we would like to schedule, at your convenience, a conference call with DHS, the Chair of the Illinois Interagency Council on Early Intervention, and any other appropriate representatives from the stakeholders' meeting to solidify the improvement action plan. The final improvement action plan must be developed and submitted to this Office within 45 days of receipt of this letter.

Follow-up Procedures

Enclosure A outlines the findings DHS must address in its improvement action plan. The findings in this letter are final, unless within 15 days from the date on which DHS receives this letter, DHS concludes that evidence of noncompliance is significantly inaccurate or that one or more findings

is incorrect and requests reconsideration of such finding(s). Any request for reconsideration must specify the finding(s) for which DHS requests reconsideration, the factual and/or legal basis for the request, and must include documentation to support the request. OSEP will review any DHS request for reconsideration and, if appropriate, issue a letter of response informing DHS of any revision to the findings. Requests for reconsideration of a finding will not delay the development of the improvement action plan and implementation timelines for findings not part of the reconsideration request. Our staff is available to provide technical assistance during any phase of the development and implementation of DHS' improvement plan. Please let me know if we can be of further assistance.

I would like to thank you and the DHS staff, particularly Ms. Miller and the Child and Family Connections managers, for their cooperation and assistance during our review. Throughout the monitoring process, DHS staff was very responsive in providing information that enabled OSEP staff to acquire a better understanding of the implementation of Part C in Illinois.

The Committee Report that accompanied the reauthorization of the IDEA, Pub. L. 105-17, recognized the importance of early intervention services for infants and toddlers with disabilities and reconfirmed our belief that it is in the best interest of these children, their families, schools, and society in general that services continue to be provided. We thank you for your efforts to improve early intervention services and results for the youngest of children with disabilities in Illinois.

Sincerely,

Thomas Hehir
Director
Office of Special Education Programs

Enclosures

cc: Ms. Mary Miller
Bureau Chief/Part C Coordinator

ENCLOSURE A

FINDINGS AND REQUIRED FOLLOW-UP ACTIONS

In order to begin immediate correction of the findings set forth in the following table, DHS must take the following general corrective actions:

1. DHS must distribute OSEP's letter of findings to all public agencies and early intervention providers involved in the Part C program, together with a memorandum directing them to determine whether they have complied with Part C requirements, as clarified by OSEP's Letter of Findings. The memorandum must further direct these agencies and providers to discontinue any noncompliant practices and implement procedures that are consistent with Part C, and submit documentation to DHS that they have implemented revised procedures that correct the cited deficiencies. DHS must submit this memorandum to OSEP within 30 days of the date on which DHS receives this letter. Within 15 days of OSEP's approval of the memorandum, DHS must disseminate it to all appropriate agencies and early intervention providers throughout Illinois. For the Provider Areas where OSEP identified deficiencies, DHS must submit documentation to OSEP verifying that the noted deficiencies have been corrected.
2. DHS must develop an improvement plan, in conjunction with OSEP, the Illinois Interagency Council on Early Intervention, and other appropriate partners, to address the deficiencies detailed in this letter of findings. The final improvement action plan must be developed and submitted to this Office within 45 days of DHS' receipt of this letter, and must be disseminated widely to inform the public of the actions being taken to address the findings. In addition, DHS must send to OSEP verification that the deficiencies have been corrected.

OSEP identified findings in three areas: service coordination, provision of early intervention services, and general administration and supervision. A discussion of each follows.

I. SERVICE COORDINATION

Background:

Consistent with 34 CFR §303.22, each State must ensure that service coordination is available for each eligible child and the child's family upon referral to the public agency and throughout the child's eligibility for services. Service coordination is an active ongoing process that involves assisting parents of eligible children in gaining access to early intervention services and other services identified in the individualized family service plan (IFSP), facilitating the timely delivery of available services and continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility. It is the service coordinator who is the single point of contact between the family and the early intervention system, and provides support in negotiating the identification and evaluation process, development and implementation of the IFSP, and facilitating linkages with other services, including medical services, outside the immediate purview of the early intervention system.

Finding 1:

OSEP finds that Illinois is not ensuring that service coordination that meets the requirements of Part C is provided to all eligible children and their families. In general, service coordinators are not assisting parents in obtaining all needed services for eligible children and families.

Service coordinators must assist parents of eligible children in gaining access to early intervention services and serve as the single point of contact in helping the family obtain the services and assistance needed. 34 CFR §303.22. However, Child and Family Connections managers, service coordinators, service providers, and parents across the State told OSEP that parents typically were not given direct assistance in obtaining services, but rather were provided with a list of provider phone numbers. The list contains the names and telephone numbers of service providers who are enrolled² in the Illinois early intervention system. Information provided to parents about service coordination did not appear to be sufficient to inform parents about the service coordination function. Parents often did not know to call their service coordinator if they had a concern; in fact, many of the parents stated that they did not know who their service coordinator was. Without the assistance of their service coordinator or other IFSP team members, parents must research provider availability, schedules, method of providing services, and location of services in order to obtain the early intervention services needed for their child. Service coordinators are therefore not coordinating services from different providers nor serving as the single point of contact for families. The required purpose and very intent of service coordination, to assist parents in gaining access to the appropriate early intervention services identified on their child's IFSP, is not occurring. During the stakeholders' meeting, Ms. Miller confirmed this practice and stated that service coordination in Illinois is not being provided as required.

Another responsibility of the service coordinator is to identify needed resources and to coordinate services across agency lines for an eligible child and the child's family. 34 CFR 303.22(a)(2). However, service coordinators and providers in Provider Areas B, C and E reported that if the services needed by a child were not available within their own provider agency, the child and family did not get that particular service. Further, service coordinators in Provider Areas D and E, and a Child and Family Connections manager from Provider Area B, stated that they did not know where to locate other service providers who might be available to provide services because there is a delay in receiving updated lists of newly enrolled providers in the Illinois early intervention system, or because of a shortage of available service providers.

Service coordinators in Provider Areas A, B, D, and E reported that they only coordinated services from their own provider agency, even if needed services were not available from the agency. As an example, a parent from Provider area B told OSEP that she herself made numerous telephone calls to obtain respite care for her child that was not available from the agency where her child received a majority of her services. She also stated that the service coordinator only coordinated services from her employing agency, not outside or across agency

2 An "enrolled" provider is a service provider who has been enrolled by DHS in the participating provider network and is approved to receive reimbursement for costs of providing early intervention services to eligible children and their families, consistent with Part C requirements.

lines, as required by Part C. Another parent, from Provider Area A, stated that the physical therapy services listed on her child's IFSP were not provided because the service coordinator said there were no available enrolled providers. However, the parent then located a physical therapist outside the provider network who was willing to provide the needed services for her child.

When OSEP interviewed service coordinators, they responded that they did not know they were required to perform many of the service coordination functions contained in §303.22. In every site OSEP visited, the Child and Family Connections managers and service coordinators expressed the need for training related to their positions. This is particularly critical for service coordinators who are required to assist families in many ways and facilitate the timely delivery of services. The initial service coordinators, who typically perform intake functions and initial contact with families, reported that they had completed the brief State training activity targeted for them. However, in every site visit, ongoing service coordinators reported that, although they had not yet received training, they were working with families to the best of their abilities. Child and Family Connections managers and ongoing service coordinators reported that training was scheduled for the near future. At the stakeholders' meeting, Ms. Miller confirmed that at the time of OSEP's visit, many of the ongoing service coordinators had not received any training for their jobs, but that training was scheduled. The May 26, 1998 quarterly report, submitted as a condition of the State's high risk grantee status, contained information that training of 525 ongoing service coordinators had been completed from February 1 through April 30, 1998.

A review of 20 IFSPs across the sites visited revealed that service coordination was listed on the IFSPs as an early intervention service, with a specified amount of time and frequency for service coordination for each child. However, all eligible children and their families are entitled to ongoing service coordination to ensure the provision of appropriate early intervention services and the identification and linkage to medical and other services, as needed. Congress recognized that service coordination, by its very nature, is an ongoing process, and it that would be difficult, if not impossible, to predetermine the amount of service coordination time needed due to the individual needs of children and families at various times throughout an eligible child's enrollment in Part C. Service coordination is, therefore, not a specific early intervention service for which frequency and intensity is identified on a child's IFSP. An IFSP which specifies a particular amount and frequency of service coordination may not allow for the full range of service coordination activities needed to provide supports to a particular child and the child's family. Specified time allocations conflict with the requirement for ongoing service coordination and may restrict the major benefits of service coordination to a family.

Of the twenty IFSPs examined, twelve indicated 30 minutes or less of service coordination per month, with seven of these listing one service coordination event per month for 15 minutes. Of the remaining eight IFSPs, two indicated four hours of service coordination per month, and three stated two hours, resulting in an average across all 20 IFSPs reviewed of 50 minutes per child per month. In these 20 IFSPs, there did not appear to be a relationship between the frequency and intensity of service coordination listed on the IFSPs and the particular needs of the child and the child's family. In addition, service coordinators in Provider Area E stated that families in their catchment area did not receive sufficient amounts of service coordination or ongoing contact. Recent studies of home visiting and service coordination indicate that the time needed to provide the array of activities for active, ongoing service coordination could not be accomplished within

the time constraints indicated on many of these IFSPs (Roberts, R., Akers, A.L., and Behl, D.D., 1996; Roberts, R.N., Behl, D.D., & Akers, A.L., 1996). OSEP noted that one possible factor contributing to these limitations on the frequency and intensity of service coordination is that the Child and Family Connections sites were only receiving \$61 per month for two hours of billable service coordination per eligible child from DHS. (In addition, DHS informed OSEP that DHS is moving to a fee-for-service system for all services in the future. This change may have a further impact.)

II. PROVISION OF EARLY INTERVENTION SERVICES

Background:

Each State must develop policies and procedures to ensure that IFSPs are individually developed and implemented for each eligible child and the child's family. The State must ensure that all appropriate early intervention services are identified and provided consistent with 34 CFR §303.344.

Finding 2:

OSEP finds that DHS has not ensured that early intervention services are individually determined and that needed services are included on the IFSP and provided. The law requires that each IFSP must include a statement of specific early intervention services necessary to meet the unique needs of the child and the child's family to achieve the outcomes identified, including the frequency, intensity, and method of delivering services; the natural environments in which early intervention services will be provided; the location of the services; and payment arrangements, if any (§303.344(d)).

A. Lack of individualized decisions by the IFSP team –

Decisions related to the provision of early intervention services must be made in an IFSP meeting, by a multidisciplinary team that includes the parent. OSEP was told by Child and Family Connections managers, service coordinators, and providers in each of the Provider Areas visited that enrolled service providers predetermine the location and intensity of the services they provide regardless of the child's needs or the results of the evaluation and assessments, and that these decisions are not made by the IFSP team. Service coordinators in Provider Area D reported that the method of service delivery was based on the philosophy of a particular program/ provider and often the number of available staff. For example, in Provider Area C, a Child and Family Connections manager reported that all physical therapy services are provided in a center and all special instruction is provided only in the child's home without individualized decision-making by the IFSP team. In Provider Area B, speech services are only provided in group settings in a center-based program. In Provider areas A and B, all therapy services are provided only in a center setting. Services to a child and the child's family are most often based on the availability of the existing services and the configuration of the service delivery system (e.g., services only available on a certain day from only one available provider). Across the State, OSEP was told by ongoing service coordinators and providers that the early intervention services identified on a child's IFSP were those services available within their own agency or the DHS "participating provider network." OSEP was also told that unless a payment source could be readily identified for a specific needed early intervention service, it was typically not included in a child's IFSP.

OSEP was told that the type and location of services, and particularly the identification of a service provider was based on “family choice.” Child and Family Connections managers explained to OSEP that the expressed desires of the family related to the choice of the provider of early intervention services were honored in an effort to be “family-friendly.” Many decisions about service providers were not made by the multidisciplinary team in an IFSP meeting with parental input, but rather unilaterally by one team member, the parent. Families and service providers in the rural areas served by Provider Areas B and C reported that often the only options for families were a single available provider or no service at all.

B. Lack of personnel –

During the initial and exit interviews with DHS staff and others, all acknowledged the critical need to greatly expand the participating provider network in order to ensure that sufficient numbers of service providers are available and to ensure that no child wait for services. The lead agency, in its application, assured that it would fully implement the statewide system of early intervention services. In order to do so, it must have adequate numbers of appropriately certified and trained personnel. 34 CFR §§303.360 - 303.361. OSEP found this not to be the case. Statewide, Child and Family Connections managers, service coordinators, service providers, and parents identified specific personnel shortages within each of their service areas. The result of these shortages was evidenced in one of two ways: either specific early intervention services were not listed on a child’s IFSP although there was a documented need, or the service was identified on the IFSP and the child was placed on a waiting list until a service provider became available within the “participating provider network.” As examples: the Child and Family Connections managers in Provider Area A reported that there were not enough providers of occupational and physical therapy services; a service provider from that same area confirmed that many children were not receiving the services on their IFSPs because of the lack of providers. Service coordinators from Provider Areas B and C stated that a needed early intervention service was not listed on a child’s IFSP if there were not available providers. A service provider from Provider Area C told OSEP that vision services were not currently available to children with documented needs for this service on their IFSP, because the enrolled vision provider “was swamped.” Child and Family Connections managers and service providers from Provider Area E told OSEP that there were waiting lists for some therapy services (e.g., speech services) due to “program capacity” issues. Both in meetings with OSEP and at the stakeholders’ meeting DHS staff acknowledged the need for additional service providers across the State.

C. Lack of sufficient funds or other resources –

The IFSP is designed as a comprehensive document used to identify the specific early intervention services needed to meet the unique needs of the child and the child’s family, as well as medical and other services needed that are not the direct responsibility of the early intervention system. Child and Family Connections managers, ongoing service coordinators, and families across the State told OSEP that transportation, assistive technology, and respite care are not typically identified services on a child’s IFSP, even though the need was documented. Child and Family Connections managers reported that these three services were not included in agency contracts from DHS and there was no other fiscal mechanism to support these services. For example, Child and Family Connection managers and service coordinators in Provider Area C reported that they did not know how to access reimbursement of any costs associated with parent travel for early

intervention services, therefore needed transportation services were not included on IFSPs. These managers also reported that they could not obtain language interpreters for IFSP meetings because there was no method for financial support (e.g., for parents who are deaf or have limited English proficiency). This violates Part C requirements “that IFSP meetings must be conducted . . . in the native language of the family or other mode of communication used by the family, unless it is clearly not feasible to do so.” 34 CFR §303.342(d) and (e).

A Child and Family Connections manager from Provider Area B also stated that the lack of transportation services prevented some of the children they served from receiving other needed early intervention services identified on their IFSP. A service coordinator from Provider Area C told OSEP that a child with an auditory impairment in need of a hearing aid was referred back to the child’s own physician for assistance in obtaining a hearing aid because of the lack of funding resources within the early intervention system. The practice detailed above has resulted in children being denied appropriate early intervention services that have been documented as a need based on evaluations and assessments.

III. GENERAL ADMINISTRATION AND SUPERVISION

Background:

Under §303.501, each State must ensure that all programs and activities used to implement the statewide early intervention system are consistent with 34 CFR Part 303. The State is required to adopt and use proper methods of administering the program, including: monitoring agencies, institutions and organizations used by the State, enforcing obligations imposed on those entities as a result of these regulations, providing technical assistance if necessary, and correcting deficiencies that are identified through monitoring. Each State’s application must contain information and procedures to ensure the above. Illinois’ FY 1996 - 1998 Part C application contains the required procedures and documents.

Finding 3:

OSEP finds that the lead agency has not fulfilled its obligation for the general administration, supervision and monitoring of programs and activities used by the State, whether or not they receive assistance under Part C, to implement the statewide system of early intervention services in the following areas:

A. Confidentiality - (34 CFR §303.460) -

Each State must establish or adopt procedural safeguards to ensure that the rights of children and their families are protected, including protection of family privacy. The protection of any personally identifiable information collected, used, or maintained must meet the requirements in 34 CFR §§300.560 through 300.576, with appropriate modifications for Part C. 34 CFR §303.460. Illinois provided assurances in its FY 1996 - 1998 application that it adopted policies and procedures governing confidentiality of personally identifiable information that are consistent with §§300.560 - 300.576. As explained below, OSEP found a number of ways in which DHS is not meeting the confidentiality requirements of IDEA, particularly those related to the storage and maintenance of records.

Section 300.563 of the IDEA regulations provides for protection in the disclosure of personally identifiable information. Consistent with 34 CFR §300.563, the Illinois Early Intervention Services System Procedure Manual, at 02.20.00 and 02.60.20, states that each participating agency must maintain a record of individuals who obtain access to a child's records, including the name of the individual, date of access, and the purpose for which that individual is authorized to examine the records. However, none of the children's records that OSEP reviewed had the required access forms. In addition, records at Provider Area C were not stored in a secure location, but rather maintained in open shelving in an area where there was general access by all agency staff, many of whom were not associated with the infants and toddlers program. See §300.572.

In addition, Illinois' monitoring protocol does not address implementation of the requirements regarding the protected access of personally identifiable information and other confidentiality matters. Page 20 of the "Child Record Review, FY 1995" only requires documentation of release of information forms, not verification of the existence of access logs, as required by 34 CFR §300.563. Page 16 of the "Local System Development Review, FY 1995" requires documentation that "The LSA has procedures in place to ensure the confidentiality of all personally identifiable information about a child and the child's family", and, "There is evidence in the child's record that information is not released to other agencies unless the parent gives written consent." However, based on OSEP's monitoring visit, the lead agency needs to modify its monitoring procedures to address confidentiality.

B. Procedural Safeguards: Prior Notice; Native Language - (34 CFR §303.403(c)) –

In order for parents to exercise their rights under the IDEA, they must have access to and understand all of the procedural safeguards, including confidentiality provisions. IDEA provides that information communicated to parents be in their native language, unless not feasible to do so, in accordance with 34 CFR §§303.403(c) and 300.561(a)(1). Procedure 01.00.00 of Illinois' Early Intervention Services System Procedure Manual (page 2) confirms that family due process rights and other procedural safeguards are to be provided in the family's primary language or other mode of communication. However, across the State OSEP was told by Child and Family Connections managers and service coordinators that the Parent's Rights booklet, which is used as part of notice to inform parents about procedural safeguards, is only available in English. Service providers from Provider Areas D and E stated that there were families in their catchment area who needed a Spanish version of the Parent's Rights booklet because they were mono-lingual, but there were no such translations available³. A Child and Family Connections manager from Provider Area D reported that they sought out local assistance in order to provide the Parent's Rights booklet in Spanish to a Spanish-speaking family.

C. Policies Related to Payment for Services and Fees - (34 CFR §§303.520 - 303.521)

Each lead agency is responsible for establishing State policies related to how services to eligible children and their families will be paid for under Part C. These policies must specify, among other

3 Similarly, OSEP did not find evidence of child find activities designed to effectively reach out to Hispanic families living in rural areas of Illinois. A service coordinator from Provider Area C stated that she was unaware of any materials (e.g., child find) in Spanish that could be used with families in her catchment area.

items, which functions or services, if any, will be subject to a system of payments, including information about the payment system and schedule of sliding fees, if any, that will be used. These policies would also address use of third party private insurance, as appropriate in the State.

OSEP was told by many parents and service providers that there is great confusion across the State about the collection of fees and there is considerable inconsistency related to whether or not fees will be collected, and if so, who will collect them. Several service providers stated that they are not collecting the required fees because they have received conflicting instructions from the State and had decided not to further confuse families until the State makes a definitive decision on implementation of fees.

During the six months prior to OSEP's visit, providers reported that they were told by ISBE (lead agency at the time) that the system of fees was to be implemented, then told by ISBE to suspend collection, and then just prior to our visit, providers reported that they were informed by DHS to re-institute the fee collection. More than one provider stated that she was going to wait until DHS was certain about the permanency of the fee procedures before imposing it on families who received early intervention services. Parents from Provider Areas A, C, and D, told OSEP that families paid a fee for services based on the income information provided on the Family Resource Inventory, even though their private insurance had already paid one hundred percent of the cost of the early intervention services for which they were being billed. The State is not consistently applying its policies on fees as set forth in its FY 1996 - 1998 Part C application.

D. Supervision and monitoring of programs (§303.501) –

DHS, as lead agency for Part C, is responsible for the general administration and supervision of programs and activities used to implement Part C statewide. The lead agency is required to adopt and use proper methods of administering each program including: (1) monitoring agencies, institutions, organizations used by the State to carry out Part C; (2) enforcing any obligations imposed on those agencies under Part C; (3) providing technical assistance, if necessary, to those agencies, institutions, organizations; and (4) correcting deficiencies that are identified through monitoring.

As part of DHS' responsibility for general administration, DHS must ensure that all policies (e.g., State statutes, regulations, Governor's order, directives, other written documents that represent the State's position on this program - see 34 CFR §303.19) related to the implementation of Part C are consistent with 34 CFR Part 303.

1. Monitoring -

Appendix O of Illinois' FY 1996-1998 Part C application contains information and procedures about the Comprehensive Quality Review System (FY 1995) that the lead agency follows to conduct its monitoring efforts. This system, as described in Appendix O of the FY 1996 - 1998 application, includes a self-assessment process, an annual plan update, a consumer satisfaction survey, on-site quality review visits, and technical assistance. The Comprehensive Quality Review System of the Illinois Early Intervention Services System (e.g., local system development review and child record review) does include elements that would enable the lead agency to identify implementation problems. However, a review of these documents indicates inaccuracies in the following areas:

- * Local System Development Review (FY 1995) - Pages 16 and 17: The monitoring section on confidentiality does not contain all the required elements, consistent with 34 CFR §§300.560 - 300.573. Illinois' document is missing the following: §§300.562, 300.564 - 300.573.
- * Child Record Review (FY 1995) - Page 3 (item 1.2, 3) incorrectly includes children at risk of developmental delay as an eligible population for Part C in Illinois, which is inconsistent with Illinois' FY 1996 - 1998 application.

2. Guidance -

Each of the Child and Family Connections managers told OSEP that the Early Intervention Services System Procedure Manual is their primary source of guidance for implementation of Part C. This document was developed and implemented statewide prior to January 1, 1998, when DHS became the lead agency for Part C. The Early Intervention Services System Procedure Manual, which was distributed to all Child and Family Connections sites, contains a number of procedures that are inconsistent with 34 CFR Part 303, including:

1. Throughout the Manual, reference is made to submitting information to ISBE and ISBE's responsibilities for the early intervention system in Illinois.
 - * The document needs to be revised to refer to DHS' responsibility as lead agency.
2. P. 4 states that, "Either party may request a delay in convening a hearing and/or the pre-hearing conference."
 - * In the State's FY 1996 - 1998 application, the State included due process procedures that met the requirements of §§303.421 - 303.425 (Part C due process procedures).
 - * Part C does not permit extension of timelines. The document must be revised to ensure that timelines for due process hearing decisions are not extended, consistent with 34 CFR §303.423; and
3. Throughout the document Illinois residency and citizenship are required as a condition of receiving early intervention services (see 02.50.00, 02.50.20, 02.50.30, 02.50.40, item 2.0).
 - * The document must be amended to ensure that appropriate early intervention services are available to all children in the State who are eligible and their families. Part C does not permit the exclusion of eligible children who do not have citizenship.

ENCLOSURE B

OVERARCHING SYSTEM CONCERNS

OVERARCHING CONCERNS RELATED TO SYSTEM'S DEVELOPMENT

During the visit, OSEP identified several issues of concern which are raised as technical assistance to the lead agency as further refinements of the statewide system of early intervention service delivery occur:

1. There is confusion about the responsibilities of and relationship between the Local Interagency Councils and the Child and Family Connections offices, particularly with respect to which entity has responsibility for child find, public awareness, and the compilation of local directory information. Child and Family Connections managers also stated their confusion around who, if anyone, was responsible for supervising the Local Interagency Council director, whose salary is included in each Child and Family Connections' budget. In some cases, the Local Interagency Council director is supervised by the Child and Family Connections' manager, while in other areas the Local Interagency Councils director is independent of the Child and Family Connections, regardless of the functions that each entity performs.
2. There were a variety of concerns related to the communication linkages within the State system –
 - (a) There did not appear to be a mechanism for communication between the Local Interagency Councils and the State Interagency Coordinating Council which could facilitate better communication within the State;
 - (b) In addition, communication links between the Child and Family Connection offices and the Local Interagency Coordinating Councils were inconsistent;
 - (c) Child and Family Connections managers consistently stated that they had little access to locally generated data that was sent to DHS and didn't know which providers were newly registered with the Central Billing Office in the State. This often caused confusion or inability to identify available service providers. The Lead Agency also expressed a similar concern that at the time of OSEP's visit, Child and Family Connections offices could not access statewide data; and
 - (d) There appears to be no direct communication among the State Interagency Coordinating Council, the Local Interagency Coordinating Councils, and DHS. OSEP was told that this often results in the lack of valuable information for the Lead Agency and the State Interagency Coordinating Council to formulate strategies for system improvement.
3. The interagency linkages at both the State and local levels continue to be a challenge. The OSEP team found no evidence that early intervention service coordinators were working with other case management or service coordination programs in which a child may already be receiving services, such as Maternal and Child Health (Title V) or Medicaid (Title XIX). There also appears to be no mechanism for a service coordinator already working with a child and his/her family, but employed by another public agency, to also serve as the child's

early intervention service coordinator under Part C. This may result in duplication of service coordination for some children and their families.

4. In addition to the inconsistent implementation of the system of payments noted in the report above, there is evidence that the State may not be determining, on a consistent basis, a family's "ability to pay." Parents from Provider Areas B, C, and E, service providers and Child and Family Connections managers from Provider Areas A and B stated that they knew of families who had been previously enrolled in the early intervention system, but had withdrawn their children from services when fees were implemented. This statement was repeated by families across the State, particularly for children whose families incurred high medical costs for their care. A family from Provider Area B told OSEP that they were required to pay the sliding fees even though they owed large sums of money for expensive medical interventions and were considering bankruptcy because of the debt. Another family from Provider Area E stated that over an eighteen month period they had gone through \$1.5 million of private insurance expenditures, another \$40,000 out-of-pocket for medical treatment for their daughter, and they were also being assessed for early intervention services on the Part C sliding fee scale.

OSEP was also told by several Child and Family Connections managers that they knew of families who decided not to avail themselves of early intervention services because they did not want to complete the Family Resource Inventory as a condition to receive early intervention services. Based on this information, the State needs to examine whether it is uniformly implementing the requirement in §303.520(b)(3)(ii) that "the inability of the parents of an eligible child to pay for services will not result in the denial of services to the child or the child's family."