

Statement of Lowell Arye, Executive Director*
Alliance for the Betterment of Citizens with Disabilities (ABCD)

My name is Lowell Arye and I am the Executive Director of Alliance for the Betterment of Citizens with Disabilities (ABCD). I want to thank Senator Rice for introducing S2455, a bill to ensure that New Jersey maximizes its federal revenues for people with developmental disabilities by applying for all Home and Community Based Services Waivers (HCBS). I also want to thank Chairman Vitale for posting this bill and for his continued leadership on behalf of people with developmental disabilities.

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.

The Alliance for the Betterment of Citizens with Disabilities supports S2455 requiring the Department of Human Services to apply for all possible federal Medicaid Home and Community Based Services (HCBS) waivers to serve people with developmental disabilities. ABCD has been at the forefront of educating and informing the developmental disabilities community about HCBS waivers and ensuring that the State maximizes all of its federal revenues through the HCBS waivers.

For a number of years prior to the McGreevey Administration, ABCD and others requested that the State ensure the maximization of all federal revenues under our current HCBS waiver for people with developmental disabilities, called the Community Care Waiver, and to apply for all federal HCBS waiver including one for Family Support. Community advocates were told the State was already maximizing all of its federal revenues. However, when the McGreevey Administration came in, their review demonstrated that the State was not receiving its full federal revenues under the current Community Care Waiver nor was it applying for other available dollars under HCBS waivers for services to people with developmental disabilities.

In September 2002, the Department of Human Services released a plan to move forward. The *New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Families* detailed a vision to provide more services and supports to a larger number of individuals who live at home with their families. The plan explained that the State must obtain additional federal revenue through broadening the use of Medicaid waivers to encompass services to families living at home, including personal care, respite care and assistive devices. The plan specifically targeted maximizing federal revenues by developing "an enhanced waiver that would provide a 50% federal reimbursement for these services which now cost the State \$35 million with no federal match."

It is now two and a half years later and New Jersey spends \$37 million of State only money on Family Support. New Jersey ranks 37th in the nation for funding provided to individuals living at

home with their family. New Jersey is one of only a dozen states which receive NO federal family support dollars.

Acting Governor Codey and his Administration are working to determine what services are not being claimed for federal money under the current waiver. Through this work, the Administration will receive additional federal money for these services. ABCD supports this effort. However, over the past several months, the leadership in the Assembly and the Senate, based on initial reports of the State Auditor, has expressed their view that additional federal revenues from the current federal waiver for people with developmental disabilities can and should be maximized. Estimates by the leadership have ranged from \$18 million to as high as \$65 million in additional federal revenues that could be maximized in the current waiver.

Clearly, more must be done to ensure that we maximize federal revenues and bill S2455 does just that. S2455 directs the Department of Human Services to apply for all possible federal HCBS waivers and will ensure that there is participation by all stakeholders in the process.

S2455 requests specific information is provided to the legislature and stakeholders on a regular basis. The requested reporting and updates are necessary in determining and understanding that all possible options for federal revenues are being explored. Further, it will provide a transparency to the legislature and stakeholders on specific information about current waiver services, non-medical reimbursable services, and the number of individuals served through the waiver and through State-only funded services. This data is important to planning for future services and in determining whether the State should apply for other HCBS waivers.

New Jersey has begun conversations with the federal Centers for Medicare and Medicaid Services (CMS) to develop a residential waiver similar to our current Community Care Waiver, a support services waiver and a waiver for medically fragile children. However, it is our understanding that there are no discussions of a family support waiver, even though the State could net millions of federal dollars and increase services to families.

Family Support Options Under an Expanded Waiver

New Jersey should maximize federal revenues by applying for a Federal Home and Community-Based Services Waiver (HCBS) for family support. 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 Family Support to receive the federal match through a waiver.

The cash subsidy program under Family Support is not reimbursable by the federal government because federal Medicaid law does not allow cash payments to be made to or on behalf of beneficiaries. Since cash subsidy programs are not reimbursable from the federal government, the \$10 million currently used by Family Support for cash subsidies must be set aside as State only funds. Federal Medicaid law says the State must first spend all of the funds for services before requesting reimbursement under a waiver. New Jersey has the opportunity to create a HCBS waiver using as much as \$20 million of State-only funds from Family Support. These funds would then be reimbursed from the Federal government netting the State at least \$10

million in additional revenue. Those additional federal funds must be re-invested in family support services to expand services to other families.

Using an HCBS waiver, home and community services can be furnished to individuals who live with their families or in their own home just as readily as to individuals who are served in residential services. States have wide latitude in configuring their eligibility policies to expand access to home and community services for people who live with their families.

States that make services and supports more readily available to people with developmental disabilities who live with their families experience lower demand for group home and similar services. These programs typically operate under stricter cost caps than the State's parallel HCBS waiver program for the same population. However, these programs give individuals and families considerable flexibility in selecting a mixture of services and supports that best meet their needs and preferences.

Conclusion

While the efforts to maximize federal revenues are imperative, we also must ensure that all federal funds from the Community Care Waiver and any additional waivers mandated by this bill be re-invested in community services for the Division of Developmental Disabilities (DDD). If the federal government is reimbursing the State on a dollar for dollar match to provide services to people with developmental disabilities, those federal dollars should go back to DDD's budget to ensure that more individuals and their families are served.

New Jersey has been moving forward on a new approach to self-directed services called *Real Life Choices*. ABCD supports this new approach as part of a broad array of community services for people with developmental disabilities. It is still unclear though whether all services under Real Life Choices are reimbursable through the current Community Care Waiver.

In this time of state fiscal constraints, New Jersey should do everything possible to ensure that all federal funds are maximized by ensuring that all possible services are reimbursed through a federal HCBS waiver. It has been more than two years since a plan was developed by the Division to begin to maximize federal revenues and ensure that there are additional dollars for services. It was years before that the Developmental Disabilities communities began urging the Department to move forward on maximizing its federal dollars. This delay in movement on applying for all federal monies to expand services for people with developmental disabilities makes legislation S2455 necessary.

Passage of bill S2455 will mandate that the Department move forward in an expeditious fashion, with reports to the legislature on its efforts, to ensure that there are adequate federal dollars for people with developmental disabilities.

****Testimony delivered by Batool Hassan, Legislative Associate, ABCD
Senate Health, Human Services Committee: June 9, 2005***

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 \$1756 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.