

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 for service provision, and many families had difficulty locating and obtaining needed services. Searching for resources placed a great strain on families.

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

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

Validation Planning and Validation Data Collection

Based on the Self-Assessment, the New Jersey Part C Steering Committee identified several needs and priorities related to public awareness and child find, such as need for: (1) standardized planning, selection, review and tracking of child find and public awareness materials to ensure linkages with the needs of target populations, (2) identifying gaps in public awareness materials in languages represented in the State, and (3) improved ongoing outreach to physicians and hospital personnel.

The public forums corroborated the Self-Assessment findings and added that: (1) physicians tend to adopt a "wait and see" response to parental concerns about their child's development; (2) physicians who are aware of the early intervention system may not understand the scope of services offered in the system; (3) early identification and referral of infants and toddlers with autism, hearing and visual impairments need to improve; (4) broader dissemination of public awareness materials to the general public needs to occur, and (5) increased public awareness activities are needed to reach non-English speaking families.

State data, however, do show that referrals to the early intervention program are increasing (e.g. from 1998 to 1999, an increase of 8%) despite a declining birth rate. The system receives over 6,000 referrals in a year and approximately 77% of these referrals are found eligible for early intervention. Contributing to this increased referral rate was the fact that one county, Camden, has done an exceptional job of recruiting service coordinators who represent the races, ethnicities, and cultures of the community and serve as ambassadors for the early intervention system.

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

A. STRENGTHS

1. Special Child Health Services Registry

New Jersey is one of a handful of States nationwide that has a systemic linkage between its Special Child Health Services Registry and the provision of immediate case management services. This long-standing Registry includes mandated reporting of children born with certain established medical conditions and voluntary reporting of children with other special health care needs. As children are enrolled in the Registry, parents of registered children are contacted by letter and by personnel located in county case management units. This process ensures timely referrals to Part C service coordinators housed within the case management units. The central Registry is located within DHSS.

2. Newborn Hearing Screening

New Jersey is providing innovative programs to ensure that newborns at risk for hearing impairments are identified within the first three months of life. At the time of OSEP's visit, New Jersey had a Newborn Hearing Screening program that requires hearing screening of newborns at risk for hearing impairment. Approximately 42 percent of newborns are currently screened. However, by the year 2002, all birthing facilities will be required to screen all newborns electrophysiologically, prior to discharge or before the newborn is one month of age regardless of the presence or absence of risk factors.

3. Autism Registry and Research

The State is demonstrating a strong commitment to children with autism and their families. Just prior to OSEP's visit, the State Legislature and Governor created two initiatives to address increasing concern about meeting the needs of children with autism and their families. The goal of both initiatives is to enable analysis of the causes of autism and to plan for and provide appropriate services to children with autism and education for their families. One initiative is the creation of the Center of Excellence for Autism where basic and applied biomedical research, diagnosis and treatment for autism will take place. The other is the creation of a registry for autism within DHSS. This registry is to be organized similarly to the current Special Child Health Services Registry in that it will require professionals qualified to make the diagnosis of autism to register children with this diagnosis with DHSS.

4. Coordination of Child Find with Social Security Administration

DHSS has established an effective coordinated child find procedure with local Social Security Offices in that it receives monthly printouts from the Social Security Disability Determination Unit that identifies all children applying for Supplemental Security Income. The county case

management staff provides outreach to all Supplemental Security Income applicants to ensure that appropriate referrals are made to early intervention and other education and social service agencies.

Although child find activities are coordinated with local Social Security Offices, the implementation of an effective coordinated, interagency child find system is not yet in place as cited later in this Section.

B. AREAS OF NONCOMPLIANCE

1. Inadequate Documentation of Dissemination Practices

DHSS must have procedures in place to determine the extent to which primary referral sources, especially hospitals and physicians, disseminate information on the availability of early intervention services to parents of infants and toddlers with disabilities. 34 CFR §303.321(d)(2)(iii). DHSS has not ensured that procedures are in place to determine the extent to which primary referral sources, particularly physicians, disseminate information to parents of infants and toddlers with disabilities about the availability of early intervention services.

State Part C staff acknowledged to OSEP that the State does not have effective procedures for determining the extent to which primary referral sources receive the information about the early intervention system or disseminate it to families. Service providers, service coordinators and parents in three Regions of the State, reported that information about early intervention services is not in physician's offices.

Many families throughout the State reported to OSEP that they did not obtain information about early intervention services from their physicians. Some families said they had to do their own research to obtain information about the early intervention system. The preponderance of these reports were from families who have children with developmental delays of unknown etiology, children suspected of having autism spectrum diagnoses, children born in nearby States and who are in the military.

In one Region that OSEP visited, parents, interagency representatives and providers stated that doctors need information about the benefits of the early intervention system for children and families. Parents reported that doctors take a "wait and see" approach even when parents express concern about their child's development. Participants in the public forums also reported that physicians need to have information about the importance of the early intervention program and the types of services the early intervention system provides. Service providers and service coordinators in one Region reported that families in certain socioeconomic categories are not referred to the early intervention system by physicians or others until their private insurance coverage for private services expires.

2. Child Find Activities Not Coordinated

DHSS, with the assistance of the State's Interagency Coordinating Council, must ensure that child find under Part C is coordinated with all other major efforts to locate and identify children

conducted by other State agencies responsible for administering the various education, health, and social service programs relevant to Part C. 34 CFR §303.321(c).

With the exception of the Social Security agencies (noted above in the "Strengths" section), DHSS has not ensured that all public agencies collaborate in child find activities. By not ensuring that infants and toddlers who may be eligible for Part C services are referred to the State's early intervention program, DHSS may be denying eligible children and families the rights, protections, service coordination and services they would be entitled to receive under an IFSP.

The Part C staff stated that a coordinated child find system is not yet in place. The Steering Committee reported that improvements in coordinating child find activities with relevant agencies are needed. Other State interagency representatives reported that State health and social service agencies generally operate with minimal interagency coordination and implement their programs "in silos". This group stated, however, that the DHSS Stakeholder initiative provided a strong foundation to begin the process of building interagency coordination.

All parents in one area told OSEP that they had not received information about the early intervention system from any social service agency with which they had had contact. Service providers in two Regions reported that coordination of child find activities is not occurring with health and social service programs implemented by the visiting nurses and the State agency responsible for foster care. Local interagency representatives, in one Region, stated that no procedures exist to ensure coordination of child find efforts with other agencies at the local level.

In three areas OSEP visited, service providers, service coordinators, parents and interagency representatives told OSEP that efforts to coordinate child find and outreach with doctors, and community and social service agencies that serve Hispanic and immigrant families, have not been effective. One member of the State interagency group told OSEP that anecdotal data indicate that Hispanic children are being referred to the early intervention system later than other groups. To address this concern, the Catholic Charities and the Parent Training Center are collaborating on a project to employ outreach workers for Hispanic communities and agencies to ensure timely referrals to early intervention and other programs. This State group also reported that effective, coordinated strategies are needed to provide outreach for families who recently immigrated to the U.S. through New Jersey cities.

Prior to OSEP's visit, the State had initiated regional needs assessments to determine whether gaps existed between children enrolled in the early intervention program in comparison to the census, the Special Child Health Services Registry and other demographic data, including racial, ethnic, and cultural groups. DHSS hoped to use data from these studies to ensure a comprehensive, coordinated child find system. Although State data show that referrals to the early intervention program are increasing, data from one Regional report, available to OSEP at the time of the visit, indicated that outreach and coordination of child find with other agencies could have a positive impact on the early referral and identification of underrepresented groups within that Region.

The Lead Agency is implementing a variety of strategies to ensure that the child find system is reaching all audiences and is coordinated. Two State interagency agreements that define roles and responsibilities for child find were being reviewed by the relevant agencies at the time of OSEP's visit to the State. The State is developing a management information system that will provide feedback on gaps in referral sources so that child find activities can be targeted to relevant audiences. While this system is being developed, DHSS formed a workgroup with the NJSDE to identify and coordinate the various child find activities occurring throughout the State. The State Interagency Coordinating Council formed a workgroup to focus on the early identification of young children in New Jersey to include examination of ways to improve coordination across agencies to improve child find. DHSS plans to incorporate the activities and recommendations from the NJSDE, State Interagency Coordinating Council and the needs assessments of the four Collaboratives, so that a coordinated, targeted child find system is in place.

DHSS will need to evaluate the results of these steps and be able to demonstrate compliance with the requirements for the provision of a coordinated child find system to ensure the early referral of children needing early intervention services.

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

Coordination with Newborn Hearing Screening, Staff from the Early Identification and Monitoring Program, and New Jersey's Center for Birth Defects Research and Prevention

The Service Delivery Task Force suggested that the Part C staff in DHSS work with staff responsible for the newborn hearing-screening program in DHSS to determine how to coordinate this program and referrals to early intervention prior to the 2002 implementation of universal newborn hearing-screening program. Experts in this field suggest that a neonate who is deaf looks and acts like any other baby and may go home from the hospital with an undetected hearing impairment or profound deafness if not screened in the hospital or shortly thereafter. In addition, studies have indicated that 30% of childhood hearing loss develops after the newborn period; therefore, periodic hearing screening may need to continue throughout early childhood.

Other relevant activities within DHSS, such as the newly formed work group to improve physicians' reporting to the Birth Defects registry (known as the Early Identification and Monitoring Program), and the Birth Defects Research project that has established (or is establishing) collaborative relationships with various hospitals and health facilities across the State, might have common goals and objectives with the Part C system, such as outreach and collaboration with physicians and hospitals. OSEP encourages the early intervention staff to collaborate with these activities wherever feasible so that a coordinated child find system can be improved and primary referral sources are informed about and make referrals to the early intervention system.