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

September 14, 2001

Honorable Antonia C. Novello, M.D.
Commissioner
Department of Health
Corning Tower, Room 1408
Empire State Plaza
Albany, New York 12237

Honorable Richard P. Mills
Commissioner of Education
New York State Education Department
111 Education Building
89 Washington Avenue
Albany, New York 11234

Dear Commissioner Novello and Commissioner Mills:

The U.S. Department of Education's Office of Special Education Programs (OSEP) conducted a review in New York during the weeks of February 8, 1999 and April 19 - 23, 1999. The purpose of that visit was to assess the New York State Education Department (NYSED) and New York Department of Health's (NYDOH) compliance with the implementation of the Individuals with Disabilities Education Act (IDEA), and assisting the State in developing strategies to improve results for children with disabilities. The 1997 Amendments to the IDEA focus on "access to services" as well as "improving results" for infants, toddlers, children and youth with disabilities. In the same way, the Continuous Monitoring Improvement Process is designed to focus Federal, State and local resources on improved results through a working partnership between OSEP, NYSED, NYDOH, and parents and advocates in New York.

A critical aspect of the Continuous Monitoring Improvement Process is collaboration between a Steering Committee of broad-based constituencies, including representatives from NYDOH, NYSED and OSEP. The Steering Committee is asked to assess the effectiveness of State systems for ensuring improved results for children with disabilities and protection of individual rights, and to assist in the design and coordination of improvement strategies. The Introduction section of this report provides a more detailed description of the process used in New York.

OSEP's review placed a strong emphasis on those areas that are most closely associated with positive results for children with disabilities. OSEP focused on five *Cluster Areas* for Part C of the IDEA (services for children aged birth through 2) – Child Find and Public Awareness, Family Centered Services, Early Intervention Services in the Natural Environment, Early Childhood Transition, and General Supervision. Components were identified for each *Cluster Area*, and were used by OSEP and the Steering Committee as a basis to review the State's performance.

Typically an OSEP monitoring report would include OSEP's review of both Parts B and C of IDEA. However, due to the unexpected illness and subsequent retirement of the State contact and primary writer for the Part B section of the New York report, we were unable to reconstruct the findings related to Part B from the 1999 monitoring. Thus, this report does not include the OSEP findings related to the Part B program but reflects only the strengths, areas of noncompliance and areas of suggested improvement for the Part C program administered by NYDOH. OSEP has developed a collaborative plan with NYSED and NYDOH to move forward in the continuous improvement monitoring process to the improvement planning phase of the process. OSEP and NYSED have agreed on the issues that continue to be areas of concern for the state as well as the areas of strength.

Through a joint steering committee process representing stakeholders from NYDOH and NYSED, OSEP will move forward to the improvement planning process that will outline the strategies employed to improve results for children and families since the OSEP visit in April of 1999. Once the plans are finalized and approved by OSEP, they will be available on the Department of Education's web site. Since Part C in New York has never been monitored by OSEP, it was decided to issue that portion of the Report to be used as a baseline for the improvement planning process.

The enclosed Report addresses strengths noted in New York, areas that need improvement, and areas that require corrective action because they represent noncompliance with the requirements of IDEA. Included in the body of the Report, you will find an Executive Summary of information, an Introduction including background information, and a description of the issues around the *Cluster Areas*.

We understand that this Report will be shared with members of the Steering Committee, the State Interagency Coordinating Council and other constituents. OSEP will work with your Steering Committee to develop corrective actions and improvement strategies to ensure improved results for children with disabilities.

Thank you for the assistance and cooperation provided by your staff during our review. Throughout the course of the review, Mr. Dennis Murphy and Dr. Donna Noyes were responsive to OSEP's request 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 system for implementing IDEA. A significant effort was made to arrange the public input process during the validation planning week and as a result of their efforts, OSEP obtained information from a large number of parents, advocates, agency personnel, regional administrators, local health clinic and program administrators, service providers, and interagency collaborators.

Thank you for your continued efforts toward the goal of achieving better results for infants, toddlers, children and youth with disabilities in New York. Since the enactment of IDEA and its predecessor, the Education of All Handicapped Children Act, one of the basic goals of the Law, ensuring that children with disabilities are included in their communities, has largely been achieved. Today, families can have a positive vision for their child's future.

Due a variety of internal problems, the issuance of this report has been significantly delayed. OSEP apologizes for this delay and we accept responsibility for our failure to issue these findings in a more timely manner. A comprehensive internal review of this incident has resulted in significant modifications to our internal procedures related to Part B and Part C monitoring activities. We commend Larry Gloeckler for his willingness to assist us in learning from this monitoring experience and his commitment to improving results for children and youth with disabilities while awaiting the release of this report and the new OSEP activities related to Improvement Planning.

While agencies and programs have made great progress, significant challenges remain. Now that children with disabilities and their families are receiving services, the critical issue is to place greater emphasis on attaining better results for those individuals. To that end, we look forward to working with you in partnership to continue to improve the lives of individuals with disabilities.

Sincerely,

Patricia J. Guard
Acting Director
Office of Special Education Programs

Enclosures

Cc: Dr. Donna Noyes
Mr. Lawrence Gloeckler

EXECUTIVE SUMMARY

NEW YORK MONITORING 1999

The attached report contains the results of the first two steps (Validation Planning and Validation Data Collection) in the Office of Special Education Programs' (OSEP) Continuous Improvement Monitoring of the Individuals with Disabilities Education Act (IDEA), Part C, in the State of New York during the weeks of February 8, 1999 and April 19, 1999. The process is designed to focus resources on improving results for infants, toddlers and children with disabilities and their families through enhanced partnerships between the State agencies, OSEP, parents and advocates. The Validation Planning phase of the monitoring process included a series of public input meetings with guided discussions around core ideas of IDEA. As part of the public input process OSEP and the State made efforts to include multi-cultural and underrepresented populations. The Validation Data Collection phase included interviews with parents, agency administrators, regional and local program administrators, service providers and service coordinators, and reviews of children's records. Information obtained from these data sources was shared in a meeting attended by staff from the New York State Department of Health (NYDOH) and the Steering Committee.

The Report includes a detailed description of the process utilized to collect data, and to determine strengths, areas of non-compliance with IDEA, and suggestions for improved results for children.

Early Intervention Services for Infants and Toddlers with Disabilities: Part C of IDEA

Strengths

OSEP observed the following strengths:

- Intra-agency and Interagency Coordination to Ensure Compliance
- Implementation of an Integrated Computerized Data Base System
- Computerized Data System to Improve Child Find Efforts
- Coordination of Resources to Enhance Child Find and Public Awareness
- Child Care and Assistive Technology Initiatives
- Development of Service Guidelines to Promote Individualized Determinations
- Enhancing Local Capacity through Local Interagency Coordinating Councils
- Parent Guides to Enhance Awareness and Increase Participation in the Early Intervention System
- Parent Involvement Subcommittee of State Early Intervention Coordinating Council
- Local Partnerships Enhance Transition Efforts

Areas of noncompliance

OSEP observed the following areas of noncompliance:

- Failure to Monitor Participating Programs and Agencies Consistent with Part C Application
- Deficiencies Identified through Monitoring Not Corrected
- Delays in the Provision of Technical Assistance to Programs and Agencies
- Failure to Issue a Written Decision on Complaints within the 60-Day Timeline and to Provide the Appropriate Follow-up Activities to Ensure Compliance
- Failure to Hold IFSP Meetings within 45 Days
- Failure to Provide Services in Natural Environments
- All Service Coordination Activities are not Provided to Families
- Failure to Identify and Document Family Needs, Supports and Services on the IFSP
- Failure to Ensure Smooth and Effective Transitions

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INTRODUCTION

The general resident population in New York for 1995 was 18,178,000, based on an analysis of the census data. The racial/ethnic composition of this population was reported as 14,025,999 whites, 3,249,000 blacks, 2,372,000 Hispanics, 864,00 Asian/pacific islanders, and 57,000 American Indian, Eskimo and Aleut. New York has one of the highest per capital incomes in 1995. The 1998 census data estimates some 737, 354 children, birth to three, residing in the State which reflects a steady increase in the number of children, birth to three. The State has put in place several key initiatives to minimize the health disparity among underrepresented populations in an effort to improve the overall health status and wellbeing of all children birth to three. The Children's Health Insurance Benefit Package expanded health and medical coverage to moderate and low-income families with children, and the State established standard criteria to ensure that all children have a medical home[1] and services are coordinated with the Part C system for those children found eligible. In 1995, eighty-two percent of the children in New York were immunized by age 2, compared to the national norm of seventy-eight percent. The infant mortality rate and the incidence of low birth-weight, two high- risk factors that impact on acquired and developmental disabilities and delays, were both reported to be 7.6, which is equal to or below the national norm.

Administrative Structures and Children Served

The Part C System

The New York Department of Health (NYDOH) is designated by State law as the lead agency for the implementation of the State's Part C program. NYDOH is responsible for the general supervision and monitoring of 57 municipalities and New York City, in addition to 900 agencies and 2400 individual providers.

NYDOH administers the Early Intervention Program through its Bureau of Child and Adolescent Health. NYDOH sets programmatic and fiscal standards and regulations to ensure compliance, among both public and private providers, in the implementation of Part C of IDEA. NYDOH fully, partially or through in-kind contributions supports 45 state-level positions and ten regional positions to provide program development and administrative oversight, program evaluation, fiscal operations and to address legal issues. Local health departments assist the State in the implementation of the early intervention system in 54 of 57 municipalities. NYDOH contracts with private agencies to administer early intervention services in the other three municipalities, and, in New York City, NYDOH contracts with the State Department of Mental Health.

The U.S. Department of Education's Data Analysis System reported, in December 1998, that in New York 20,592 children, or 2.75% of all children 0-3 in New York, were receiving Part C services as a result of a developmental delay or established condition. The number of children in

[1] A medical home is an approach to providing health care services in a high-quality and cost-effective manner to children and their families in partnership with a pediatrician or physician. This approach is to ensure the identification and access to all medical and non-medical services needed to assist the child and family in achieving their maximum potential. American Academy of Pediatrics

the Part C system reported to be under one year of age was 1,410, there were 4,932 children between the ages of one and two, and 15,250 were between two and three years of age.

Validation Planning and Data Collection

In preparation for the Validation Planning visit, OSEP reviewed the State's current Part C application, annual performance reports, annual child-count data, and interagency data that reflected the health status of the birth-to-three population. OSEP staff solicited input from representatives of Parent Training and Information Centers and other collaborating agencies, and reviewed requests for complaints from constituents.

During the week of February 8, 1999, OSEP and the Steering Committee conducted public stakeholder focus meetings in New York City, Westchester, Long Island, Buffalo, Syracuse, and Saratoga to obtain further information about issues and concerns regarding IDEA service delivery. To ensure that the needs of its constituent groups were addressed, and that sufficient space was available to accommodate those who wished to attend the focus meetings, NYDOH provided an opportunity for its constituents to prioritize or pre-select the focused discussion in which they wished to participate. They could choose from five areas under Part C of IDEA (services for children birth through 2) - Child Find and Public Awareness, Family Centered Services, Early Intervention Services in the Natural Environment, Early Childhood Transition, and General Supervision. Simultaneously individual focus meetings on each cluster area were conducted at each location. Attendance in these locations ranged in number from 100 to as many as 300 participants.

Preliminary results from the public focus meetings as well as the results of the self-assessment conducted by NYDOH were shared with the Steering Committee at the end of the week. Recommendations for strategies and sites that might be visited when OSEP returned were also discussed, and the next steps in the joint planning for OSEP's Validation Data Collection Visit were identified.

OSEP visited the State during the week of April 19, 1999 to collect additional information on issues identified during the Validation Planning process. As part of its review, OSEP collected information concerning the status of NYDOH's implementation of the 1997 Amendments to the IDEA.

During its onsite Validation Data Collection, OSEP teams collected data in New York City and Suffolk, Onondaga, Schoharie, Rensselaer, and Washington Counties. These sites represent rural and suburban areas where resources for service delivery for children with disabilities may vary considerably and urban areas with their diverse populations.

At these sites, OSEP reviewed children's records, including Individual Family Service Plans (IFSPs) and minutes from IFSP meetings. OSEP also reviewed local policies and procedures. OSEP conducted interviews with personnel responsible for implementation of Part C, and included local service providers, service coordinators, administrators and related service personnel as appropriate. OSEP selected service coordinators who serve children with

disabilities in a variety of settings and who are involved in the development or implementation of IFSPs.

Improvement Planning

On Thursday October 12, 2000, OSEP staff met with representatives of NYDOH's Early Intervention Program, Donna Noyes, Denise Berletic, Brenda Knudson Chouffi, Elizabeth Kerins and Daniel Rowland to discuss the progress being made to address the concerns identified in this report. In response to this report, NYDOH will develop an action plan addressing areas of noncompliance as identified in the report.

Approximately 60 days after the issuance of this report, OSEP will visit New York to work with NYDOH to finalize an improvement plan. During this visit, OSEP will assist the Steering Committee in identifying strategies that exist or would be required to implement changes, sources of technical assistance, timelines for completing strategies, and methods for evaluating the effectiveness of the improvement plan.

I. PART C: GENERAL SUPERVISION

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 supervisory and administrative 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.

Validation Planning and Data Collection

As part of the validation planning phase, OSEP reviewed the State Interagency Coordinating Council's Part C Annual Reports for 1994-1998, the applications for Federal Part C funds for the period 1995-98, complaints and letters from families and advocates, requests for Secretarial Review, policies, procedures and guidance documents. OSEP's review of these documents provided a framework for the review of the State's self-assessment and afforded a greater understanding of NYDOH's Part C statewide early intervention system.

The State's steering committee played an integral role, in collaboration with State staff, in the development of the Self-Assessment. The Self-Assessment identified several accomplishments in the area of general supervision. These accomplishments included: (1) intra-agency collaboration within NYDOH to enhance child find and public awareness efforts; (2) interagency agreements with the NYSED and the Office of the Advocate for Persons with Disabilities; (3) utilization of monitoring protocols and evaluation tools; (4) implementation of guidance documents and clinical practice guidelines in response to identified areas of concern; and (5) contractual arrangements with the New York State Association of Counties and the New York State Dispute Resolution Association Inc. to provide technical assistance and training.

Areas of concern identified in the Self-Assessment included: (1) the need to improve collaborative efforts with other State level agencies, such as the Office of Mental Health and the Office of Children and Families; (2) the need to resolve issues regarding IFSP development and implementation; (3) the need to improve the response time in answering complaints; (4) the lack of timely reimbursement for services; (5) the need to monitor all programs; and (6) the implementation of corrective actions, enforcement and technical assistance. The State Interagency Coordinating Council identified areas for improvement including data analysis to

identify gaps and trends in the service delivery process, and concerns with the level of parent involvement.

During the public input process, parents, providers, local administrators and stakeholders expressed concern in the following areas: (1) the need for consistency and timeliness in the monitoring process so that timely feedback is provided to agencies and programs; (2) the need for timely technical assistance to address concerns regarding the provision of services, particularly in the area of natural environments; and (3) the need for improved communication between the local programs and the State to ensure timely access to information regarding changes in Federal and State laws, regulations and/or policies.

Based on the information from the Self-Assessment, the public input process and a review of monitoring reports, local applications, contracts, and State and local procedures, OSEP identified the following areas of concern: (1) monitoring of all programs in a timely manner; (2) implementation and evaluation of technical assistance to ensure compliance; (3) ensuring compliance with Part C requirements regarding due process and complaints; and (4) timely reimbursement for services.

Through actions forged by State staff and the State Early Intervention Coordinating Council, NYDOH has already begun to identify, analyze, and address several of the areas of concern identified during the validation planning and data collection phase of OSEP's continuous monitoring process.

To investigate the concerns regarding monitoring activities identified during the validation planning process, OSEP reviewed children's early intervention records, State and local policies and procedures, monitoring reports and interviewed State staff, local program administrators, service coordinators, service providers, interagency collaborators and parents.

OSEP reviewed and analyzed the data and identified the following areas of strength, noncompliance, and suggestions for improved results for infants and toddlers and their families.

A. AREAS OF STRENGTH

1. Intra-agency and Interagency Coordination to Ensure Compliance

NYDOH's Part C application for fiscal year 1998 funds described State efforts to maintain and implement a coordinated intra-agency and interagency system for the provision of early intervention services. Key intra-agency administrators within NYDOH provide from 5% to 75% of their time to assist the State in carrying out its general supervision and administration responsibilities. These intra-agency administrators play a key role with the development of policies, oversight for programs, financial management, budgeting and internal accounting operations to assure consistency among Federal, State and local policies, procedures and operations.

The State Interagency Early Intervention Coordinating Council (SICC) provides ongoing support to assist NYDOH in the implementation of the Part C system. The SICC has an executive committee to ensure that time-sensitive issues are addressed and to provide overall guidance and support to the four standing committees: training, data parent involvement, and quality improvement. The data committee played a significant role in data analysis, presentation of the base-line data, identification of issues, and incorporating these components into the development of the Self-Assessment. As a result of this data analysis, NYDOH's approved application for FY 1999 Part C funds targeted specific statewide initiatives to address some of the areas of non-compliance. These statewide initiatives identified in the Part C application include: (1) targeting public awareness efforts in the medical community and the dissemination of clinical practice guidelines; (2) training regarding the IFSP process; (3) technical assistance to address regional and cultural diversity; (4) family initiatives that provide parent mentoring and a process to solicit parent input; (5) enhancing the mediation process; and (6) expediting the reimbursement process.

In addition, NYDOH has formalized interagency agreements with NYSED and the Office of Mental Health. These agreements allow the agencies to approve prospective programs and providers, to provide early intervention services under the auspices of their respective agencies, to monitor program activities, and to submit to NYDOH quarterly and annual reports on the status of monitoring, corrective actions and technical assistance, and dispute resolution activities.

OSEP and the State will use the outcomes of the intra-agency and interagency initiatives and other activities in the development and implementation of the State's improvement plan.

2. <u>Implementation of an Integrated Computerized Database System</u>

NYDOH used Federal Part C funds to develop a computerized database, Kids Integrated Data System, that allows for the integration of demographic and family information on Part C-eligible children who may also be receiving services from the Infant-Child Health Assessment Program, or the Physically Handicapped Children's Program. The Kids Integrated Data System also allows for the tracking of potentially eligible children through the use of a diagnostic coding system based on the International Classification of Diseases (ICD) 9th Revision. The Data System also allows for the monitoring of at-risk children, to determine their developmental progress over time, and to refer them to the Part C system when appropriate. The Kids Data System includes a billing module that allows the State to record and track reimbursement sources such as private insurance, Medicaid, Part C and other State Department of Health funds. NYDOH is able to generate various reports from this system to identify strengths and challenges within the various regions, and to provide guidance to the 57 municipalities and New York City in the management of the service delivery system. NYDOH compiled the data from the 57 municipalities and New York City over a four-year period and created an annual report that confirmed several areas of concern. NYDOH will train local administrators on how to utilize the database to assess local performance.

B. AREAS OF NONCOMPLIANCE

1. Failure to Monitor Participating Programs and Agencies Consistent with Part C Application

34 CFR §303.501 requires that all programs and activities used by the State to implement the statewide early intervention system be monitored to ensure that the State is in compliance with Part C of IDEA. The lead agency is required to adopt and use proper methods of administering the program including: monitoring, correcting deficiencies, enforcing obligations imposed on those agencies under Part C, and providing technical assistance, if necessary.

As discussed below, OSEP determined that NYDOH has not fulfilled its obligation for general administration and supervision. NYDOH has not implemented monitoring procedures as specified in its approved Part C application.

OSEP reviewed NYDOH's monitoring protocols to ascertain if the procedures outlined were adequate to determine compliance with Part C requirements. OSEP's review indicated that, on their face, the existing monitoring protocols contained all the necessary components to determine compliance with all Part C requirements. Although State policy, monitoring protocols and the approved FY 1998 Federal Part C application indicated that participating programs would be monitored on an annual basis, OSEP's review of NYDOH's monitoring log and monitoring reports indicated that not all programs and agencies used by the State in the provision of early intervention services have been monitored annually; in fact the State had never monitored 32 municipalities at all.

The Self-Assessment identified, and State staff, local administrators, and providers in all parts of the State confirmed, that the State's monitoring system was only partially implemented from 1996-1999. During that three year time period, NYDOH monitored New York City and 25 of the participating 57 municipalities. NYDOH told OSEP that the remaining 32 municipalities that have never been monitored were scheduled to be monitored during the 1999-2000 period.

State staff acknowledged that they were unable to implement an annual monitoring schedule because of limited resources and the unanticipated time needed to provide technical assistance to the local administrators and providers as part of the monitoring activities. The lack of effective monitoring procedures may have contributed to the areas of noncompliance OSEP found, particularly in the provision of services in natural environments and the identification and documentation of family needs, concerns, priorities and resources on the IFSP, as further described in this monitoring report.

The State recognized the need for additional assistance in the implementation of its monitoring process and allocated funds in the Federal Part C application for 1999 and subsequent years to contract for the support and resources necessary to ensure that in subsequent years all programs and agencies would be monitored on an annual basis.

2. Deficiencies Identified through Monitoring Not Corrected

States are required to adopt and use proper methods of administering the early intervention program, including monitoring activities that will identify deficiencies and provide for correction of those deficiencies. 34 CFR §303.501(b)(4). NYDOH must ensure that effective procedures are in place to correct deficiencies and to implement the provisions of the early intervention system consistent with Federal Part C regulations. OSEP determined that NYDOH's procedures for corrective action do not ensure the timely correction of deficiencies identified through its monitoring activities.

NYDOH provided OSEP with monitoring materials used to monitor participating programs and agencies. OSEP reviewed NYDOH's monitoring protocols and reports for six municipalities and New York City. OSEP visited five of these municipalities and New York City during the validation data collection activities, and found that NYDOH had identified several areas of noncompliance that OSEP identified in these same municipalities. Some common areas included: (1) the lack of timely evaluations; (2) IFSPs not completed within the 45 day timeline; (3) the lack of family supports, assistive technology and respite services; (4) IFSPs lacked a justification when services were not provided in the natural environment; (5) transitions were not being conducted in a timely manner; and (6) transition from Part C to Part B were not smooth and timely. From 1996 to 1999, NYDOH identified noncompliance in New York City and 25 municipalities, but approved corrective actions in only 10 of the municipalities. Although NYDOH's monitoring system identified deficiencies, NYDOH does not have an effective mechanism to ensure timely correction of the identified deficiencies.

The State's Self-Assessment and monitoring protocols indicate that correction of identified deficiencies is assured by conducting follow-up activities, including technical assistance with the programs. However local administrators and providers stated that NYDOH has not provided follow-up activities or the needed technical assistance to facilitate compliance, and as a result, identified areas of noncompliance persist. Local administrators statewide told OSEP that they needed technical assistance in order to develop effective and appropriate corrective actions in the areas of identified deficiencies. Local administrators and providers informed OSEP that current corrective action procedures do not include a mechanism to address the systemic nature of the identified areas of noncompliance. Local administrators also reported that NYDOH does not have a mechanism to inform local programs of noncompliance issues in other regions, in order that they may contact those regions to help identify corrective actions. They indicated that such a mechanism would improve their own program. OSEP confirmed that the lack of follow-up has contributed to ongoing noncompliance in the areas of natural environments and transition, as indicated in the sections that follow in this report.

3. Delays in the Provision of Technical Assistance to Programs and Agencies

The Part C regulations at 34 CFR §303.501(b)(3) require States to adopt and use proper methods of administering each program including the provision of technical assistance, if necessary. Technical assistance is one technique that States can use to assist agencies and programs to

correct deficiencies identified through monitoring and to enforce any obligations imposed on those agencies under Part C.

OSEP reviewed NYDOH's procedures for technical assistance and determined that they were not effective to ensure that programs and agencies receive timely and appropriate assistance. The lack of needed and requested guidance may have contributed to the areas of noncompliance described in Sections II through V of this monitoring report.

NYDOH as part of its general supervision activities requires each of the 57 municipalities and New York City to submit a 6-month progress report that identifies administrative issues, a description of problems encountered and technical assistance needs. OSEP reviewed the progress reports, for the period of April 1998 through September1998, for each of the municipalities visited and identified that requests for technical assistance was indicated in all of the reports. Further analysis by OSEP determined that requests for technical assistance was made in the following areas: (1) procedures to determine the frequency and intensity of early intervention services; (2) guidance to determine the need for early intervention services such as respite, assistive technology, and behavioral therapy; and (3) guidance to address the need for providers to conduct evaluations and early intervention services.

In April 1999, OSEP found that follow-up activities, including the provision of technical assistance to correct many of the areas of concern as noted above by local administrators, service coordinators and providers, was not timely, or had not occurred. OSEP was told by local administrators, service coordinators and providers across the State that they are unclear regarding the implementation of certain policies and procedures in the provision of early intervention services. Local administrators and service coordinators in all areas expressed the need for more guidance and involvement of State Part C administers to clarify issues such as: (1) coordinating child find provisions with the Infant-Child Health Assessment Program and Maternal and Child Health tracking program; (2) determining caseloads for service coordinators; (3) parent choice versus the team decision-making process in determining services; (4) procedures for obtaining approval for respite services; (5) implementing Medicaid waiver provisions; (6) ensuring qualified personnel for the provision of services; (7) the complaint process; and (8) provisions for monitoring agencies and programs and providing timely feedback.

Administrators and providers reported that if they contacted NYDOH for clarification of an issue, the response from the State was not timely and often resulted in delays in services to families and children. While waiting for a response from the State, some local administrators and providers reported that they would continue to implement the activities or services without clarification in an effort to minimize any delay in services for the child and family. However, later, without providing the requested technical assistance, the State would send a letter citing the program for a noncompliant practice. In all areas of the State OSEP visited, administrators and providers reported that timely communication and technical assistance are needed to ensure that locals are provided the guidance they need to understand policies and implement the requirements as set forth in State and Federal regulations.

The State, in its Self-Assessment, acknowledges the need to assess local capacity in the provision of services and to provide guidance to local administrators to ensure compliance with the

provisions of Part C of IDEA. OSEP will continue to work with NYDOH through the development of improvement strategies, to ensure that the provision of technical assistance results in better outcomes for children and families throughout the State.

4. Failure to Issue a Written Decision on Complaints within the 60-Day Timeline and to Provide the Appropriate Follow-up Activities to Ensure Compliance

Consistent with 34 CFR §303.512 (a), States must issue a written decision to the complainant that addresses each allegation in the complaint within 60 calendar days. The lead agency may extend this timeline if exceptional circumstances exist with regard to a particular complaint.

OSEP found that NYDOH failed to investigate and render written decisions within the required 60 calendar days. OSEP reviewed the State's complaint procedures, including guidance for parents, *The Early Intervention Program-A Parent's Guide*, that includes procedures on how to file a complaint. OSEP determined that on its face, these documents contain the appropriate procedures to meet Federal requirements. The State's Self-Assessment indicated that since the State went into full implementation in 1993, NYDOH has received and acted upon 165 Part C complaints. OSEP reviewed the State's complaint log for the past three years and noted that for 30 complaints NYDOH had not issued a written decision within the required 60 calendar days. OSEP's review did not identify information to indicate that time-lines had been extended as a result of exceptional circumstances, nor was there information to indicate whether there was a violation of Part C requirements or the need for corrective action. NYDOH identified in the Self-Assessment that of the 15 complaints received in FY 1998, none were resolved within the required 60 calendar days; the State only sent letters within two working days to acknowledge the receipt of the complaint. For these complaints, the number of days exceeding the 60-day timeline ranged from by a couple of days up to 120 days. NYDOH staff interviewed attributed the backlog to shortage of personnel to handle the volume of complaints.

Providers and service coordinators statewide told OSEP that the State's process for rendering a decision is not timely. Services providers and service coordinators in three areas told OSEP that often a response from the State takes four to six months. Therefore, the practice that is the subject of the compliant, which may be noncompliant, continues (e.g., the decision-making process in the development of the IFSP to determine the location for services) until the State issues a written decision. Providers and coordinators in these three areas also told OSEP that the State, instead of providing timely guidance to assist them in changing the practice in question, will respond by sending a letter to the program citing the program for implementing a noncompliant practice. These providers and coordinators also reported that follow-up activities were seldom provided in a timely manner, including technical assistance, as described above in issue 3 of this section.

NYDOH must ensure that effective complaint procedures are in place to assure the effective implementation of the lead agency's decision, including technical assistance activities. 34 CFR §303.512 (b).

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

1. Assessing the Impact of Managed Care and Third Party Reimbursement Procedures

One of the required functions of the SICC is to assist the lead agency in the effective implementation of the statewide system, by establishing a process that includes: (1) seeking information from service providers, service coordinators, parents, and others about any Federal, State or local policies that impede timely service delivery, and (2) taking steps to ensure that any policy problems identified are resolved. 34 CFR §303.650(a)(3). The State must also ensure that Part C funds are not used to satisfy a financial commitment for services that would otherwise have been paid for from another public or private source. See 34 CFR §303.527(a). These provisions require that Part C funds are used only for early intervention services that are not currently covered under any other Federal, State, local, or private source; and any policy issues that have the potential to impede recommended services are resolved. The potential problem areas listed below were identified by OSEP from the data gleamed from the Self-Assessment, validation planning or data collection process.

NYDOH must ensure that there are effective procedures in place to ensure that evaluations, assessment and early intervention services are administered consistent with Federal requirements and are not in any way affected or diminished due to the funding or payor source (i.e. Part C funds, managed care or any other source). Providers and local administrators informed OSEP that current managed care guidelines specify allotted amounts of time to perform evaluations and assessments, indicate the frequency of early intervention services, and identify allowable providers for services. Providers and local administrators stated that guidance is needed to ensure that managed care guidelines do not result in delays in the identification and evaluation of children suspected of developmental delays and disabilities.

Local administrators and service coordinators also reported to OSEP that current managed care policies requiring pre-approval for recommended early intervention services may have a negative impact on the IFSP decision making process. Providers and service coordinators told OSEP that early intervention services covered under managed care are not as readily accessible as services previously provided under the State Medicaid system. Service coordinators reported that the managed care approval process for evaluations and services is more time consuming and may place an undue burden on service coordinators who already have limited time to coordinate and negotiate the needed services for eligible children and their families.

In addition, local providers and service coordinators told OSEP that some private insurance companies have reduced or denied coverage for early intervention services, since the enactment of Part C of IDEA. These providers and service coordinators told OSEP that private insurance companies have informed them that Part C Federal dollars are the primary payor for early intervention services. Service coordinators reported that the reimbursement process from insurance companies is not timely. These service coordinators stated that the lack of timely reimbursements places an undue burden on local resources. Administrators told OSEP that it is becoming more difficult to subsume these costs with limited local fiscal resources and service

coordinators struggle to balance recommendations for services with the availability of resources to pay for them. The State must ensure that services needed by each child and identified on the IFSP are provided in a timely manner, and not delayed due to funding or reimbursement problems. 34 CFR §§303.520(c), 303.527(b).

In addition, NYDOH in collaboration with the State Interagency Coordinating Council may want to work with representatives from the State agency governing health insurance and the Governor's office to identify and address factors that may contribute to the denial and lack of reimbursements for services by private insurance companies and the reduction in services being imposed by managed care organization.

2. Coordination with other Federally Funded Programs Operating within the State to Enhance Technical Assistance Efforts

The identification and coordination of resources within the State, including those from Federal, State, local, and private sources, is one strategy NYDOH could use to enhance its efforts to ensure the provision of technical assistance.

State staff, members of the State Interagency Coordinating Council, providers and parents told OSEP that they were not always aware of other programs or public or private initiatives that provide training and information, conduct research, or develop demonstration models funded by Federal or private sources. NYDOH may want to research sources within the Federal Department of Education and Department of Health and Human Services, to identify relevant programs and projects currently being implemented by institutions of higher education, non-profit organizations and public and private agencies that may be beneficial to NYDOH in its ongoing technical assistance efforts across the State.

These programs and projects may identify promising practices and strategies to foster collaboration across agency lines and enhance existing resources and service provision. These programs may also be beneficial to the State in the correction of identified deficiencies in the areas of child find, personnel development, provision of services in the natural environment, family centered practices, service coordination, and the impact of managed care.

NYDOH, the State Interagency Coordinating Council, and steering committee members may want to develop a process to identify, review and incorporate ongoing research, personnel training, and demonstration projects being implemented in the State in an effort to maximize interagency and statewide technical assistance efforts.

II. PART C: CHILD FIND/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 of 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 C in 1986, Congress sought to assure 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, 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 as development occurs at a more rapid rate during the first three years of life than at any other age. Early brain development research 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.

Validation Planning and Data Collection

To facilitate the Validation Planning phase, OSEP reviewed several documents that identify the State's efforts to locate and evaluate potentially eligible children and their families. These documents included, but were not limited to: the State's Self-Assessment, the Part C application for fiscal years 1995-1998, the *Annual Performance Reports* for *1994-1998*, the annual child count data, and relevant child find and public awareness materials. OSEP also examined eight discretionary projects, that OSEP awarded to New York. These discretionary programs are designed to develop strategies to assist States in the identification and evaluation of children with various developmental delays.

During the Validation Data Collection phase, OSEP collected data from local programs, providers, administrators and parents to investigate the issues identified during validation planning, as stated above, and the following issues: (1) the level of involvement and awareness about child find in the medical community; (2) timeliness of, and age of children at the time of, referral; and (3) effectiveness of child find efforts among underrepresented groups. Analysis of the data collected resulted in the identification of the following strengths, and suggestions for improved results for infants, toddlers and their families.

A. AREAS OF STRENGTH

1. Computerized Data System to Improve Child Find Efforts

NYDOH upgraded its computerized data system to improve ongoing State and Federal initiatives to locate and identify potentially eligible children. Current computerized data initiatives target linkages with NYDOH's Infant Child Health Assessment Program, NYSED's preschool special

education student information system and the universal newborn hearing screening program. By promoting data linkages with these and other statewide data bases, NYDOH and the State Early Intervention Coordinating Council anticipate that: (1) child find and public awareness for Part B, Part C, and Maternal and Child Health will be streamlined and more cost-effective; (2) gaps in the coordination of resources to identify all potentially eligible children and their families will be identified and addressed; and (3) transition of children and families from hospital and high risk programs to Part C, Part B and other appropriate community-based programs will be smooth and timely.

2. Coordination of Resources to Enhance Child Find and Public Awareness

NYDOH has developed and distributed public awareness materials in a variety of languages and formats to the general public and primary referral sources. The State's Self-Assessment highlights some of the accomplishments in this area. These accomplishments are in the following areas: (1) development and dissemination of 200,000 public awareness materials, *Early Help* brochures, and *Early Intervention Program: A Parents Guide*; (2*)* development of an early intervention web page linked to NYDOH's web-site; (3) operation of the Growing Up Healthy Hotline; (4) development and dissemination of clinical practice guidelines; (5) development of interagency agreements with the State Department of Education and the Office of the Advocate for Persons with Disabilities to facilitate the distribution of public awareness materials, and the operation of a 1-800 number for information and referrals; and (6) implementation of the *Training Together for Tots* that provides information to primary referral sources including physicians.

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

1. Procedures to Ensure that all Potentially Eligible Children are Identified, Especially Among Underrepresented Populations

To address the growing need for strategies to ensure access to Part C programs among underrepresented populations and to address areas of concern identified in the validation planning and data collection process, NYDOH instituted several initiatives. A primary initiative was to expand child find efforts by entering into interagency agreements with targeted agencies that serve this population, such as: Developmental Disabilities Planning Council, Office of the Advocate for Persons with Disabilities, and the Office of Alcoholism and Substance Abuse Services. In addition, NYDOH developed partnerships with churches, community agencies, ethnic radio stations and newspapers. The State has provided culturally sensitive training activities such as *Training Together for Tots* and *the Early Intervention Partners in Policy Making* to encourage participation from underrepresented groups. NYDOH has provided guidance and training to municipal officials and service providers regarding the needs of multilingual families. Municipal officials, to locate, select and train bilingual translators designed a protocol and curriculum for use. A video, *Something Got Lost in the Translation*, and training sessions on capacity-building for translation services were also provided.

Although NYDOH has implemented several interagency and outreach initiatives, as described above, these strategies have not fully resolved the concerns relative to the timely identification and referral of all potentially eligible children and families from underrepresented groups as described below.

OSEP was informed by providers, parents and service coordinators across the State, that although NYDOH is providing Part C services to 2.75 of the 0-2 population, which is significantly above the national average, there are potentially more eligible children that have not been identified. Local administrators, service coordinators and providers across the State told OSEP that the percentage of children in the Part C system was not representative of the diverse cultural, socio-economic, ethnic, and religious groups reflected in the general population in the regions they serve. They further reported that these under-identified groups include: indigent families, children of parents with disabilities (particularly the deaf), those living in shelters, children of parents known to the courts and the criminal justice system, those with mental health issues, those living in public housing, those combating substance abuse, physical abuse, children in the foster care system, and those living on reservations geographically located within the State. The State's Self-Assessment and Annual Child Count Report for FY 1998 indicated the need to enhance coordination efforts among agencies that serve underrepresented groups.

Advocates and service providers, some of whom provide services in both the early intervention and Part B preschool programs, told OSEP that too many children with disabilities enrolling in preschool programs had not been served by early intervention, and exhibit significant developmental delays that could have been identified earlier if they had been referred to the early intervention system.

The State's Self-Assessment and Child Count Data for FY 1998 also indicated that although there has been a steady increase in the number of referrals from the health care community, referrals from physicians, visiting nurses, county health programs, and the Infant-Child Health Assessment Program were relatively low even though some of these programs are administered by NYDOH. The health community is critical in ensuring access to services for underrepresented groups. Providers and service coordinators confirmed the lack of efficient coordination among these agencies, and stated that families do not receive the support they need to access the Part C system.

Local administrators and providers across the State reported to OSEP that while the State has embarked on several statewide child-find initiatives to target these populations, there were impeding factors that impacted on their effectiveness. Some of these factors include: (1) the increasing number of culturally and ethnically diverse immigrant and minority populations moving into and across the state; (2) lack of culturally appropriate materials and services; (3) families' negative perception of disabilities and developmental delays; and (4) the lack of available resources. Providers and advocates confirmed to OSEP that these factors challenge the State in its efforts to ensure access for these families and their children to early intervention services. These individuals reported to OSEP that NYDOH should design innovative and effective strategies to ensure the participation of all agencies and programs in the identification and referral of potentially eligible children and their families.

State staff told OSEP that regional round-table forums were scheduled to be held in various regions across the State to solicit information regarding the barriers to child find, particularly among underrepresented and under-served populations. The information will be used to develop recommendations to enhance existing collaborative and child find efforts in targeted communities across the State.

2. Procedures to Ensure Timely Referrals for Evaluations

OSEP reviewed NYDOH's Annual Child Count for FY 1998, and the data from the State's Self-Assessment. The data indicate that while there has been a significant increase in the number of children identified and referred for an evaluation, the timely completion of evaluations is an area of concern. Service providers and parents across the State told OSEP that the medical community tends to have a "wait and see" attitude, and is reluctant to refer children early for an evaluation, even when parents express concern regarding their child's development, or in instances when the child exhibited a physical delay.

Service coordinators and providers in three regions told OSEP that State policy and procedures might contribute to delays in conducting evaluations. They reported that State policy on child find stipulates that referral sources must obtain parent consent before making a referral to the Part C system. Previously, the State's policies and procedures for child find required that referral sources obtain parent consent before making a referral to the Part C system. NYDOH staff told OSEP that this policy was revised in 1996 to be consistent with Federal requirements (parents may refuse to consent to their child's evaluation, but no affirmative consent is needed for referral). NYDOH has not been effective in informing primary referral sources of this change. Accordingly, many referral sources are continuing to delay referral unless/until they can obtain parent consent. Service coordinators and providers told OSEP that they were not aware of the change in policy, and they were unaware that their practice was not consistent with existing State policy.

These providers told OSEP that other State agency policies may also contribute to the lack of timely referrals for evaluations. They reported that policies related to foster care within the Department of Social Services require the primary referring agency to obtain parental consent before making a referral to the early intervention system, resulting in delays in referrals for evaluations. Service coordinators and providers confirmed that referrals for potentially eligible children in the foster care system were delayed an average of 8-12 months.

New York should review its policies regarding referrals, to ensure that primary referral sources are aware of those policies, and work with relevant State agencies to improve the referral process.

III. PART C: EARLY INTERVENTION SERVICES IN NATURAL ENVIRONMENTS

In creating the Part C legislation, Congress recognized the urgent need to ensure that all infants and toddlers with disabilities and their families receive early intervention services according to their individual needs. Three of the 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 ensures that the rights of children and families are provided, arranges for assessments and IFSP meetings, and facilitates the provision of needed services. The service coordinator coordinates required early intervention services, as well as medical and other services the child and the child's family may need. With a single point of contact, families are relieved of the burden of searching for essential services, negotiating with multiple agencies and trying to coordinate their own service needs.

Part C requires the development and implementation of an IFSP for each eligible child. The evaluation, assessment, and IFSP process is designed to ensure that appropriate evaluation and assessments of the unique needs of the child and of the family, related to the 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 identified 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 could 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.

Validation Planning and Data Collection

The State's Self-Assessment identified several accomplishments and concerns related to the provision of early intervention services in natural environments. Some of these accomplishments included the: (1) number of children receiving services in natural environments, including child care settings (2) variety of service models to enhance better outcomes for children and their families; (3) number of personnel training programs

implemented by institutions of higher education; and (4) diverse strategies used to ascertain the effectiveness of the State's system. A major concern identified as a result of the needs assessment process was the need to develop a data-driven approach to determining the capacity of the local service delivery systems across municipalities and in New York City. In addition, NYDOH collaborated with the Office of Children and Family Services to disseminate guidance documents to local administrators regarding Medicaid billing and ensuring the provision of service coordination through the Care-at-Home and the Home and Community Based Waiver. These initiatives facilitate support for ongoing service coordination and the provision of services in a variety of natural environments by ensuring financial reimbursement to localities and private providers.

OSEP reviewed the State's Self-Assessment, Annual Performance Reports, Part C Application for FY 1998 funds, State and local contracts, IFSPs, and other relevant documents, and after discussion with the Steering Committee, the following areas were targeted for investigation during the Validation Data Collection: (1) provision of timely services, (2) continuous services for those children receiving services from local education agencies, (3) services in the natural environment, (4) adequate number of personnel, and (5) ongoing supports and services for families.

To investigate Early Intervention Services in Natural Environments, OSEP collected data from local programs, and providers in the early intervention system, parents, and NYDOH State staff. Analysis of the data resulted in the identification of the following strengths, areas of non-compliance, and suggestion for improved results for infants, toddlers and their families.

A. AREAS OF STRENGTH

1. Child Care and Assistive Technology Initiatives

According to NYDOH staff, State law provides support to the child care community, including access to assistive technology to support the integration of Part C-eligible children in community child care settings. In addition, NYDOH engaged in interagency planning with the New York State Child Care Coordinating Council and a variety of agencies that resulted in the funding of 40 Child Care Resource and Referral Agencies to implement activities to support early intervention service delivery in family and child care homes, child care centers, and other typical early childhood settings. As a result, the number of children receiving services in childcare settings increased from 4.9% in 1993-94 to 6.49% in 1997-98.

NYDOH entered into an interagency agreement with the Office of the Advocate for Persons with Disabilities to provide technology-related assistance for families with children with disabilities. This assistance promoted more independence among participating families and their children and fostered greater involvement in community activities. NYDOH has documented the success of these strategies by the increase in services in natural environments from 60% in 1994-95 to 75% in 1997-98, and as a result of child care initiatives and interagency agreements, the increase in the number of authorizations for services in a variety of service models across the State. Although there has been continued progress in increasing options for services in a variety of

settings, children continue to be served in segregated center-based programs, as noted in issue 2 of the noncompliance section below.

2. Development of Service Guidelines to Promote Individualized Determinations

NYDOH, recognizing the need for guidance and training to assist providers and families in making informed decisions regarding service practices, developed a series of clinical practice guidelines in the areas of communication disorders and pervasive developmental disorders. The guidelines are entitled: *The Report of the Recommendations, The Quick Reference Guide, and The Guideline Technical Report*. These guidelines highlight best practices, delineate research findings, and are user-friendly and informative for both families and providers.

Development of these guidelines was an interdisciplinary effort by a panel of developmental experts in the field of communication and a project staff with extensive research and clinical practice experience. The guidelines have proven to be a valuable reference tool for IFSP teams making decisions regarding effective service delivery models that reflect the individualized needs of the child and family. These documents include recommendations to assist early intervention providers to assess and provide intervention as needed for potentially eligible children and their families.

3. Enhancing Local Capacity through Local Interagency Coordinating Councils

According to NYDOH officials, NYDOH established local early intervention coordinating councils to collaborate with and advise early intervention officials in the 57 municipalities and New York City regarding the provision of services, inclusive of services in natural environments. Local early intervention coordinating councils have been instrumental in addressing issues regarding the timely referral of children in foster care and initiating innovative service delivery models, such as the *Mom and Me Programs*, to enhance opportunities for the services in natural environments.

B. AREAS OF NONCOMPLIANCE

1. Failure to Hold an IFSP Meeting within 45 Days

Each early intervention system must ensure the performance of a timely, comprehensive, multidisciplinary evaluation in each of the five developmental domains. The initial evaluation, assessment and initial IFSP meeting must be held within 45 days of referral. 34 CFR §§303.321 and 303.322.

NYDOH has not ensured that each child referred for evaluation receives a timely multidisciplinary evaluation and assessment and that the IFSP meeting is held within the required 45-day timeline.

OSEP reviewed NYDOH's monitoring reports, for the 1997 and 1998 monitoring period, for the six areas visited by OSEP. In the six areas, OSEP found that NYDOH identified the failure of early intervention programs: (1) to complete timely evaluations and assessments; (2) to ensure

that evaluations were completed in all required developmental areas; (3) to ensure that evaluations and reports were completed and available to conduct IFSP meetings. OSEP reviewed the active client roster tracking form for December 1,1998, for each of the five municipalities and New York City and determined that 169 of the 300 initial IFSPs still exceed the required 45-day timeline. Further analysis by OSEP indicated that delays ranged from 46 days to one year after the child and family were referred to the public agency. OSEP reviewed the reasons for delays as indicated in the corrective action plans submitted to the State; or as listed on the early intervention services tracking form. Of the 169 IFSPs exceeding the 45-day timeline, 85 identified personnel issues, such as shortage of staff to conduct evaluations, or the inability of service coordinators to schedule and follow-up on evaluations and schedule IFSP meetings. Service coordinators in four of the six areas visited told OSEP that due to large caseloads and the lack of available evaluators they were unable to complete the process within the 45 days.

In addition, administrative procedures, such as scheduling problems resulting from the State's requirement for an early intervention official to attend IFSPs meeting and review IFSPs, were also indicated. Service coordinators and providers in three areas and local administrators in one area told OSEP that development of initial or periodic IFSPs are often delayed due to the inability of early intervention officials to schedule to attend an IFSP meeting within the 45-day timeframe. The ability of the early intervention officials to attend the IFSP meeting must not, in any way, delay conducting timely IFSP meetings for the develop of the IFSP as required within 45 days.

2. <u>Failure to Provide Services in Natural Environments</u>

Consistent with 34 CFR §303.344(d)(1)(ii), States must ensure that all IFSPs identify the natural environments in which early intervention services will be provided, and include a justification of the extent, if any, to which the services will not be provided in a natural environment. 34 CFR §303.18 defines natural environments as settings that are natural or normal for the child's age peers who have no disabilities. 34 CFR §303.12(b) requires that, to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate.

As discussed below, NYDOH has not ensured that eligible children receive all of the early intervention services needed, and that these services are provided in natural environments. Further, NYDOH has not ensured that IFSPs contain a justification if services will be provided in settings other than a natural environment.

Providers and parents across the State informed OSEP that early intervention services were frequently not provided in the child's natural environment, and, of the 35 IFSPs reviewed by OSEP, 19 IFSPs representing 3 of the 6 municipalities identified the provision of early intervention services in an environment that did not meet the definition for natural environment and further did not contain a justification. Further review by OSEP indicated that services were being provided in segregated early intervention classrooms, the office of service providers or segregated preschool centers. Service providers reported to OSEP several reasons for not providing services in natural environments. These include a lack of providers, resulting in a

waiting list for vision services, occupational and physical therapy, and special instruction services.

Service providers and service coordinators across the State told OSEP that family "choice," rather than the needs of the child, determines where services are provided, and that many families choose to have services provided in segregated center-based programs. OSEP was informed by providers that the use of family "choice" is also driven by Medicaid. Medicaid provisions require participating agencies to offer families options to select eligible providers. However, early intervention for an eligible infant or toddler can only occur in a setting other than a natural environment when early intervention cannot be achieved satisfactorily for the child in a natural environment. 34 CFR §303.167(c).

Further, the needs of the child and not family "choice" must be the determining factor when making IFSP decisions. While the participants in an IFSP meeting must carefully consider family preferences, family “choice” does not diminish the responsibility of the IFSP team, as a team, to develop the IFSP, including ensuring the provision of early intervention services in natural environments. The service options presented to families must meet the natural environment provisions, unless there is a justification that can be documented on the IFSP that warrants otherwise. Families must be presented with service options that are consistent with Federal regulations, and not based on the availability of services or the lack thereof.

Providers and parents informed OSEP that decisions about where services are provided are based on available resources rather than on the individual needs of the child and family. For example, when a provider is also an employee of a local school system, the early intervention services are only provided in a preschool classroom until the month of June when school closes, and then they are provided in the home, if another provider is available.

NYDOH must ensure that all children receive the early intervention services they need in natural environments.

3. All Service Coordination Activities are not Provided to Families

States must ensure that all eligible children are assigned a service coordinator upon referral to the Part C program. 34 CFR§§303.23, 303.321(e). Participating agencies and programs must ensure that service coordination is an active, ongoing process that assists and enables an eligible child and the child’s’ family to receive their rights, procedural safeguards, and services. Service coordinators must be able to effectively coordinate services across agency lines, serving as the single point of contact in helping parents obtain the services and assistance they need. 34 CFR §303.23.

NYDOH has not ensured that all families receive active, ongoing service coordination. Providers and service coordinators across the State informed OSEP that due to high caseloads, (the highest being around 500) it is often not possible to carry out the necessary service coordination activities. NYDOH’s Annual Report indicated that the recommended caseload for a full time service coordinator ranged from 35-60, far below the numbers reported by service coordinators. Providers, parents, and service coordinators reported that high caseloads resulted

in children not being referred for evaluations and assessments in a timely manner and IFSP meetings not being held within the required 45-day timeline, as described above in the areas of noncompliance, Finding 1. Also, service coordinators are not coordinating family supports and services as delineated in Section IV B of this monitoring report. NYDOH confirmed the need to evaluate service coordinator caseloads and the impact on the provision of services as part of the State's Self-Assessment.

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

Improve Guidance on Respite Services and Assistive Technology

NYDOH's guidance document on respite, assistive technology services and devices is unclear for many service coordinators and providers. Service coordinators and parents across the State told OSEP that current practice allows the participants in an IFSP meeting to recommend respite services or assistive technology, but approval of the service, frequency, intensity and allocation of cost is determined after the IFSP meeting. Service coordinators and providers told OSEP that when a family/individual is applying for respite services or assistive technology funded by the Early Intervention Program, the early intervention service coordinator completes an assessment form and submits the request to the early intervention program director. The program director approves the request for the service and indicates the frequency and intensity of service to be provided. In the case of assistive technology the early intervention director approves the type of the device or equipment and the associated cost. This policy and practice may be inconsistent with Federal requirements that the participants in an IFSP meeting make individualized decisions for services, and determine frequency of services.

In addition, State policy on the authorization for respite and assistive technology might contribute to the delay and /or impede access to needed services. Service coordinators and providers across the State informed OSEP that there is a waiting list for respite services, and there is a delay in obtaining approval for assistive technology devices or equipment. Consistent with 34 CFR §303.344 (f)(1), the initiation of services on the IFSP must be as soon as possible after the IFSP meeting.

NYDOH's Annual Performance Reports for the fiscal years 1994 to1997 indicated that authorization for respite services ranged from 90% in only one county to less than 5% in 24 of the counties and only 1% for assistive technology. Service coordinators and providers informed OSEP that respite guidelines were unclear and the approval process was time consuming. Respite services are not to be used in lieu of child-care, but only when it is to meet the needs of the family related to enhancing the child's development. However, it appears that in New York families who are eligible or determined to need respite services are not receiving the service.

The lack of access to assistive technology was also indicated as an area of concern by providers and families. The State in the Annual Performance Report for fiscal years 1994 to 1997 stated that they believed that the failure of municipalities to utilize assistive technology devices at an appropriate level is due to the failure of NYDOH to finalize and disseminate appropriate

guidance documents. The Annual Performance Report identified that the development and dissemination of appropriate guidance would be a priority of the State.

NYDOH may want to improve their guidance to providers and agencies to ensure that eligible children and their families have timely access to respite services, assistive technology and devices as appropriate.

IV. PART C: FAMILY-CENTERED SYSTEM OF 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 the 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, to the development of the IFSP, through transition activities before their child turns three. Parents bring a wealth of knowledge about their own child 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 a family-centered system of services.

Validation Planning and Data Collection

NYDOH identified several areas of concern in its Self-Assessment regarding the need to improve access to family supports. Counseling and training were identified as needs for families. To address issues regarding culturally appropriate practices, the Self-Assessment recommended sensitivity training for programs and agencies providing services to culturally divergent families. OSEP also learned that the State administers the *Promoting Community Membership* project that includes a survey of parents of children who had an active IFSP as of December 31, 1995. At the time of OSEP's visit the analysis of the data showed that of the 28% of families that responded, most felt that they were receiving the services that they needed. Families responding also indicated that they were active in the planning of services, that service coordinators were attentive to their concerns, and that overall the family felt better as a result of participating in the Early Intervention Program. In some areas of the State, Family Resource Centers collaborate with local programs to provide needed supports and services. Providers indicated that the present Early Intervention Program is more family-driven. Various parent-training models were identified, including the parent-infant program for the deaf that has been effective in training parents and helping them support their child's development.

During the Validation Planning and the Validation Data Collection visits, parents, providers and administrators informed OSEP of the following concerns: (1) need for parent training in different languages and modalities to address needs of cultural and ethnic diversity, (2) lack of support groups for immediate and extended family members, (3) family supports and concerns need to be identified and addressed to enhance access to services and (4) the need for development and dissemination of culturally-relevant and family-friendly materials and documents.

To investigate the concerns identified during the Validation Planning process, OSEP collected information from the review of children's records, State and local polices and procedures, and interviews with NYDOH personnel, local program directors, service coordinators, and parents. Information was also obtained from several of the Parent Training and Information Centers.

OSEP reviewed and analyzed the data and identified the following strengths and area of noncompliance.

A. AREAS OF STRENGTH

1. Parent Guides to Enhance Awareness and Increase Participation in the Early Intervention System

NYDOH has made a concerted effort to reach out to families and get information to them. An example of a family-centered strategy was the development of a series of documents that included: *The Early Intervention Program-A Parent's Guide*, *The Quick Reference Guide for Parents and Professionals on Communication Disorders* and *The Quick Reference Guide for Parents and Professionals on Autism/Pervasive Developmental Disorders.* The State did a massive dissemination of documents across the State.

The *Early Intervention Program Parent's Guide* informs families how the Early Intervention Program works, defines frequently used terminology, describes parents' rights, and provides the reader with a list of phone numbers of programs and individuals who may assist them in answering questions.

The Quick Reference Guides on Communication and Pervasive Developmental Disorders were partially in response to the needs of the growing numbers of children birth-to-three being identified whose primary or secondary condition may manifest itself in communication disorders, and/or pervasive developmental delays. *The Reference Guides* were designed to assist families, professionals and public officials in making informed choices about early intervention services by presenting recommendations regarding diagnostic and intervention practices. During the public input process OSEP was informed by parents and professionals that these guides were useful in assisting parents to understand their child's delay and in preparing parents to ask questions. Parents reported that they felt more confident in participating in the Early Intervention System.

2. Parent Involvement Subcommittee of State Early Intervention Coordinating Council

The State Early Intervention Coordinating Council has a parent involvement subcommittee that has played a pivotal role in responding to the concerns regarding family participation and involvement in the State Early Intervention System. The committee proposed six activities to ensure that meaningful family input occurred. These recommendations included: (1) identifying promising practices for replication; (2) planning and hosting family forums to solicit information; (3) developing a family survey, (4) developing technical assistance documents for local programs and agencies, (5) developing articles concerning issues and promising practices for inclusion in the Focus on Families newsletter, and (6) developing orientation materials for newly identified State and local parent representatives.

B. AREA OF NONCOMPLIANCE

Failure to Identify and Document Family Needs, Supports and Services on the IFSP

NYDOH must ensure the performance of a timely, comprehensive, multidisciplinary evaluation of each child, birth through age two, referred for an evaluation, and a family-directed identification of the needs of each child's family to appropriately assist in the development of the child. 34 CFR §303.322(a)(1). The family-directed assessment is designed to determine the resources, priorities and concerns of the family and to identify the supports and services necessary to enhance the family's capacity to meet the developmental needs of their child. 34 CFR 303.322(d). The IFSP must include a statement of the major outcomes expected for the child and family, as well as a statement of the specific early intervention services necessary to meet the unique needs of the child and family to achieve the outcomes, as determined by the participants in the IFSP meeting. 34 CFR §303.344(c) and (d).

NYDOH has not ensured proper procedures to ensure that a voluntary family-directed assessment is conducted for each family, to identify the needs of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of the child.

OSEP reviewed 35 IFSPs and determined that 31 did not appropriately document the identification of family resources, priorities and concerns and supports to assist the family to enhance the development of the child. The State's Annual Report for FY 1998 indicated that the proportion of families authorized for family supports declined from 24% in 1995-96 to 21% in 1996-97. Local administrators indicated that more training is needed to adequately address the needs of the family and document them on the IFSP. Some providers indicated that the assessment of family supports and services is equivalent to a social history, rather than an assessment of the needs leading to the identification of needed services and supports. Families informed OSEP that more supports and assistance are needed to identify needed resources and to network with other families. Parents stated that they had to seek out resources on their own and to act as their own coordinator. Families stated this was stressful and they wished someone would have assisted them in finding needed services and resources.

NYDOH recognized the need to investigate the area of family support and services and has recommended that this issue be analyzed by the Parent Involvement Subcommittee of the State

Early Intervention Coordinating Council. OSEP will continue to work with the State to ensure that any recommendations resulting from the subcommittee's actions will result in correction of the identified deficiencies.

V. EARLY CHILDHOOD TRANSITION

Congress included provisions to assure that preschool or other appropriate services would be provided to eligible children leaving early intervention at age three. Transition is a multifaceted process to prepare the child and the child's family to leave early intervention services. Congress recognized the importance of coordination and cooperation between the educational agency and the early intervention system by requiring that a specific set of activities occur as part of a transition plan. Transition activities typically include: (1) identification of steps to be taken to prepare the child for changes in service delivery and to help the child adjust to a new setting; (2) preparation of the family (i.e., discussions, training, visitations); and (3) determination of other programs and services for which a child might be eligible. Transition planning for children who may be eligible for Part B preschool services must include scheduling a meeting, with approval of the family, with the lead agency, the educational agency and the family, at least 90 days (with parental permission up to six months) prior to the child's third birthday. Transition of children who are not eligible for special education also includes making reasonable efforts to convene a meeting to assist families in obtaining other appropriate community-based services. For all Part C children, States must review the child's program options for the period from the child's third birthday through the remainder of the school year and must establish a transition plan.

Validation Planning and Data Collection

The State's Self-Assessment, Annual Report, and correspondence indicated areas of strength and concerns. Local municipalities in some jurisdictions were implementing a seamless birth-to-five system through effective communication and coordination of services. Early Intervention Officials were commended for participating in joint training with the chairpersons of the preschool eligibility committee. OSEP reviewed the Self Assessment and other data sources and, after interviews with local, and State staff, providers and parents, determined that the following areas of concern should be investigated: (1) documentation in IFSP regarding transition planning, (2) identifying goals for the child to adjust to the new environment, (3) timeliness of transition meetings, (4) attendance of appropriate personnel at transition meetings, (5) children and families remaining in Early Intervention Program even if the child had been found eligible for Part B, due to a lack of space and (6) need for family training.

To investigate the concerns identified during the Validation Planning process, OSEP collected information from the review of children's records and State and local polices and procedures, and interviews of State personnel, local program directors, service coordinators, parents.

OSEP reviewed and analyzed the data and identified the following strength and area of noncompliance.

A. AREA OF STRENGTH

Local Partnerships Enhance Transition Efforts

NYDOH, in collaboration with the transition committee of the State Interagency Coordinating Council, has implemented interagency training for early intervention officials and chairpersons

of the Committee on Preschool Special Education across the State regarding provisions for transition from Part C to Part B, and innovative partnerships have been forged at the local level. Collaboration among local programs and agencies to ensure a smooth transition process has been demonstrated in some communities and may serve as model programs for other jurisdictions in the State. Local interagency coordinating councils, early intervention programs, local education agencies, early childhood direction centers and community based programs, such as Head Start, have formed local transition committees that include all the players in the transition process. A parents' manual was developed that describes, in user- friendly language, various roles and activities for parents and outlines differences between the child's activities in the early intervention environment and a typical day in a preschool program. As a result, providers and parents told OSEP that a birth- to-five seamless system of services for children and families has evolved in some communities. School districts in some areas work in partnership with the early intervention programs in their jurisdiction to schedule and conduct Committee on Preschool Special Education meetings during the summer months to minimize delays for families of children who turn 3 years of age during the summer.

B. AREA OF NONCOMPLIANCE

Failure to Ensure Smooth and Effective Transitions

The NYDOH must ensure that procedures are in place to ensure a smooth and effective transition of eligible children and their families from Part C to Part B preschool programs or other appropriate services by the child's third birthday. In the case of a child who may be eligible for preschool services under Part B of the Act, with the approval of the child's family, a conference must be convened with the lead agency, the family and the local education agency, at least 90 days before the child's third birthday to discuss any services that the child may receive and review the child's program options for the period from the child's third birthday through the remainder of the school year. 34 CFR §303.148(b)(2)(i). The lead agency must also ensure that procedures are in place to ensure that the local educational agency for the area in which the child resides is notified that the child will shortly reach the age of eligibility for preschool services under Part B. 34 CFR §303.148(b)(1). In addition if the Sate educational agency, which is responsible for administering preschool programs under Part B of the Act, is not the lead agency, under this part, an interagency agreement between the two agencies to ensure coordination on transition matters. 34 CFR §303.148(c).

OSEP found that NYDOH has not ensured that a smooth and effective transition is afforded eligible children and their families who transition from Part C to Part B preschool and other appropriate services by the child's third birthday.

As noted in the General Supervision section of this monitoring report, NYDOH's corrective action procedures were not effective to ensure that follow-up activities, inclusive of technical assistance was implemented to correct identified areas of noncompliance relative to the transition of children and their families from Part C to Part B preschool. OSEP reviewed NYDOH's monitoring log for July 1998 and identified that in three of six areas OSEP visited, the State had identified noncompliance in the provision of transition services. NYDOH's monitoring reports in these three areas also indicated the lack of coordination between the lead agency staff and the

local education agency, and the inability of service coordinators to coordinate required transition activities for children and families with local education agencies in a timely manner, due to large caseloads as described in Section III of this monitoring report.

NYDOH's policies and procedures specify that Part C funds may be used to provide services to children from their third birthday to the beginning of the following school year. Providers and parents told OSEP that although this option was intended to ensure continuous services, transition from Part C to Part B is often fragmented. Service coordinators across the State told OSEP that children who turn three during the summer months are given the option to remain in the Part C program from September until January 1st. However, Part C funds can only be used from the 3rd birthday until the school year begins, (i.e., September), and must be used to provide FAPE in accordance with Part B. Providers reported that they were not always sure whether parents who were given the option of remaining in Part C were adequately informed of their rights. Specifically, providers told OSEP that they were not sure that all children who turned three during the summer months and remained in Part C had an IEP and were receiving FAPE services. Parent and providers in three areas told OSEP that service coordinators do not adequately plan transition activities with them. Parents in three areas reported that families who chose to continue their services in the Part C program may not transition in a timely manner in January because the preschool program in their designated area was often full by September, thus, families had to wait for preschool services.

Parents also told OSEP that they did not fully understand the transition process. Parents stated that transition is confusing, overwhelming and they state that staff did not listen to them. Thus, they may be reluctant to give consent to transfer records and to conduct evaluations, when requested by service coordinators or local administrators. This may contribute to the lack of timely transitions.

Administrators, service coordinators and providers reported that transition is difficult because each school district has its own policies and procedures, therefore service coordinators and local administrators must be knowledgeable of the varied transition procedures in order to correctly inform parents. Local school district administrators do not always attend transition meetings as required and do not delegate their responsibilities to a person who can make decisions regarding transition activities, therefore the process is delayed. In addition, some school districts close down during the summer months; therefore transition plans are developed in the beginning of the school year in September or October. As a result IEPs are not developed in a timely manner and implemented by the child's 3rd birthday. This was confirmed by administrators, service providers, and parents.

OSEP's review of NYDOH's written policies and procedures regarding transitions determined that they were adequate, and if implemented could lead to smooth and timely transitions for eligible children and toddlers, and correct the areas of noncompliance. NYDOH needs to continue to work to eliminate the barriers as delineated above to correct the areas of noncompliance.