



**Testimony
Public Hearing**

of the

**ASSEMBLY BUDGET COMMITTEE
Louis D. Greenwald, Chairman**

**on the proposed
Fiscal Year 2006 State Budget**

**Thursday, March 26, 2005
9:30 a.m. – 12:30 p.m.
State House Annex, Committee Room 11
Trenton, New Jersey**

**Submitted by
The New Jersey State Interagency Coordinating Council
*William S. Agress, Chair***



Good Morning:

I am Bill Agress, chairman of the New Jersey State Interagency Coordinating Council (SICC). The federally mandated SICC consists of twenty-five voting members who assist and advise the New Jersey Department of Health and Senior Services in implementing the New Jersey Early Intervention System for infants and toddlers with disabilities.

Since my appointment as chair in December 1999 and in all the years of the existence of the Early Intervention System, there is one constant fact. Every single year the number of children from birth to three who are evaluated increases. Correspondingly, each year the number of children requiring early intervention services goes up dramatically. In SFY 2003, 14,271 children received an Individualized Family Service Plan (IFSP). In SFY 2004, that number of children increased to 15,289.

Furthermore, we are not reaching all the children and families entitled to, and deserving of, early intervention services. I believe this is especially true in homes where English is not the primary language; in single parent households; in urban areas; in rural areas; and among our minority populations.

I believe every infant and toddler in New Jersey deserves access to coordinated, comprehensive, therapeutic and rehabilitative health care. I believe every family needs to know that the developmental needs of their children from birth to three can, and will be, met.

For years, the State has offered two hours of service, but that is not in any way sufficient for the types of disabilities early intervention addresses. The addition of the family cost share may produce some additional revenue, but not nearly enough based on the rising levels of need.

In the area of Autism Spectrum Disorders, for example, it was estimated years ago that 1 in 10,000 births resulted in autism. Today, that estimate has been revised to less than 1 in 200 births.

We need to provide therapy to children who have cerebral palsy, down syndrome, fragile x syndrome (the most common inherited cause of mental retardation), spina bifida, achondroplasia (where bones fail to grow normally), rhett syndrome, with its progressive loss of mental and manual skills, genetic disorders such as autosomal dominant disorder and autosomal recessive disorder, various other pervasive developmental disorders, visual defects, auditory impairments and speech disorders.

The funds you budget for early intervention bring only positive results; in some cases (as with my own son), great success; in other cases, vast strides; and in others, just improvement. But, in

all cases there are long term benefits. In fact, more than 90% of the money budgeted is allocated for the provision of direct services for children and their families. But we are not doing enough.

Why is New Jersey serving only 2.36% of the birth to three population, while New York State serves 4.42% and Rhode Island serves 3.48%? We are not doing all we could in many areas. We need to provide more family support services. We must encourage more people to enter the early intervention professions, such as speech and physical therapy. We need to examine additional funding sources, such as Medicaid and insurance.

Some of you may have personally experienced the enormous benefits of early intervention. I know you are aware that early intervention families are from all parts of our state; of all races, religious and socio-economic groups. They all share one belief. They want the best for their children. They want their children to be happy, productive, successful individuals who will persevere.

I'm asking you to please pass Assembly Joint Resolution 117, establishing the third week in May as annual "Early Intervention Week." And, most importantly, increase the funding annually -- as you have in the past -- for early intervention services. It truly does work!

I should now like to share the attached factual information about the SICC and the Early Intervention System.

**State Interagency Coordinating Council
Fact Sheet for 2006 Budget Hearing**

- The State Interagency Coordinating Council (SICC) appreciates the support and commitment of the legislature and administration to ensure that the early intervention system in New Jersey is responsiveness to the needs of children and families eligible for services.
- The Early Intervention System (Early Childhood Intervention Program) is a federally mandated entitlement program which provides a comprehensive system of services for infants and toddlers, birth to age three, with developmental delays/disabilities and their families.
- The Governor's proposed budget includes state aid of \$59,965,000 for "Early Childhood Intervention Program" and a special purpose appropriation of \$300,000 for the EIS Identification System. This represents a \$3 million increase in state aid. The SICC and all the families served through the early intervention system are very grateful for the continued support and increased funding.
- The SICC appreciates the continued support for a Central Management Office that provides timely availability of data to support monitoring and system evaluation and the opportunity to link families across systems and programs.
- The fiscal 2006 budget recognizes the historical growth experienced by the early intervention system.
- As of May 1, 2004, the early intervention system began implementation of a monthly family cost share for families with incomes above 350% of the federal poverty level. A sliding fee scale is being implemented for families at or above 350% Federal Poverty Level (FPL) starting at \$10 per month toward the cost of their family's early intervention services.
- A Central Management Office (CMO) is responsible for ensuring enrollment of appropriately qualified personnel; accountability data; payment of authorized services; revenue collection from Medicaid and family cost share; and assurance that families receive an explanation of benefits for services received; and, as appropriate, accurate billing.
- Early intervention services include early identification, service coordination, evaluation, and, if eligible, implementation of an Individualized Family Service Plan in compliance with Federal requirements established under the Individuals with Disabilities Education Act (IDEA).
- Services are provided in natural environments (home, child care) and within family routines to facilitate inclusion of the child and family into their community and use of natural family and community supports and opportunities for children to be with peers that are not disabled.
- An infant or toddler in New Jersey must meet a moderate eligibility requirement when compared to eligibility definitions across the nation and territories. In New Jersey a child is eligible if under the age of three and experiencing:
 - Developmental delay of 25% in two or more areas of development or 33% in one area (i.e. gross motor, fine motor, communication, self-help, social-emotional, sensory); or
 - A diagnosed physical or mental condition that has a high probability of resulting in developmental delay (i.e. Autism Spectrum Disorders, Down Syndrome, Cerebral Palsy, vision impairments, hearing impairments)
- A unique aspect of the early intervention system is a system point of entry established within the County Special Child Health Services Case Management Units that provides an effective early identification and referral system to and from

EIS for children registered under the New Jersey Birth Defects and Special Needs Registry.

- The early intervention system continues to experience an increase in the number of children and their families needing services. This may result in a need to request additional state appropriations to ensure that the state complies with Federal requirements to meet the individualized needs of eligible children and their families.
 - The annual growth rate for eligible children has ranged between 8-18 percent each year since DHSS became the lead agency in 1993.
 - During SFY 2004 the system received 11,899 referrals, conducted over 9,000 evaluations, and provided 15,829 children with early interventions services in accordance with an Individualized Family Service Plan.
 - During SFY 2004 the system continued to experience a 12% increase over SFY 2003 in the number of referrals, eligibility evaluations and eligible children.
 - Direct intervention services account for annual expenditures of over \$60 million, with costs averaging \$8,500 per child, but the intensity of services needed for certain disorders/delays such as autism may reach \$50,000 per child per year.
 - New Jersey has experienced a 70% growth in the number of children needing early intervention services under an Individualized Family Service Plan (IFSP) in the last four years (4,760 in 2000 to 8,091 in 2003).
 - New requirements for referral of children with substantiated child abuse and neglect, including children affected by illegal substance abuse, will likely increase the cost of evaluation, assessment and identification of children in need of early intervention services.
 - Over 91 percent of funds support direct intervention services to children and their families.

**Early Intervention System
System Statistics**

<u>State Data</u>	<u>SFY 2003</u>	<u>SFY 2004</u>
Referral	11,008	11,889
Cumulative Served -IFSP	14,271	15,829

- New Jersey has experienced 8-18% growth in the number of eligible children each fiscal year.
- The U.S. Department of Education, Office of Special Education is reviewing national data to establish performance benchmarks and triggers.
- Based on FFY 2003 Federal data (excluding at-risk populations), states currently serve from under one percent of the birth population to as high as 5.75%.
- On a scale of broad eligibility criteria to narrow, New Jersey currently has moderate criteria for eligibility and is serving 2.36% of the birth to three population. NJ does not include "at-risk" children under the eligibility criteria.
- A review of FY 2003 Federal December 1 data documents that New Jersey is serving a lower percentage of the birth population than other states with similar moderate eligibility criteria (New York - 4.42%, Rhode Island - 3.48, Connecticut- 2.96%).
- National data indicates that New Jersey will likely continue to experience growth during the next few years.