

Statement of Lowell Arye, Executive Director Alliance for the Betterment of Citizens with Disabilities

My name is Lowell Arye and I am the Executive Director of the Alliance for the Betterment of Citizens with Disabilities (ABCD). I want to thank Chairman Vitale, Vice Chair Karcher, and the other members of the Senate Health and Human Services Committee for the opportunity to testify on the needs of the Early Intervention (EI) System.

ABCD is a statewide advocacy organization comprised of 13 member agencies that provide an array of community based services to more than 8,000 people with multiple physical and developmental disabilities and their families. Most of the people served by these agencies are medically complex, have ambulation issues, and require frequent monitoring and assistance with their daily needs. A significant number of these individuals have swallowing and/or seizure disorders. ABCD's Early Intervention (EI) providers comprise six agencies that serve more than 17% of all children and families served in the Early Intervention System.

Adequate Funding is Imperative

Adequate funding for EI is imperative. A long term funding solution to EI is needed to support the expected growth rates. Over the past several years, short-term fixes were necessary to ensure adequate funding, such as the one time transfer of funds in fiscal year 2004 from the Catastrophic Illness in Children's Relief Fund. New Jersey needs to explore all revenue streams to maintain adequate funding for the future.

According to the National Early Childhood Technical Assistance Center (NECTAC): "Building a systemic approach to financing a statewide system of services is a complex process that includes the identification, understanding, and full utilization of all existing funding resources."

Since the inception of the Early Intervention (EI) program in 1986, the intent of Congress has been for states to finance their early intervention systems through a variety of federal and state public and private sources including Medicaid, private insurance, and cost sharing from families.

In New Jersey's enacted FY 2005 budget, funds for Early Intervention include \$52.9 million in State funds, with an additional estimate of \$16 million in other federal and Medicaid funds. The budget assumes an additional \$7 million in funds collected from family cost participation.

Medicaid Funding

Medicaid is an important funding source for the Early Intervention Program. Generally, Medicaid is the payer of last resort for health care; meaning that all other third party source(s) including Medicare and private insurance pay prior to Medicaid reimbursement for health care. However for Part C (Early Intervention) of the federal Individual with Disabilities Education Act (IDEA), the statute clearly states that prior to any IDEA funds being used for services, all other sources of revenue, including Medicaid, are to be used. The federal Medicaid statute also states that Medicaid is to be used prior to Part C of IDEA funds.

New Jersey Should Maximize Federal Medicaid Revenue

It is not clear whether New Jersey is maximizing its federal revenue. Our neighboring state of Pennsylvania, in FY 2004, received 38.5% of their funds for the early intervention system from the federal government (\$29.7 million in federal funds, including Medicaid and \$47.3 million in State funds). Contrast that with New Jersey in FY 2004, which received 25% of its funds for early intervention from the federal government (\$16 million in federal funds, including about \$4 million Medicaid funds and \$39 million in State funds). If New Jersey received the same proportion of their funds from the federal government, in FY 2004, the early intervention system would have received approximately \$8 million more in funding.

New Jersey should begin to increase its federal Medicaid funds in two ways. First, the Department of Health and Senior Services should perform a funding stream analysis and determine whether we are adequately using Medicaid including Early Periodic Screening Diagnostic and Treatment (EPSDT) for early intervention. Second, we should apply for a Medicaid Home and Community Based Services Waiver for Early Intervention from the federal government.

Early Periodic Screening Diagnostic and Treatment (EPSDT)

EPSDT is a required Medicaid benefit that provides comprehensive “well child” and medically necessary treatment services to all Medicaid eligible children birth to age 21. EPSDT components are designed to target health conditions and problems for which growing children are at risk, including iron deficiency, obesity, lead poisoning, and dental disease. They are also intended to detect and correct conditions that can hinder a child’s learning and development, such as vision and hearing problems. For many children, especially those with chronic conditions, EPSDT is important in identifying the need for essential medical and supportive services, and in making these services available.

EPSDT enables health professionals to assess the child's health needs through initial and periodic examinations and evaluations. It also assures that the health problems found are diagnosed and treated early, before they become more complex and their treatment more costly. Diagnostic and treatment services are provided when a screening examination indicates the need for further evaluation of an individual's health. Any diagnostic or treatment that is medically necessary to improve a condition detected in a screen must be provided.

New Jersey’s participation and treatment rates for EPSDT are inadequate. Screening rates for children under age 1 and ages 1-2 were 88% and 71% respectively. Although this is well over the overall participation rate of 51% for all children ages birth to 18, it is still relatively

low. The rate of children referred for corrective treatment is extremely low. New Jersey can and should have higher referral rates for corrective treatment.

New Jersey Annual EPSDT Participation in FY2003

	Total Eligibles receiving at least one periodic screening	Participation rate	Total Eligibles referred for corrective treatment	Percentage of eligibles receiving screening referred for corrective treatment
Under age 1	29,639	88%	171	0.5%
Age 1-2	52,572	71%	336	0.6%

Source: Form CMS-416 Annual EPSDT Participation Report (March 30, 2004) from the State of New Jersey to CMS

The Department should initiate a funding stream analysis to determine that it is taking full advantage of all federal Medicaid revenue including funding under the EPSDT program.

Medicaid Home and Community Based Services (HCBS) Waiver for EI

New Jersey should also maximize federal revenues by applying for a Federal Home and Community-Based Services Waiver (HCBS) for EI under Medicaid.

Waiver services are paid through Medicaid. Medicaid costs are shared by the state and the federal government. In New Jersey, the state/federal match is 50, meaning that for every dollar the state contributes, the federal government matches it. New Jersey could use some of the State funds it already allocates for Early Intervention to receive the federal match through a waiver.

Several states, including Pennsylvania, Nebraska, Wisconsin, Maryland, and Colorado have some form of early intervention Medicaid waiver program. Some are specific to population groups such as autistic children and to specific services such as respite. The state of Pennsylvania seems to have the most comprehensive waiver for the early intervention system.

Before explaining Pennsylvania’s waiver, a few brief points about waivers. (See Appendix for a comprehensive explanation of HCBS waivers)

Home and Community Based Services waivers (HCBS) (also known as 1915 (c) waivers) allow States the flexibility to develop and implement community alternatives to placing Medicaid eligible individuals in hospitals, nursing facilities, and Intermediate Care Facilities for the Mentally Retarded (ICF/MR).

HCBS waiver programs may serve seniors and people with disabilities, including developmental disabilities. A state may target the waiver to specific illnesses or conditions, such as technology dependent children or individuals with AIDS.

States must demonstrate to the federal government agency, Centers for Medicare and Medicaid Services (CMS), that they are providing waiver services only to people who are eligible for institutional placement. States have the flexibility to design waiver programs and

select the mix of waiver services that best meets the needs of the population they wish to serve.

States have the opportunity to provide home and community-based services, through a waiver, available to individuals who would have otherwise received Medicaid only if they lived in an institutional setting. In other words, individuals receiving services under an HCBS waiver program must meet an institutional level of care (LOC) that is defined by the state and approved by the federal government.

There is no federal requirement that an institutional standard requires a severe level of medical need or functional limitation.

Pennsylvania’s Medicaid Early Intervention Waiver

Pennsylvania’s waiver serves almost 16% of all infants and toddlers who receive early intervention services. In FY 2004-2005, Pennsylvania will serve 25,221 children (unduplicated) through Early Intervention Services, with 3,985 receiving those services through the Waiver.

Pennsylvania defines the institutional level of care for its waiver with a broad definition that allows infants and toddlers to be eligible. The definition is stricter than eligibility for early intervention services, but is not overly restrictive.

Brief Overview of Eligibility for Medicaid Waiver and Early Intervention Services

Eligibility for Medicaid Waiver Services (Institutional Level of Care)	Eligibility for Early Intervention Services
Developmental delay of 50% in one area or 33% in two areas of development: including cognitive, physical, social, communicative; or substantial functional limitations in three or more areas including self care, learning, mobility, self-direction.	Developmental delay of 25% of a child's chronological age in one or more developmental areas including cognitive, physical, communication, social or emotional and adaptive.
Certification that intellectual functioning is more than 2 standard deviations below the mean of an intelligence test; or slightly higher than two standard deviations if infant or toddler manifests serious impairments of adaptive behavior or the professional certifies that the child has other related conditions including cerebral palsy and epilepsy.	Developmental delay in one or more developmental areas as documented by test performance of 1.5 standard deviations below the mean in a standardized test. A diagnosed physical or mental condition which has a high probability of resulting in a developmental delay.

Pennsylvania received its initial waiver from the federal government in July 1998. A renewal of its waiver was approved in July 2001. New Jersey should examine and craft a similar waiver for Early Intervention services.

Appendix: Home and Community Based Services Waivers

- Home and Community Based Services waivers (HCBS) (also known as 1915 (c) waivers) allow States the flexibility to develop and implement community alternatives to placing Medicaid eligible individuals in hospitals, nursing facilities and Intermediate Care Facilities for the Mentally Retarded (ICF/MR).
- HCBS waiver programs may serve seniors and people with disabilities, including developmental disabilities. A state may target the waiver to specific illnesses or condition, such as technology dependent children or individuals with AIDS.
- States must demonstrate to the federal government agency, Centers for Medicare and Medicaid Services (CMS) that they are providing waiver services only to people who are eligible for institutional placement. States have the flexibility to design waiver programs and select the mix of waiver services that best meets the needs of the population they wish to serve.
- States can make home and community-based services, under a waiver, available to individuals who would otherwise qualify for Medicaid only if they are in an institutional setting. In other words, individuals receiving services under an HCBS waiver program must meet a hospital, nursing facility or intermediate care facility for persons with mental retardation level of care.
- There is no federal requirement that an institutional standard requires a severe level of medical need or functional limitation.
- State may use a higher income standard for Medicaid eligibility purposes for individuals residing in institutions. If the State chooses this option, they may also extend that standard to individuals eligible for the Waiver.
- The standard is 300% of the maximum Federal Benefit Rate for SSI. This year, that amount is \$1635 a month.
- Persons who qualify for services based upon this income standard must maintain resources within Medicaid eligibility limits (\$2,000).
- States may receive matching federal funds to provide services in the home or community if they meet certain requirements. To receive approval for the waiver, states must demonstrate to CMS that the program is “cost neutral” as defined by a CMS formula.
- Currently, states must only demonstrate the average costs of providing home and community-based services through the waiver will be equal to or less than the average costs without the waiver. This means that states must only demonstrate that on average, spending for those receiving services would not exceed the average amount for those in institutions.

- Necessary safeguards are in place to protect the health and welfare of consumers and to assure financial accountability for funds expended;
- State must evaluate a consumer's need for institutional services;
- Individuals must be informed of their right to select from among all "qualified Medicaid providers", including an institution or community agency;
- State must provide an individual plan of care developed by qualified individuals;
- State must have provider standards.
- Waivers can be used to access Medicaid services that are not normally available to Medicaid beneficiaries.
 - In a home or community-based setting these services may include non-medical services such as case management, homemaker/home health aides, personal care, habilitation, and respite care.
- Room and board are excluded from coverage except in limited circumstances.
- States use the HCBS as the primary funding stream to deinstitutionalize and develop community services.
- The amount of total federal outlays for Medicaid has no set limit (cap); rather the federal government must match whatever the State decides to provide, within the law, for eligible beneficiaries.
- The portion of the Medicaid program which is paid by the federal government, known as Federal Financial participation (FFP) is determined annually for each State by a formula that compares the State's average per capita income level with the national average.
- New Jersey's FFP rate is 50%. That means for every dollar New Jersey puts in, the federal government matches a dollar for eligible beneficiaries.