



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

JUNE 5, 2002

Honorable Ted Stilwell
Director of Education
Iowa Department of Education
Grimes Office Building
Des Moines, Iowa

Dear Director Stilwell:

The U.S. Department of Education's Office of Special Education Programs (OSEP) conducted a review of your State's early intervention program in Iowa during the week of October 22, 2001 for the purpose of assessing compliance in the implementation of Part C of the Individuals with Disabilities Education Act (IDEA) and assisting your State in developing strategies to improve results for children with disabilities. The IDEA Amendments of 1997 focus on "access to services" as well as "improving results" for infants, toddlers, children and youth with disabilities. In the same way, OSEP's Continuous Improvement Monitoring Process is designed to focus Federal, State and local resources on improved results for children with disabilities and their families through a working partnership among OSEP, the Iowa Department of Education (IDE) and parents and advocates in Iowa.

A critical aspect of the Continuous Improvement Monitoring Process is the work of Iowa's Steering Committee of broad-based constituencies. The Steering Committee assessed the effectiveness of State systems in ensuring improved results for children with disabilities and protection of individual rights. In addition, the Steering Committee will be designing and coordinating implementation of concrete steps for improvement. Based on information in the State's self-assessment, previous OSEP monitoring visits and reports, and review of the Eligibility Documents for Part B, OSEP determined that it did not need to conduct a monitoring review of the Part B special education program at this time.

This Report reflects OSEP's first monitoring review of the State's Part C system. OSEP's review of Part C placed a strong emphasis on those areas that are most closely associated with positive results for infants and toddlers with disabilities. In this review, Part C (services for children aged birth through 2) requirements are clustered into five major areas: Child Find and Public Awareness, Family-Centered Systems of Services, Early Intervention Services in Natural Environments, Early Childhood Transition, and General Supervision. Through examination of State and local indicators, OSEP identified components for each major area as a basis to review the State's performance.

The enclosed Report addresses significant areas of noncompliance with the requirements of Part C of the IDEA. Although Iowa has a strong history of providing quality services to infants and toddlers through its special education program and through hospital and clinic programs, the implementation of a statewide, comprehensive coordinated multidisciplinary, interagency system

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of early intervention with collaboration of all major public and private efforts in the State remains a challenge. Issues identified in this report include the coordination of child find activities to ensure all children eligible for Part C are identified and evaluated; ensuring the identification and coordination of all available resources for early intervention services within the State, especially the inclusion of the vast array of hospital and clinic services; and ensuring that the State Interagency Coordinating Council (SICC) is not impeded in the execution of its duties as specified in the Part C regulations.

OSEP believes that many areas of noncompliance are of a serious and systemic nature and will require, from IDE, intense and sustained efforts in order to bring about necessary correction of all deficiencies. If the State does not believe it can correct all of the violations within one year from OSEP's approval of a State improvement plan, IDE may want to consider requesting that the Secretary enter into a compliance agreement with the State for those areas requiring more than one year. The purpose of such an agreement would be to bring the State into full compliance with the applicable requirements of law as soon as feasible, and in any case, not longer than three years from the date of the agreement (20 U.S.C. 1234f).

In addition to a discussion of the areas of noncompliance, the Report also addresses suggestions for improvement. These suggestions include areas that were not targeted for investigation during this OSEP visit, but either need further investigation by the State to determine compliance or, with technical assistance would enhance the system's ability to provide services to infants, toddlers and their families. Enclosed you will find an Executive Summary of the Report, an Introduction including background information, and a description of issues and findings.

Incidental to our monitoring of IDE, OSEP identified a concern about possible improper use of Part C funds in the State Department of Health. The Technical Assistance staff person in that agency, whose salary was paid for 100% with Part C funds, reported having duties associated with children 0-18 years of age. This issue was raised during an exit conference call with you and other representatives of the lead agency. It is our understanding that currently, State staff is investigating this issue to ensure appropriate use of Part C funds. Please advise us of its resolution.

IDE has indicated that this Report will be shared with members of the Steering Committee and the State Interagency Coordinating Council. In response to this Report, the Iowa Department of Education must develop an improvement plan to address the areas of noncompliance identified in the Report. OSEP will work with your Steering Committee to develop corrective actions and improvement strategies to ensure improved results for children with disabilities.

We appreciated the opportunity to meet with you and Judy Jeffrey during the week of the review. We also want to thank you for the assistance and cooperation provided by your staff during our review. Throughout the course of the review, Ms. Brenda Oas and Ms. Lynda Pletcher were responsive to OSEP's requests for information, and provided access to necessary documentation that enabled OSEP staff to work in partnership with the Steering Committee to better understand the State's systems for implementing the IDEA. We appreciate the effort made by State staff to arrange meetings and interviews during the Data Collection week; as a result of their efforts, OSEP obtained information from a large number of parents (including members of

underrepresented groups), advocates, service providers, regional service coordinators, and agency personnel.

Thank you for your continued efforts toward the goal of achieving better results for infants, toddlers, children and youth with disabilities in Iowa. While schools and agencies have made great progress, significant challenges remain. Now that infants, toddlers and children with disabilities are receiving services, the critical issue is to place greater emphasis on attaining better results. To that end, we look forward to working with you in partnership to continue to improve the lives of individuals with disabilities.

Sincerely,

Stephanie S. Lee
Director
Office of Special Education Programs

Enclosures

cc: Ms. Judy Jeffrey
Ms. Lana Michelson

EXECUTIVE SUMMARY **IOWA MONITORING 2001**

The attached Report contains the results of the Data Collection activities by the Office of Special Education Programs (OSEP) as a part of its Continuous Improvement Monitoring Process. The process is designed to focus resources on improving results for infants, toddlers, children and youth with disabilities and their families through enhanced partnerships between the OSEP, State agencies, parents and advocates. The Self Assessment phase of the monitoring process included the organization of a Steering Committee, the completion of a Self-Assessment of Iowa's Part B and Part C programs, an analysis of that Self-Assessment by the Steering Committee, and a series of public input meetings to obtain comment on the Self-Assessment. The Data Collection phase, focusing only on the Part C system, included interviews with parents, agency administrators, local program administrators, service providers, service coordinators, State Interagency Coordinating Council members, State staff and reviews of children's records. Information obtained by OSEP from these data sources was shared in a meeting with the Iowa Department of Education on October 25 and 26, 2001.

This report contains a detailed description of the results of the process utilized to collect data. OSEP's monitoring activities focused on Iowa's implementation of Part C of the Individuals with Disabilities Education Act (IDEA). This data was used to determine strengths, areas of noncompliance with IDEA, and improvement in four of the five core IDEA areas. OSEP did not identify findings in the Transition Cluster.

As the Iowa Department of Education develops an improvement plan to address the areas of noncompliance identified in the Report, OSEP will be available to provide assistance to IDE and the Steering Committee to complete the improvement plan.

Early Intervention Service for Infants and Toddlers With Disabilities: **Part C of IDEA**

Strengths

OSEP observed the following strengths:

- Flexible schedules for early intervention services providers and coordinators help to ensure a family-centered approach in provision of early intervention.
- Development of Medicaid rules to improve coordination of payment sources for early intervention services to improve service delivery.

Areas of Noncompliance

OSEP observed the following areas of noncompliance:

- Not all children who may be eligible for early intervention services are located and evaluated to determine their eligibility for Part C services, and IDE does not ensure coordination of child find.

- Service coordinators are not performing all duties required by Part C.
- IFSPs do not include all early intervention and other services as required by Part C regulations.
- Transportation is not discussed at the IFSP meeting and, if needed, would not be provided as an early intervention service.
- When it is determined that services will not be provided in the natural environment, a justification statement is not included in the IFSP.
- Services and supports necessary to enhance the family’s capacity to meet the developmental needs of their child are not consistently identified and included in a statement of the specific services needed to meet the unique needs of the child and family on the IFSP.
- A single line of responsibility is not established.
- The State Interagency Council does not perform all required duties.
- All resources in the State are not coordinated or identified.
- The State has not implemented procedures to collect data on the Statewide system from various agencies and service providers.
- IDE has not ensured that all programs are monitored, and that monitoring is effective in identifying and correcting all non-compliance in local programs providing early intervention services.

IOWA MONITORING REPORT
TABLE OF CONTENTS

INTRODUCTION..... 1

I. CHILD FIND AND PUBLIC AWARENESS..... 4

 A. AREAS OF NONCOMPLIANCE..... 5

 B. SUGGESTION FOR IMPROVED RESULTS FOR INFANTS, TODDLERS AND
 THEIR FAMILIES..... 8

II. EARLY INTERVENTION IN NATURAL ENVIRONMENTS 10

 A. STRENGTH..... 11

 B. AREAS OF NONCOMPLIANCE..... 11

 C. SUGGESTIONS FOR IMPROVED RESULTS FOR INFANTS, TODDLERS, AND
 THEIR FAMILIES..... 16

III. FAMILY-CENTERED SERVICES 18

 A. STRENGTH..... 19

 B. AREA OF NONCOMPLIANCE 19

IV. GENERAL SUPERVISION AND ADMINISTRATION..... 22

 A. AREAS OF NONCOMPLIANCE..... 23

INTRODUCTION¹

Iowa is considered a rural, farming State although manufacturing is the largest source of personal income. The largest population center is the Des Moines area where approximately one-fourth of the total population of the State resides. Other significant urban areas include the Iowa City/Cedar Rapids region and the Council Bluffs area. There are three State universities, 62 public and private colleges, and 28 community college campuses.

According to the State's self-assessment document, demographics in the State are changing, and minority enrollment in schools has doubled since 1985. The number of limited-English speaking students has increased annually by 14 percent. Iowa ranks second in the nation in the percentage of families with preschool children in which all parents in the household are employed. An estimated 59 percent of Iowa children under the age of five are in some form of unregistered child care.

Information from State staff and Iowa's self assessment also noted that, by the mid 1970's, Iowa already had two well-developed service systems for children with disabilities. One is the health care system organized under the University of Iowa Hospital, in which clinics and programs reached out across the State to serve children with special health care needs. In addition, the University of Iowa Hospital began operating one of the first High Risk Follow-up Programs within the newborn nursery program that was replicated by other major hospitals in the State in the following years. Developing at the same time as the health and disabilities service system, the education system established services for infants, toddlers, children and youth with disabilities. As early as 1974, State law mandated that "Special Education" services were to serve children from birth to 21 years of age. By the middle of the 1980's, these special education services were offered through 15 "Area Education Agencies". Infants and toddlers received home instruction, group instruction, and related services. All Part B Federal and State special education regulations and procedures were applied to infant and toddler services.

In 1986, the Governor appointed the Iowa Department of Education as the lead agency for early intervention in Iowa. The first State Interagency Coordinating Council (SICC) was established in 1988. During the course of implementation of Part C, the four representatives on this SICC from the Child Health Specialty Clinics, and the Departments of Education, Human Services, Public Health began to meet formally as a "Management Team" for the implementation of the interagency requirements of the Federal law.

Staff for the Early Access program, the State's Part C early intervention program, includes a full time coordinator, five Technical Assistant positions and 20 full or halftime regional coordinators. The Part C coordinator and three of the Technical Assistants are assigned to the Department of Education and report to the Director of Special Education. The fourth Technical Assistant is assigned to the Department of Health and reports to the Bureau Chief for the Family Services. The fifth Technical Assistant position, assigned to the Child Health Specialty Clinics, was vacant at the time of OSEP's visit. The Medical Director of Child Health Specialty Clinics in Iowa City supervises this position.

¹ Information obtained from Iowa publications and State staff.

For administrative purposes, the State is divided into fifteen regions that are responsible for provision of early intervention services. The regions follow the boundaries of the Area Education Agencies, crossing multiple county lines. (The Area Education Agencies are intermediate units composed of several local school districts.) The Area Education Agencies have special education and early intervention compliance responsibilities, in addition to other educational program responsibilities. The regional early intervention programs are administered by the Area Education Agencies and these agencies provide the majority of services for eligible infants and toddlers. The Technical Assistants at the State level are each assigned approximately three to five regions. According to the data reported by the State, Early Access, the State's Part C early intervention system, was serving 1420 infants and toddlers with disabilities on December 1, 2000, which was 1.26 percent of the birth to three population of the State at that time. This is an increase over the counts of December 1, 1998 of 964 and December 1, 1999 of 1114.

Self Assessment and Data Collection

As part of the Continuous Monitoring process, IDE organized and conducted a self-assessment of Iowa's implementation of IDEA. According to the State's Self Assessment report, IDE established a 16-member Steering Committee comprised of members representing a broad variety of stakeholders, including parents, school boards and administrators, teachers, representatives of higher education, area education agencies, protection and advocacy groups, and parent groups. In addition, the Chief of Iowa's Education Department Bureau of Children, Family, and Community services, three administrative consultants from the Bureau, and a representative of the Great Lakes Area Regional Resource Center (GLARRC) served on the Steering Committee. The Self-Assessment work groups also included 72 additional members serving on nine subcommittees. Each of the nine subcommittees was responsible for assessing the implementation of one of the nine Cluster areas, five for Part C and four for Part B, identified in OSEP's Continuous Monitoring documents for assessment of the implementation of IDEA. The Part C workgroups included members from the partnering agencies of Health and Human services. The results of the Self-Assessment process were submitted to OSEP in December 2000.

OSEP reviewed the Self-Assessment document during January and February 2001. After the review, OSEP requested additional information from the Part C, Early Access program. This information was obtained during a series of phone conversations, and through the submission of additional monitoring and other documents related to implementation. At the end of its review of the Self-Assessment documents, prior monitoring reports for Part B, Iowa's IDEA Part B Eligibility Documents and other information from the State, OSEP determined that a data collection visit for the State's Part B program would not be necessary at this time. If OSEP determines at a later date that further data collection is needed to ensure compliance with Part B of IDEA, OSEP will make arrangements to visit the State and obtain needed information.

The Steering Committee, subcommittees and State staff worked diligently to determine the status of early intervention for infants, toddlers and their families under Part C. These participants in the self-assessment activities identified numerous areas where insufficient data impeded their ability to determine whether or not Part C services were provided according to the requirements under Part C. Based on the self-assessment information, the State's previous monitoring reports

and conversations with State staff, OSEP determined that a data collection visit to the State would be necessary for OSEP and the State to ascertain the status of compliance with Part C in the State.

During the week of October 22, 2001, OSEP visited six regions and three hospitals providing services to infants and toddlers. OSEP visited the following Area Education Agencies and regions: Western Hills - 12, Green Valley -14, Council Bluffs -13, Arrowhead -5, Grant Wood - 10, and Heartland -11. Hospitals visited included the University of Iowa in Iowa City, and Mercy Hospital and Blank Children's Hospital in Des Moines. Preliminary results were presented to State staff, members of the State Interagency Coordinating Council, Special Education Directors for the Area Education Agencies and regional coordinators.

As part of the data collection process, OSEP reviewed children's records including Individualized Family Service Plans (IFSPs). OSEP conducted interviews with personnel responsible for the implementation of Part C at both the State and local levels. OSEP interviewed State administration staff, the Management Team, SICC members, Technical Assistance staff, local administrators, service coordinators, service providers, hospital staff and parents. OSEP, in collaboration with the State and local administrators, selected the sites visited and individuals that were interviewed.

I. CHILD FIND AND PUBLIC AWARENESS

The needs of infants and toddlers with disabilities and their families are generally met through a variety of agencies. However, prior to the enactment of Part C of IDEA, there was little coordination or collaboration for service provision, and many families had difficulty locating and obtaining needed services. Searching for resources placed a great strain on families.

With the passage of Part H in 1986 (now Part C), Congress sought to ensure that all children needing services would be identified, evaluated, and served, especially those children who are typically underrepresented, (e.g., minority, low-income, inner-city, American Indian and rural populations) through an interagency, coordinated, multidisciplinary system of early intervention services.

Each State's early intervention system must include child find and public awareness activities that are coordinated and collaborated with all other child find efforts in the State. Part C recognizes the need for early referral and short timelines for evaluation because development occurs at a more rapid rate during the first three years of life than at any other age. Research in early brain development has demonstrated what early interventionists have known for years: that children begin to learn and develop from the moment of birth. Therefore, the facilitation of early learning and the provision of timely early intervention services to infants and toddlers with disabilities is critical.

Self-Assessment and Data Collection

The State's self-assessment committee analyzed the information gathered in the area of child find and public awareness, and identified the following areas of strength: the State has developed a wide variety of public awareness materials that are available in English, Spanish, Braille, and on tape for non-readers; and Iowa has multiple child find services available to identify and refer children. The self-assessment committee also identified the following areas of concern: low percentage of children identified and served; the need for data on collaboration among agencies on referral; dissemination of materials and training; cultural appropriateness of materials; actual dates of referral; and the need to identify appropriate data to collect and analyze to measure effectiveness. The self-assessment committee also identified the need to standardize eligibility definitions across the State, establish a committee to define terms for data collection, and then implement a plan for reporting and collecting the child find data.

After review of the State's self assessment and other documents from the State, OSEP identified the following concerns/issues as areas to be investigated during the Data Collection week: coordination of the child find system and collaboration with other major public agencies; identification of all children who may be eligible for Part C; and dissemination of culturally appropriate child find and public awareness materials.

To investigate these child find and public awareness issues, OSEP collected data from parents, service providers, service coordinators, local program staff, hospital and clinic staff, interagency collaborators, SICC members, and central office personnel. OSEP reviewed and analyzed the data and identified the following areas of non-compliance and suggestion for improvement.

A. AREAS OF NONCOMPLIANCE

Failure to Identify and Evaluate All Children Who May Be Eligible For Early Intervention and Failure to Coordinate Child Find Efforts

Each State's child find system must include the policies and procedures that the State must follow to ensure that all infants and toddlers in the State who are eligible for services under Part C are identified, located, and evaluated. The lead agency, with the assistance of the Council, must ensure that the child find system under Part C is coordinated with all other major efforts to locate and identify children conducted by other State agencies. See CFR 34 §303.321(b) and (c). Each system must also include the performance of a timely, comprehensive, multidisciplinary evaluation of each child, birth through age two, referred for evaluation. See CFR §303.322.

IDE has not ensured that all children in the State who may be eligible are identified and evaluated. Some Area Education Agencies do not apply the State's Part C criteria in determining eligibility, but only consider children eligible if they meet the Part B eligibility criteria for special education. Prior to the enactment of Part H (now Part C) of IDEA, Iowa provided Part B services to infants and toddlers, and some Area Education Agencies continue to use the more restrictive Part B definition exclusively, rather than the broader eligibility definition under Part C. For example, hospital staff reported to OSEP that a child with Down syndrome was referred to the Early Access program, but was not accepted into the early intervention program until the child demonstrated a 25 percent delay in development. In spite of the fact that the child has a condition that leads to delays under Iowa's definition of eligibility, the child was not considered eligible to receive services through the Early Access system.

A review of IFSPs noted that many of the 36 early intervention records reviewed noted eligibility for special education rather than early intervention in the evaluation report. Some of Iowa's local programs are serving children under the age of three only if they also qualify for services under Part B. Several administrators told OSEP that free appropriate public education (FAPE) was provided to children eligible for Part B in addition to service coordination, and one administrator stated that "Part C has always been viewed as a mini-Part B program." The State must ensure that all infants and toddlers with eligible conditions or who have a developmental delay under the State's definition receive all the Part C rights and services to which they are entitled.

States may provide a free appropriate public education (FAPE) to infants and toddlers, but they must also follow the requirements of Part C for this population, including the Part C eligibility requirements. In addition to different eligibility requirements, Part C requires that eligible children receive service coordination, a family assessment and services for families as well as early intervention services for the child.

Another problem identified during the monitoring visit is that not all children referred are evaluated in the five required developmental areas to determine eligibility for early intervention services. Local service coordinators from across the State told OSEP that when a child is referred because of a suspected developmental delay, usually one person makes a home visit and

determines if evaluations are needed for eligibility, or that the child “does not qualify.” In another region, Area Education Agency staff told OSEP that the secretary asks the parent a series of questions over the phone and, based on this information, a determination is made whether to evaluate for eligibility for early intervention or that the child “does not qualify.” In all of the regions visited by OSEP, service coordinators and administrators told OSEP that instead of evaluating a child to determine eligibility, families of these children are provided with a variety of strategies, but children are contacted infrequently, thus delaying services and Part C protections for eligible children.

Area Education Agency staff told OSEP that some children referred because of a concern about a developmental delay are not evaluated in a timely manner to determine eligibility for early intervention services. In one of the regions, service providers and service coordinators stated that they implemented strategies over a period of months to address the delay before evaluating a child to determine if improvement in the child’s development occurred. Although using pre-intervention strategies as a part of evaluation is permissible if it does not delay the 45-day timeline, OSEP found that in Iowa the strategies led to violation of the 45-day timeline.

IDE also has not ensured that IDE child find efforts are coordinated with all other major efforts conducted by relevant State agencies involved in identifying and serving children who may be eligible for Part C. Many children who would be eligible for Part C in Iowa receive services outside the State’s early intervention system. A State Technical Assistance staff reported that the State’s Medicaid waiver program serves approximately 130 children who are likely to be eligible for Part C services, but there is no system to indicate whether these children have been referred to Early Access. Staff from one High Risk Follow-up Program reported that very few children are referred from Neonatal Intensive Care Units to Early Access programs. State Early Access staff told OSEP that efforts to integrate and coordinate these State programs have been unsuccessful. An early intervention system can certainly use a variety of agencies to implement its child find efforts, but must ensure a coordinated and collaborative effort. See 34 CFR §303.321(c).

The State’s Universal Newborn Hearing Screening program is not required by the Iowa Department of Health, the administering agency for that program, to refer children suspected of having hearing impairments to the early intervention program. This program is funded, in part, with Part C funds, yet the lead agency has not been successful in ensuring that children who are identified through this program are referred to the Early Access program, thus ensuring coordination of efforts and that children receive all needed services.

Local staff told OSEP that several regions have “empowerment grants” to serve families, and that families whose children may be eligible for Part C are referred to these empowerment programs. These programs then connect families to community services. Families and children in these regions receive services from the Child Health Specialty Clinics, hospitals, Department of Social Services or other community programs. These children with a suspected disability are not, however, referred to Early Access. Therefore infants and toddlers with disabilities do not receive all the services they would be entitled to under Part C.

State staff and Management Team members told OSEP that there are approximately 1,500 children, most with conditions and syndromes or who are medically fragile, who receive medical and therapy services in the Child Health Specialty Clinics and High Risk hospital clinics. These children have not been referred to the Early Access program, and therefore, their rights to receive all services needed to meet their developmental needs and protections available under Part C to which they would be entitled are not ensured. Both State staff and staff members at these clinics told OSEP that these children would likely be eligible for Early Access if evaluated for eligibility.

State, hospital and clinic staff identified a variety of reasons for not referring children to the early intervention program. Some of the reasons stated were that hospital clinics were concerned about losing their clientele, or that hospital staff would not refer until insurance was depleted. Hospitals and clinic staff also stated that there is too much paperwork to include children in the Early Access program.

Hospital and clinic personnel across the State reported that they have just begun to participate in child find activities and only to a limited degree. They stated that parents are not willing to participate in the Early Access program. They further stated that service provision through Early Access is poor, and does not meet service frequency and intensity needs of the child; and that, if they do refer a child to the early intervention system, they do not receive feedback on the referral.

Hospital staff at all three hospitals told OSEP that they did not refer to Early Access because they believed that the Early Access program was strictly educational. When the child no longer needed therapeutic services, they would refer to Early Access, if needed. Staff from one hospital stated they refer children older than three years of age, but not infants. Other hospital and clinic staff told OSEP that the inconsistency of eligibility interpretations across Early Access programs creates confusion for hospital staff regarding which children should be referred for early intervention; therefore, hospital staff did not refer. This inconsistency in eligibility criteria contributes to failure to locate all children who may be eligible.

Service coordinators in one Early Access region reported that physicians seldom refer children, especially in the rural areas where they tend to be general practitioners rather than pediatricians, and are not trained to recognize delays. Other service coordinators and providers in other areas concurred that physician referrals are not consistent, especially in rural areas. Administrators in another region reported that physicians typically refer children late or do not refer them at all. Service coordinators in this region reported that some doctors have a “wait and see” attitude, and parents seek their own assistance. A different Early Access administrator, whose child has a disability, reported that her child’s physician did not know about Early Access.

Beyond the above-mentioned identified concerns, administrators in four of six Area Education Agency regions reported a lack of guidance from the State regarding child find and public awareness requirements and activities. An administrator in a fifth region stated that there are no systematic directives from the State and indicated that such activities are managed locally.

State staff members from the technical assistance team offered some very informative insights and comments concerning interagency cooperation and coordination pertaining to Iowa's Early Access child find system. One staff said:

The biggest impediment for the Early Access program is that health and education belong to different camps. The biggest uncounted number of children is in the health system, but [they are] not getting referred. Some providers haven't figured out a way we [the technical assistance team] should be a part of Early Access.

This lack of coordination among State agency health and screening programs and Early Access may be a significant factor in Iowa's serving a relatively low number of children in this program. The number served is also a concern expressed by the Steering Committee in Iowa's Self-Assessment.

IDE must ensure that all children in the State who may be eligible are identified and evaluated, and that child find efforts are coordinated with all other major efforts in the State as required under 34 CFR §303.321 of the Part C regulations.

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

Outreach to underrepresented populations

Iowa's self assessment identified that the State has a growing immigrant population resulting in an increase of service needs for children from homes where English is not the primary language. Administrators and other personnel in all six regions visited told OSEP that their population of ethnic and minority groups is increasing. Administrators across the State told OSEP that there was not an active outreach program to ensure that those children from ethnic minorities are identified and evaluated. In some regions, the concern is that public awareness activities do not adequately reach the African-American population. Other regional staff reported that there has been a recent increase in the Hispanic and Asian populations statewide, but not specific outreach activities to ensure that children from these groups are identified and evaluated. Administrators and other personnel in one region reported having families who speak only Chinese or Russian with no access to materials in those languages or interpreters to translate for these families.

Part C regulations require that the State have policies and procedures to ensure that traditionally underserved groups, including minority populations, low-income groups, and rural families, are meaningfully involved in the planning and implementation of all the requirements of Part C and that these families have access to culturally competent services within their local geographical areas. See 34 CFR §303.128.

The State does provide public awareness materials in both Spanish and English, and some local programs have translated public awareness materials into Spanish and other languages to meet the needs of minority populations in their area. As an example, one region has developed some public awareness materials available to Bosnian families in their native language. Other regions

have participated in multicultural health events and tried to develop contacts with ethnic community centers and resource organizations for migrant workers. In spite of these activities, there are no activities implemented in all areas of the State to ensure the identification of eligible children who are part of the traditionally underserved population. In some parts of the State, administrators stated that there were no planned strategies to reach minority ethnic populations. In addition, administrators and service coordinators in several regions stated that there is not always an adequate source of interpreters and translators, and for certain languages, there are no translators available.

The data obtained during the self-assessment process and subsequently during OSEP's data collection visit is not sufficient to enable OSEP to determine the effectiveness of Iowa's Part C child find and public awareness efforts in identifying, locating, and evaluating all eligible infants and toddlers with disabilities from diverse ethnic backgrounds and/or non-English-speaking minority groups in the State. According to the State, Iowa served only 1.26 percent of the 0-3 population on December 1, 2000 (the national average was 1.8 percent). IDE should focus monitoring efforts to ensure that traditionally under-served groups, especially ethnic minorities and speakers of other languages, have sufficient culturally appropriate information to ensure that eligible children from these populations will be identified, evaluated and provided the early intervention services that they need.

II. EARLY INTERVENTION 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 principles 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 assures 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 needed to meet the 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. In 1991, Congress required that early intervention services be provided 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 satisfactorily achieved in a natural environment, the IFSP must include a justification of the extent, if any, to which the services will not be provided in a natural environment.

Self Assessment and Data Collection

The State's self-assessment committee identified the following promising practices in the area of Early Intervention Services: adequate numbers of service coordinators; the change in Medicaid provisions in the State to allow reimbursement for service coordination; and the availability of qualified staff. The self-assessment committee identified the following needs for improvement: development of a data system to analyze service coordinator caseloads, and other IFSP requirements; obtaining other State and Federal resources for Early Access; development of a

system for collecting referral information and information on service provision across agencies; identification of community options for service delivery and transition; and development of an interagency plan for personnel development to train more staff for integrated services.

OSEP reviewed the State's monitoring reports, the self-assessment and other documents from the State, and identified the following issues to be investigated during the Data Collection week: determination of eligibility; adequate services; provision of transportation; service coordinators coordinating all services; and the IFSP process.

To investigate these early intervention service issues, OSEP collected data from parents, service providers, case managers, local program staff, interagency collaborators and central office staff. OSEP reviewed and analyzed the data and identified the following strength and areas of non-compliance.

A. STRENGTH

Development and Passage of Medicaid Rules to Include Reimbursement for Specific Early Intervention Services

With the assistance of the Medicaid program in the Department of Human Services, Early Access State staff, IDE staff and interested parties, the new Medicaid Program For Infant And Toddler Services (State Medicaid plan for the infant and toddler population) was enacted and rules have been written that will allow the program service providers to bill Medicaid for all Medicaid-covered required early intervention services and Medicaid-service-related service coordination activities to Medicaid-eligible infants and toddlers. Programs providing early intervention services will now be able to bill for most required early intervention services, including "developmental therapy" for special instruction activities. The new rules allow service coordination and other early intervention services to be provided by any Iowa public agency that is a Medicaid provider, or by a private agency that is a Medicaid provider subcontracting through a public agency. In addition to this expanded coverage, the reimbursement funds will be returned to the agency providing the service instead of to the State general fund. This allows the local regions to benefit from this funding source.

B. AREAS OF NONCOMPLIANCE

1. Failure to Perform All Service Coordination Duties

Each lead agency must ensure that each child under Part C and the child's family are provided with one service coordinator who is responsible for coordination of all services across agency lines and serving as the single point of contact in helping parents to obtain the services and assistance that they need. Service coordination is an active, ongoing process that involves assisting parents of eligible children in gaining access to the early intervention services and other services identified in the IFSP. Service coordination activities include coordinating the provision of early intervention services and other services (such as medical services) that the child needs or is being provided; coordinating the performance of evaluations and assessments; facilitating and participating in the development, review, and evaluation of the IFSP; assisting families in

identifying available service providers; coordinating and monitoring the delivery of available services; informing families of the availability of advocacy services; coordinating with medical and health providers; and facilitating the development of a transition plan to preschool services. 34 CFR §303.23(a)-(d).

IDE has not ensured compliance with Part C service coordination requirements including: that services be coordinated across agencies; that one service coordinator assist the family in obtaining all services identified in the IFSP; that the service coordinator coordinates all early intervention services, resources, and other services needed by the child; and that the early intervention services needed by the child and family are included in the IFSP.

Service coordination is a critical element in ensuring that eligible children and families receive assistance needed to enable an eligible child and the child's family to receive their rights, and the supports and services needed by the child and family to address the child's developmental delay. Without this service coordination, needed services are delayed or not provided at all, and families must attempt to coordinate their own services.

Administrators in all regions visited told OSEP that service coordinators did not coordinate services provided across agencies; they only assisted in obtaining services provided by the Area Education Agency even though the children and families received early intervention services from other agencies as well. They also stated that service coordinators did not coordinate medical or community services that children needed. In addition, parents and service coordinators stated that not all services a child and family may need are discussed at the IFSP meeting. Typically, only those services provided by the Area Education Agency are discussed. As pointed out in the finding on family-centered services, service coordinators are failing to identify and coordinate services needed by the family itself as support services. In addition, parents reported to OSEP that many children have more than one primary service coordinator, especially if a child receives Medicaid services.

Administrators, service coordinators and parents from five regions of the State and staff from hospitals and clinics told OSEP that Early Access service coordinators do not coordinate most of the early intervention services a child and family receive from agencies other than the education agency. Administrators, service coordinators, service providers and parents in four regions reported to OSEP that there was confusion about who coordinated what services, that there was duplication of service coordination activities in some instances, and that there was a general lack of service coordination in other instances. Service coordinators stated that they coordinate some services, but if a child receives services from another agency, they may have another service coordinator. Service coordinators further stated that they do not always know what other services a family may be receiving and are not usually in contact with the child's other case managers; they stated they depend on parents to provide information about services provided outside the Early Access agency's program.

Parents from across the State told OSEP that they do not think that agencies work together, and two parents stated that they had Medicaid case managers that did not interact with the early intervention program. Several service providers stated that they frequently did not know who the primary service coordinator was. One provider said she was not aware of any mechanisms to

ensure coordination with other agencies and that this was a problem causing duplication of services.

The Part C lead agency in a State is not required to provide or pay for the service coordinator; service coordination may be a service a child is already receiving under another program. The lead agency can arrange for another agency to provide service coordination under Part C; however, the lead agency must ensure that the requirements for service coordination under Part C are met. Those requirements include the assignment of one service coordinator who is responsible for coordinating all services on the IFSP for an eligible child and family, in addition to the other duties under 34 CFR §303.23(a)-(d). As noted in the following finding, although service coordinators and parents in three of the regions told OSEP that some service coordinators did coordinate services provided by other agencies, these services were often not included on the IFSP.

2. IFSPs Do Not Include All Early Intervention Services Needed by the Family and Child, or Other Services Needed by the Child

An IFSP must include a statement of the specific early intervention services necessary to meet the unique needs of the child and the family to achieve the outcomes identified, and, to the extent appropriate, must also include medical and other services that the child needs, but that are not required under Part C. See 34 CFR §303.344(d), (e).

IDE has not ensured that all the early intervention services needed by the child and family are included on the IFSP. In addition, IDE has not ensured that other services, including medical services, needed by the child (but not required to be provided under Part C) are included on the IFSP, when appropriate.

Service coordinators, administrators and parents stated that only services provided by their agency were listed on the IFSP, and that other early intervention services provided by other agencies were not included on the IFSP. An administrator told OSEP that if their center did not provide the service it was not put on the IFSP. Although service coordinators, service providers, parents and administrators in four areas visited told OSEP that many families receive services, such as speech, occupational or physical therapy, provided by other agencies, these services were typically not included on the IFSP. Service coordinators and administrators stated that they did not consider services to support the family in enhancing the development of their child to be early intervention services. Several service coordinators and administrators told OSEP that services not provided by the Early Access agency were not part of the IFSP, regardless of whether they were early intervention services or not.

The review of the IFSPs revealed a variety of practices. Although the majority of local staff indicated that typical early intervention services provided by other agencies were not included in the IFSP document, OSEP noted that services provided at hospitals in one region were included on the IFSP as early intervention services. Administrators and service coordinators in most regions reported to OSEP that they were unaware of the requirement to include services provided by other agencies on the IFSP. Several administrators and service coordinators reported that

they had not received guidance from the State regarding inclusion on the IFSP of services not provided by the Early Access agency.

Non-early intervention services needed by the child, such as social services, medical services, other health services, or any other services the child may be receiving were not coordinated or included on the IFSP, according to the majority of parents, administrators, service coordinators and service providers interviewed by OSEP. Note 3 to 34 CFR §303.344 clarifies that the “other services” in paragraph (e) of that section are services that a child or family needs, but that are neither required nor covered under Part C. The Note states that first, the inclusion of these services is important to provide a comprehensive picture of the child’s total service needs, and second, it is appropriate for the service coordinator to assist the family in securing the non-required services by (1) determining if there is a public agency that could provide financial assistance, (2) assisting in the preparation of eligibility claims or insurance claims, and (3) assisting the family in seeking out and arranging for the child to receive the needed medical-health services.

Some regions included medical services in outcomes on the IFSP, but not “other” services a child may need and be receiving. Most regions did not include medical services, even for children who were medically fragile and received numerous medical services. In two regions, staff told OSEP that they infrequently put other services the child needed on the IFSP, but it did not occur often. Even in these two regions, the IFSPs OSEP reviewed of medically fragile children with extensive medical needs did not include medical as “other services” that the child was receiving. In a review of 36 IFSPs, services that could be identified as “other services” were found on only a few of the IFSPs and the steps to be taken to obtain those services were not usually included on the IFSP. Service coordinators, administrators and parents told OSEP there were a variety of services children received that were not included on the IFSP. These services include transportation, any services provided by another agency, nutrition, medical services, specialized child care, and nursing services.

Administrators and service coordinators in two regions reported they were confused and did not understand the requirements regarding provision and inclusion of “other” (non-required) services. One administrator stated that other agencies in his region would not allow their services to be included on the IFSP.

The lead agency must ensure that IFSPs include all needed early intervention services, regardless of which entity provides the service, and that, to the extent appropriate, IFSPs include medical and other non- early intervention services needed by the child.

3. Transportation Not Addressed or Provided

Transportation is an early intervention service that must be listed on the IFSP and provided when needed in order enable a child eligible under this part and the child’s family to receive early intervention services. Transportation and related costs include the cost of travel including mileage, or travel by taxi, common carrier, or other means; and other costs, such as tolls and parking expenses where transportation is necessary. See 34 CFR §303.12(d)(15).

IDE has not ensured that transportation needs are discussed at the IFSP meeting or provided, if needed. Parents, service providers, service coordinators and most administrators in all regions visited told OSEP that transportation is not considered or routinely addressed. One administrator stated that transportation is addressed, but not documented. Service coordinators in two regions told OSEP that when parents need transportation for an early intervention service, they would try to assist, but it would not be provided to the family as an early intervention service and put on the IFSP. One service coordinator stated that if transportation is needed for early intervention services provided at a hospital, it is outside the responsibility of the Early Access program (clearly demonstrating a lack of understanding that transportation is an early intervention service.) In a few instances, OSEP found early intervention services that were provided at a hospital setting included on the IFSP; however staff in that region stated they did not provide transportation for hospital services, and that when parents did not have the means to get there, it was not the responsibility of the Early Access program to provide it. Hospital providers at one hospital stated that transportation is available from the hospital, but they further stated they did not think that the Early Access program was aware of this service. In one region, the administrator reported to OSEP that they would pay for taxis to bring families to the center for evaluations, but not for early intervention services. Service coordinators and service providers in most regions told OSEP that if the service for which the family needs transportation is not a service provided by their agency, they refer parents to available resources, but do not provide transportation as an early intervention service.

Although it is not required that the lead agency directly provide or pay for transportation services, the IFSP must list it when needed, and the Part C program must ensure the child and family receives the transportation needed to participate in provision of early intervention services. The lead agency can coordinate and collaborate with other public and private agencies to ensure transportation is provided when needed as an early intervention service.

4. Failure to Include a Statement of Justification on the IFSP for Services Not Provided in a Natural Environment

The IFSP must include a statement of the specific early intervention services necessary to meet the unique needs of the child and the family to achieve the outcomes identified on the IFSP, including the natural environments (as described in §303.12(b) and §303.18) in which early intervention services will be provided, and a justification of the extent, if any, to which the services will not be provided in a natural environment. 34 CFR §303.344(d)(1)(ii). The provision of early intervention occurs in a setting other than a natural environment only if early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment. 34 CFR §303.167(c)(2).

The review of IFSPs indicated that there was no written justification on the IFSP when services were provided in a setting that was not a natural environment. OSEP found a letter “J” included on the IFSP when services were not provided in a natural environment, but the reason for provision of services in a setting other than the natural environment was not included. Part C requires the justification to be a written explanation of why early intervention cannot be achieved for the child in a natural environment. When asked, service coordinators, service providers and administrators across the State told OSEP that if a child received services in a setting that was

not the child's natural environment, they only put the letter "J" on the IFSP to indicate the justification, but not the statement or reason for the justification. The State's Self-Assessment document also identified the failure to include a justification on the IFSP.

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

1. Determination of Services and Location for Provision of Services

The IFSP process requires that the participants at the IFSP meeting, which includes the parents, make the decisions regarding services to be provided based on the child's needs, and the location of services, based on natural environments of the child. Decisions cannot be made based solely on parent choice, the decision of a single participant at the IFSP meeting, or on the availability of a service provider.

The process for determining services and service location was not targeted by OSEP for investigation. However, it appears that the practice of determining services and service locations by parent's choice, rather than the IFSP meeting participants, may be widespread. Service providers, parents, or administrators in all regions reported that parents decide the location of services or that parents determine which services their child will receive. In three of the regions, some service coordinators, parents or providers told OSEP that if there was no provider available for a particular service, the service was not included on the IFSP. In one location, service providers and service coordinators stated that service providers' schedules determine the amount of service and the location of services.

In its next monitoring activities, IDE should investigate these practices to ensure that parent choice and provider availability are not the determinants of location of services and the frequency and intensity of services.

2. Use of the Interim IFSP

Service coordinators and administrators in four of the regions visited told OSEP that an interim IFSP was written when the evaluators could not complete evaluations within the required 45 days. Three of the six coordinators in one region stated they no longer do this as State staff told them that they were not supposed to write an interim IFSP for this reason. Administrators in two of the regions stated that their staff write interim IFSPs if all of the evaluations cannot be completed within the timeline. These two administrators further stated incorrectly that the purpose of an interim IFSP was to extend the 45-day timeline. One of the State's monitoring reports contained this citation to a local program: "Interim IFSPs were not consistently used when the 45 day timelines could not be met." Based on the administrators' statements and the monitoring report, it appears that the State may have been providing local programs with incorrect guidance on this issue. An interim IFSP may be developed for an eligible child before completion of all evaluations only if parental consent is obtained, the interim IFSP contains the name of the service coordinator and the early intervention services determined to be needed immediately, and the evaluations and assessments are completed within the time period required in 34 CFR §303.322.

State staff told OSEP that the use of an interim IFSP when the agency could not complete the evaluation within 45 days had been a practice based on a misunderstanding that has now been corrected; they stated that IDE gave and all providers of early intervention services information and training on the appropriate use of an interim IFSP. Nevertheless, the practice of using the interim IFSP was continuing in those four regions as reported to OSEP. OSEP suggests that the State ensure that all areas of the State, not just those visited by OSEP, are fully informed of the limited use of an Interim IFSP.

III. FAMILY-CENTERED SERVICES

Research has shown that improved outcomes for young children are most likely to occur when services are based on the premise that parents or primary caregivers are the most important factors influencing a child's development. Family-centered practices are those in which families are involved in all aspects of decision-making, families' culture and values are respected, and families are provided with accurate and sufficient information to be able to make informed decisions. A family-centered approach keeps the focus on the developmental needs of the child, while including family concerns and needs in the decision-making process. Family-centered practices include establishing trust and rapport with families, and helping families develop skills to best meet their child's needs.

Parents and other family members are recognized as the linchpins of Part C. As such, States must include parents as an integral part of decision-making and service provision, from assessments through development of the IFSP, to transition activities before their child turns three. Parents bring a wealth of knowledge about their own child's and family's abilities and dreams for their future, as well as an understanding of the community in which they live.

In 1986, Part C of the IDEA was recognized as the first piece of Federal legislation to specifically focus attention on the needs of the family related to enhancing the development of children with disabilities. In enacting Part C, Congress acknowledged the need to support families and enhance their capacity to meet the needs of their infants and toddlers with disabilities. On the cutting edge of education legislation, Part C challenged systems of care to focus on the family as the unit of services, rather than the child. Viewing the child in the context of her/his family and the family in the context of their community, Congress created certain challenges for States as they designed and implemented in a family-centered system of services.

Self Assessment and Data Collection

The self-assessment committee identified the following promising practices in the area of family-centered services: development and dissemination of a guidance paper on family-centered services; outreach materials that are culturally sensitive; and involvement of families in a number of statewide initiatives. Some of the areas identified by the self-assessment committee as opportunities for improvement included the following: developing State and regional policies on family-centered approaches that are culturally competent; monitoring family satisfaction; identifying and using family supports; and implementing greater flexibility in times of service provision.

Based on information from the State's self-assessment, monitoring reports and other documents from the State, the following issues were identified to be investigated during the Data Collection week: identification of the needs of the family to enhance the development of their child; the services and supports to meet those needs; and the inclusion of family outcomes to address those needs.

To investigate these family-centered issues, OSEP collected data from parents, service providers, service coordinators, local program staff, interagency collaborators and from central office staff.

OSEP reviewed and analyzed the data and identified the following strength and area of non-compliance.

A. STRENGTH

Flexibility of Service Providers' and Coordinators' Schedules to Ensure Family Centered Approach

Parents, service coordinators, service providers and administrators told OSEP about a variety of methods to ensure participation of the family. The most notable practice heard was the flexibility of providers' schedules. Service coordinators, parents and service providers stated that in order to accommodate families' schedules, visits and contacts are made to children and families during evening hours, early in the morning or on Saturdays in all areas of the State. Administrators and service providers spoke of flexibility in scheduling to allow this family friendly practice to occur. Families stated their gratitude and appreciation for this flexibility, especially for families who may not have any flexibility in their own work schedule. Other activities to ensure active participation of families in the program included providing daily communication notebooks, digital photo records, telephone calls, meeting parents at work during their lunch time or after work, and weekend sessions.

B. AREA OF NONCOMPLIANCE

Family Supports and Services Not Identified or Included on the IFSP

Under Part C, each eligible infant or toddler with a disability and the child's family are entitled to receive early intervention services that are "... designed to meet the developmental needs of each child eligible under [Part C] and the needs of the family related to enhancing the child's development..." 34 CFR §303.12(a)(1) (Emphasis added.) Further, the non-exhaustive list of types of early intervention services in 34 CFR §300.12(d) specifically includes "family training, counseling, and home visits." (As explained in the note following §303.12, "The lists of services in [§303.12(d) is] ... not exhaustive. Early intervention services may include such services as the provision of respite and other family support services.)

Section 303.322(a)(1) requires "the performance of a timely, comprehensive, multidisciplinary evaluation of each child, birth through age two, referred for evaluation, and a family-directed identification of the needs of each child's family to appropriately assist in the development of the child." (Emphasis added.) 34 CFR §303.322(d) requires that family assessments be family-directed and "designed to determine the resources, priorities, and concerns of the family" and "the supports and services necessary to enhance the family's capacity to meet the developmental needs" of their infant or toddler with a disability. (Emphasis added.) The IFSP for each infant or toddler with a disability must, along with other information, include: (1) with the concurrence of the family, a statement of "the family's resources, priorities, and concerns related to enhancing the development of the child," (34 CFR §303.344(b)); (2) "a statement of the major outcomes expected to be achieved for the child and family..." (34 CFR §303.344(c)) (emphasis added); and (3) "a statement of the specific early intervention services necessary to meet the unique needs of the child and the family ... " (34 CFR §303.344(d)) (emphasis added).

IDE has not ensured that the needs of the family related to enhancing the family's capacity to meet the developmental needs of their child are identified and included in family outcomes on the IFSP. In addition, the services and supports necessary to meet those outcomes are not included on the IFSP as early intervention services.

Service coordinators, parents and administrators identified a variety of activities related to the identification of family needs, and the supports and services required to meet those needs, but OSEP did not find formal or informal family assessments or other activities implemented consistently throughout the State. In all regions of the State, service coordinators and administrators told OSEP that family needs were identified through use of a family information page of the IFSP and through informally asking the family if they had any needs. However, service coordinators stated that this was not always sufficient to ensure identification of family needs.

Parents in two regions stated that the IFSP did not always reflect their needs. Parents in these same regions and other regions stated they did not know what kinds of assistance the program could provide, and some parents expressed concern that they found out about particular services and resources that they needed or could have used after it was too late to access them. Moreover, service coordinators in all areas of the State informed OSEP that they did not consider family supports, services, respite care or other family services to be early intervention services, and would not be included as such on the IFSP. Service coordinators in several areas stated that they would assist the family by providing information about respite or other services the family wanted, but these service coordinators informed OSEP that they were not required to help the family obtain these other services in the same manner they were required to ensure early intervention services for the child. Many service coordinators stated that it was best for families to locate and obtain their own services. Families in four regions responded to OSEP that they did not get needed assistance in finding support groups or needed resources; they had to find supports and resources on their own. They stated that the service coordinator provided a list of resources or phone numbers, but did not actually assist the family in obtaining the resources or support. One parent stated that, "We do it ourselves."

Staff in two regions of the State told OSEP that there were no services or resources available to support families, and therefore, none are included on the IFSP. In another region, parents requested assistance in finding a parent support group for parents of children with a particular disability. These parents stated that the service coordinator did not know of any such group and did not offer to assist them. One parent told OSEP that he assumed it was not the service coordinator's job to help them find support groups or resources, and it was only after he and his wife spent many hours on the computer that they did locate several needed sources of information and support.

Federal regulations require that outcomes for the child and family must be identified on the IFSP, as well as the services to meet those needs to assist the family to enhance the development of their child. OSEP found that inclusion of outcomes for families is inconsistent across the State. All service coordinators and providers interviewed by OSEP stated that they include family outcomes on the IFSP; however, the title on the "outcomes" page of the IFSP is "Family

outcome,” therefore all outcomes, child or family, would be identified under the heading of “Family Outcome.” The majority of service coordinators stated that a family outcome was what the family wanted, and more specifically what the family wanted for their child, rather than what was needed to address the needs of the family in enhancing the development of their child. In a review of 36 IFSPs, OSEP found a few family outcomes that related to the family, such as assisting the family to obtain social service supports, as opposed to outcomes that only address needs of the child. OSEP found evidence in some service coordinator notes that services to support families had been provided, but even in these instances, the family services or supports were not documented on the IFSP, nor was there an outcome addressing the families’ needs. Administrators reported that many family services are being provided, but are not recorded on the IFSP.

The State must ensure that the needs of the family are identified, that a family assessment is offered to each family, and that services to meet the needs of the family are included on the IFSPs as appropriate.

IV. GENERAL SUPERVISION AND ADMINISTRATION

The State lead agency is responsible for developing and maintaining a Statewide, comprehensive, coordinated, multidisciplinary, interagency early intervention system. Administration, supervision and monitoring of the early intervention system are essential to ensure that each eligible child and family receives the services needed to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay. Early intervention services are provided by a wide variety of public and private entities. Through supervision and monitoring, the State ensures that all agencies and individuals providing early intervention services meet the requirements of IDEA, whether or not they receive funds under Part C.

While each State must meet its general supervision and administration responsibilities, the State may determine how that will be accomplished. Mechanisms such as interagency agreements and/or contracts with other State-level or private agencies can serve as the vehicle for the lead agency's implementation of its monitoring responsibilities. The State's role in supervision and monitoring includes: (1) identifying areas in which implementation does not comply with Federal requirements; (2) providing assistance in correcting identified problems; and (3) as needed, using enforcing mechanisms to ensure correction of identified problems.

Self-Assessment and Data Collection

The State's self-assessment committee gathered data to identify strengths and areas for improvement for the State's early intervention program. The committee identified these promising practices in supervision and monitoring: the modification and improvement of monitoring materials for compliance review; the inclusion of parents and providers in the monitoring process; the development of public awareness materials in Braille and in Spanish, with taped versions in Spanish and English for non-readers; and the active role of regional coordinators in identifying local needs. The self-assessment committee identified the following areas in need of improvement: to collect data locally, regionally and Statewide to make informed decisions; to align the monitoring process with the Federal continuous improvement monitoring process; to ensure the interagency agreement is signed; to integrate training among agencies; and to collect data on non-English speakers. The self-assessment also identified the need to: clarify the relationship of the Management Team to the SICC; improve lines of communication among State agencies and between State administration and local programs; and clarify roles at the State level for administration of the Early Access program. The committee also identified an overarching need for better data collection, identification of appropriate data to be collected, and use of data for improvement of the early intervention system.

Iowa had established a three-year monitoring cycle; however, the State determined their monitoring activities and materials needed to be improved. While the materials and procedures were being revised, monitoring activities were suspended and had not resumed at the time of OSEP's visit. The self-assessment committee noted that the Part C monitoring process needs to be reviewed to assure that it adequately addresses all required components of the Federal regulations.

Based on information obtained through review of the self-assessment, monitoring reports, local applications, and local and State procedures, OSEP identified the following concerns: (1) structure of the governance and administration of the Part C program; (2) participation of the SICC in advising and assisting the lead agency; and (3) interagency coordination and collaboration in the implementation of early intervention.

To investigate the issues identified through the validation planning process, OSEP collected data from parents, service providers, State agency staff, interagency collaborators, the SICC, local program providers and administrators across Iowa. This data is related to the Lead Agency's responsibility for supervision and administration of the early intervention program. Analysis of the data collected resulted in identification of the following areas of noncompliance and a suggestion for improvement.

A. AREAS OF NONCOMPLIANCE

1. Failure to Establish a Single Line of Responsibility in the Lead Agency

Each early intervention system must include a single line of responsibility in a lead agency that is established or designated by the Governor of the State, and is responsible for the administration of the early intervention system. See 34 CFR §303.500. A clear management structure, with clearly defined roles and responsibilities provided to staff and constituents of the Early Access program is needed to ensure the successful implementation of early intervention services in Iowa.

IDE has not ensured a single line of responsibility in the lead agency that is responsible for administration of the Early Access program in Iowa.

During OSEP's visit to Iowa, State staff, regional staff, local staff and SICC members expressed confusion and concern about the administrative structure and governance of the Early Access program. The comments fell into two general areas of concern. One concern related to the efficacy of the Management Team, and the other concern related to the respective roles and responsibilities of the State administrators, regional directors, State agencies involved in the Early Access program, the SICC and the Management Team.

OSEP reviewed the Early ACCESS System Flow Chart Provided to OSEP by State staff in preparation for the monitoring visit and found that the line of authority appears to flow from OSEP to the four State Signatory Agencies, which are designated as the Management Team. The chart indicates that the Governor appointed IDE as the lead agency, but the chart clearly indicates equal responsibility for four State Agencies rather than the single line of responsibility in a lead agency as required by Part C. The four agencies named in the flow chart are the Department of Education, the Department of Human Services, the Department of Public Health and the Child Health Specialty Clinics. The Chart then indicates the flow of the system from the Management Team to the Part C Coordinator in the Department of Education, Technical Assistance Team and then to the Regional coordinators.

State staff members, local administrators and a Management Team member told OSEP that the Management Team's role in administration of the Part C system was not clear and that they were not certain who was in charge of the early intervention program. They did not know if the lead agency made the final decisions about Part C questions, or if the Management Team was in charge; a few local administrators thought that the SICC might be in charge.

In addition to the confusion over the entity in charge, a Management Team member expressed concern about not knowing what the primary responsibilities of the Management Team are, stating: "It is very unclear what we do. We do not set policy, supervise or establish budgets. There is confusion and we need to better define roles." One of the four Management Team members stated that, "If the Management Team is a sham, we should get rid of it and just have the lead agency."

The SICC members told OSEP that they had no clear idea which entity was responsible for the early intervention system. Local service coordinators and providers from across the State told OSEP that they were not certain how the program was managed, but believed the lack of a State Interagency Agreement was the cause of State's inability to provide clear direction for the Early Access program. Hospital staff providing services in programs across the State also told OSEP that they were not certain whether the lead agency or the Management Team was responsible for administering the State's early intervention system. They stated that they are confused about the line of authority for the State coordinator and the technical assistance staff members who are paid with Part C funds. During the exit conference, several Area Education Agency directors, responsible for local administration of Early Access in their regions, expressed confusion about which entity to go to when they had questions about the program.

State staff and regional administrators stated that it was their belief that the Management Team structure was an impediment to the administration of the program. An example of this is seen in the fact that, according to State lead agency staff, the Management Team, rather than the lead agency, sets and approves the budget for Part C expenditures. The Part C Coordinator stated during OSEP's visit that the plan for expending the Part C funds had not been approved by the Management Team; as a result, the lead agency had been unable to finalize its plans for training, technical assistance and provision of guidance to the Early Access regions and other providers of early intervention services. Apparently the Management Team also had, in more than one year, reserved certain funds for a Part C activity that it never implemented. Due in part to this practice, the U.S. Department of Education's records show that during several of the past seven fiscal years, Iowa has failed to expend large amounts of Part C grant funds.

Another impact of not having a single line of authority is demonstrated by several instances of incorrect program implementation across the State that appeared to be due to a lack of State guidance and local confusion as to which entity sets policy. The inappropriate use of an interim IFSP and the failure of service coordinators to perform all required duties, as described in findings above, are two examples of this.

IDE must ensure that there is a single line of responsibility in the lead agency that will be responsible for ensuring that all of the requirements of Part C are met.

2. The State Interagency Coordinating Council (SICC) does not perform all required duties

A State that desires to receive financial assistance under Part C shall establish an SICC. (34 CFR §303.600(a)). The SICC must advise and assist the lead agency in the development and implementation of the policies that constitute the state-wide system. (303.600(a)(1)). Each SICC shall also assist the lead agency in achieving the full participation, coordination, and cooperation of all appropriate public agencies in the State, and assist in the effective implementation of the state-wide system by establishing a process that includes seeking information from service providers, service coordinators, parents and others about any Federal, State, or local policies that impede timely service delivery. See 34 CFR §303.650(a)(2) and (3). Each Council must also advise and assist the lead agency in the identification of sources of fiscal and other support for services for early intervention programs and in the promotion of the interagency agreements under §303.523. See 34 CFR §303.651(a) and (c).

SICC members, State staff and Management Team members told OSEP that the SICC did not advise and assist the lead agency in developing policies, assist in assuring coordination among agencies, or identify resources for the implementation of the early intervention program. The SICC members stated that there is a great deal of confusion about what their specific duties are, who they are to be assisting, and the meaning of “advise and assist” in the context of the role of the SICC. When asked about the involvement of the SICC in advising and assisting the lead agency, members of the Management Team (representatives of the four major public agencies on the SICC) stated to OSEP that the role of the SICC has not been clear, and each agency has its own beliefs about the role of the SICC. Two of the four Management Team members concurred that the role of the SICC was to “advise the Management Team.” SICC members stated that their roles and responsibilities are unclear and they are uncertain about what their work includes. They also stated they are unclear about whether they were to work with the Management Team or the lead agency.

SICC members told OSEP that it was their belief, based on information provided by the Management Team members and the lead agency, that collecting information about the statewide system was not part of their responsibilities, and that they did not have a mechanism for obtaining information about policies that may impede the timely delivery of services.

SICC members reported to OSEP that they had not been asked to assist the State in achieving participation and coordination among State agencies; in fact, the members told OSEP that they had been told it was not their job to help develop the program, but to evaluate the program. SICC members interviewed by OSEP stated they were not involved in any activities to identify sources of support, financial or otherwise, for the early intervention program. The members also told OSEP that they had not been involved in advising and assisting the lead agency in the promotion of interagency agreements. In fact, as of the date of this report, there is no current interagency agreement.

Failure of the SICC to assist in achieving the full participation and cooperation of all appropriate agencies in the State, and to assist in the promotion of interagency agreements, has several

ramifications. First, the lack of coordination impacts child find efforts, as noted in the finding on identification of all eligible children. Second, it impacts the provision of all needed services to infants, toddlers and their families; because the lead agency in Iowa is the IDE, and family supports and services are typically provided by Health or Human Services agencies, the lack of coordination can impede the State's ability to ensure that families receive all needed services (see findings in Early Intervention in Natural Environments section on service coordination and family services).

The legislative history for Part C states that the "role of this Council is fundamental to the establishment of a comprehensive service delivery system for handicapped infants." The State has the responsibility of ensuring that it makes clear what is expected of the SICC, in fulfilling its obligation to advise and assist the State.

3. All Resources in the State Not Coordinated or Identified

Each lead agency is responsible for the identification and coordination of all available resources for early intervention services within the State, including those from Federal, State, local and private sources. See 34 CFR §303.522(a)(1).

The State has not ensured that all available Federal, State, and local resources for early intervention services within the State are identified and included in the statewide, comprehensive, coordinated, interagency system of early intervention services for infants and toddlers with disabilities. (As noted in the previous finding, one of the duties of the SICC is to assist the lead agency in the identification of sources of fiscal and other support for services for early intervention under Part C. See CFR 34 §§303.651(a)).

Although there is reported coordination of State agencies through the Management Team, SICC members, State staff, local administrators, parents, and local service coordinators told OSEP that all of the resources for the provision of early intervention services were not coordinated within the State. State staff reported that Early Access, the State's early intervention system, is not accessing or coordinating services provided by and paid for by other agencies, such as Title V and Title XIX (Medicaid) programs. The State staff also told OSEP that they were having difficulty coordinating the resources that Part C children are eligible for under other Federal or State programs with services they receive through Early Access programs.

Many infants and toddlers with disabilities are served by hospitals and clinics, but are not referred to the Early Access program, as discussed in the finding on Child Find, Section I, A. Hospital and clinic providers and administrators told OSEP that they do not coordinate services with Early Access.

At the local level, administrators in the Early Access regions visited by OSEP reported that they are unaware of the mechanisms for providing or obtaining services needed by families that were not provided by their agency. The administrators in the regions visited stated that there is very little interaction with other agencies and that the Area Education Agencies provide the needed early intervention services, while other agencies provide their own services. Service coordinators are generally failing to coordinate services from other agencies, as detailed in the finding in

Section II, B, 1 of this report. In addition, these services from other agencies generally are not included on IFSPs, as discussed in the finding on IFSPs, Section II, B, 2 of this report.

4. Failure of the State to Collect Data on the Statewide Early Intervention System

Each system must include the procedures that the State uses to compile data on the statewide system. The procedures must include a process for collecting data from various agencies and service providers in the State. 34 CFR §303.540(a).

IDE has not ensured adequate procedures for collecting data from various agencies and service providers in the State. The State staff told OSEP that they did not have an adequate and reliable method for obtaining data from Early Access agencies. Regional Early Access agencies responsible for child count data told State staff that it was difficult to determine an exact child count. State staff also told OSEP they had difficulty obtaining information from other State agencies on the provision of services for eligible children in order to effectively coordinate the provision of services to infants and toddlers, especially information on services offered and provided through hospitals, medical facilities and clinics.

One State agency in Iowa receives Part C funds from the lead agency for the implementation of the Universal Newborn Hearing Screening program. State staff reported to OSEP that they had no data from this program, especially data to indicate the results of the hearing screenings or that referrals had been made to the early intervention program to ensure that all children who may be eligible are located, identified and evaluated. Although Iowa's application indicates that procedures will be followed to meet all Federal requirements, State staff expressed concerns about the lack of access to information from all local and State programs providing services for eligible infants and toddlers. Throughout the State's self-assessment document, the Steering Committee referred to the inability of the committee and the State to determine the status of many components of the Part C system due to lack of adequate data. The Steering Committee identified the need to improve identification, collection and use of data. The ability to collect accurate data is important not only for Federal reporting requirements, but also for the State to fulfill its monitoring and supervisory responsibilities to ensure that appropriate services are being provided to eligible Part C children.

5. Monitoring Not Occurring or Ineffective in Identifying and Correcting Non-Compliance

Each lead agency is responsible for the general administration and supervision of programs and activities receiving assistance under Part C, including the monitoring of programs and activities used by the State to carry out Part C, whether or not these programs or activities are receiving assistance under this part, to ensure that the State complies with Part C. To meet the requirements, each State must adopt and use proper methods of administering each program, including monitoring agencies, institutions, and organizations used by the State to carry out Part C, enforcing any obligations imposed on those agencies under Part C of the Act and these regulations, providing technical assistance, and correcting deficiencies. See 34 CFR §303.501(a) and (b)(1)-(4).

IDE has not ensured that monitoring of programs and activities used by the State to implement Part C is effective in identifying and correcting deficiencies. Nor has the State ensured that all programs used by the State to carry out Part C, whether or not these programs or activities are receiving assistance under Part C, are in compliance with Federal regulations.

According to local administrators, the State's monitoring consisted mainly of a review of records. They stated that, in the past, the State would interview staff as well as review records, but had not done so recently. The State's administrative staff told OSEP they did not have the personnel to monitor in an efficient manner.

OSEP reviewed the most recent State monitoring reports (about two years old at the time of the visit) for five of the Early Access agencies OSEP visited. The State's monitoring reports contained agency strengths, citations, and concerns. OSEP found that these reports did not clearly delineate non-compliance issues, nor did they require corrective actions for all non-compliance issues identified in the reports. Many of the "concerns" identified in the State's monitoring reports were clearly violations of Federal regulations; however, IDE only required the Early Access agency to develop corrective actions for the "citations," which also were violations of IDEA. In the monitoring reports reviewed, only three citations were noted, all for the same agency. The other four reports included "concerns" that OSEP would consider violations of IDEA; however, the agencies were not required to take corrective action for the "concerns." Examples of those "concerns" found in the State's monitoring reports are "transition plans were not in place when appropriate"; "all items on the IFSPs were not complete"; "it was not documented that each area of the multidisciplinary evaluation were complete"; "the 45 day timeline was not always met for initial evaluations, nor were timelines for periodic or annual review"; and, "there was not good linkage between family identified concerns on the family information page and any written family outcomes and activities to reach these in the IFSP." All of these violations were identified on the State's monitoring reports as "concerns" not requiring implementation of corrective actions. IDE provided no documentation to OSEP indicating that these practices have been discontinued or that the noncompliance has been corrected.

Early Access agencies have the opportunity through the monitoring process to request assistance from the State. Two of the State's monitoring reports of Early Access agencies stated that the Early Access agency had requested guidance on how to determine a child's referral date in order to correctly determine if a child's initial IFSP had been completed within the 45 day timeframe between referral and the initial IFSP meeting. The State responded in the report to each agency that "this is a system issue that the State will be dealing with in the next year." At the time of OSEP's visit, Early Access agencies reported that the State still had not provided guidance on this issue.

During OSEP's monitoring, it found that early intervention records requested by OSEP did not contain all of the information to determine if the program fulfilled the requirements of the IFSP process, such as information about service coordination activities, record of service providers' visits, progress of the child or reasons for missed appointments. The records contain revised IFSPs without the information, such as progress of the child or evaluation, to determine why changes were made to the IFSP. For the State and OSEP to effectively monitor the IFSP process requires that local agencies responsible for implementation of the early intervention program

should have the necessary information included in the child's record to be able to ensure compliance with Federal regulations.

The State's monitoring has not been effective in identifying and correcting a variety of components associated with the development and implementation of the IFSP. These concerns - service coordination, inclusion of all services, timely evaluations, transportation, and services for families - are addressed in the "Early Intervention Services in Natural Environments," and "Family-Centered Services" sections of this report.

In addition to failure to effectively monitor programs within the education system, IDE has not ensured that all programs that receive Part C funding are monitored. As an example, the State's Universal Newborn Hearing Screening program receives funds from Part C, yet does not refer children to Early Access. As mentioned earlier in this report, IDE staff told OSEP that they have no mechanisms to determine if all children with a delay are referred from this program. They further stated they do not monitor this program or coordinate to ensure monitoring is done by that agency.

IDE must adopt and use proper methods of administering Part C, including monitoring agencies, institutions, and organizations used by the State to carry out Part C, enforcing any obligations imposed on those agencies under Part C of the Act and these regulations, providing technical assistance, and correcting deficiencies.