

*New and Expanded Options for New Jersey's Consumers
with Developmental Disabilities and Their Families*



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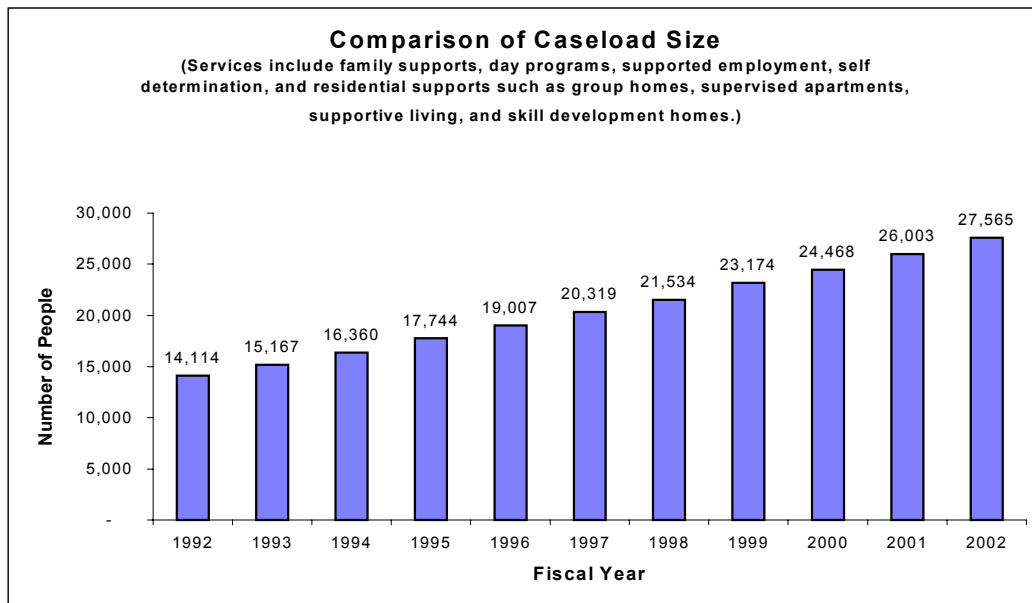
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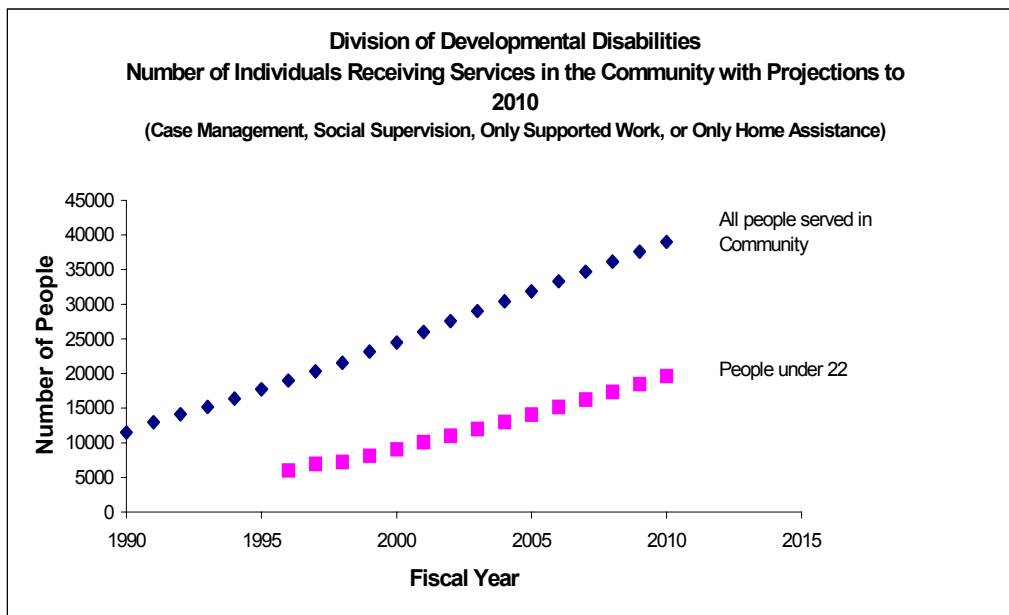
Overview

Thousands of persons with developmental disabilities live in the state of New Jersey today. They suffer from severe chronic disabilities that develop before the age of 22 and cause substantial functional limitations. Developmental disabilities include mental retardation, autism, cerebral palsy, epilepsy, spinal bifida, and other neurological impairments. The New Jersey Department of Human Services, Division of Developmental Disabilities (the Division) provides services to 30,800 such persons, including 3,300 individuals who reside in residential facilities known as developmental centers. The remaining nearly 27,500 receive services in the community through a variety of means including group homes, day program services, boarding and nursing homes, and services and supports to individuals living with their families.



New Jersey faces several major challenges in meeting the needs of this vulnerable population. The Division's caseload has experienced tremendous growth in recent years. Just a decade ago, a little over 14,000 persons with developmental disabilities relied on the State for services. Last year, the caseload almost doubled to more than 27,000, but the average age decreased.

Forty percent of the Division’s caseload is now under the age of 22 and living at home. This figure is likely to grow to 50% by the end of the decade. Yet, current Division services are largely oriented to adults. Unless the person with a disability lives in a residential setting, families are provided few options for accessing services to meet their actual needs.



In the current system, the Division utilizes a waiting list for residential services. The waiting list is the only formal mechanism to access services. While consumers “wait” there is no systematic way to provide alternative services to support them and their families while living at home. This population, the majority of the caseload, is greater than 18,000 consumers.

The Division’s large and aging developmental centers remain difficult to staff and manage while ensuring quality care for their residents. Governor McGreevey's FY'03 budget provided \$27M in new funding to address quality of care issues in the developmental centers. This funding provided for new direct care and professional staff, training, and new equipment. However, a continued commitment is needed to ensure these facilities meet high standards of care.

New Jersey lags behind other states in leveraging additional financial resources that would allow the Division to improve existing services and develop new programs. The Division needs to obtain

“There are certain functions of the State that are not discretionary. Caring for people with developmental disabilities is among them.” - Governor James E. McGreevey

additional federal revenue through 1) broadening the use of Medicaid waivers, 2) better enforcement of Medicaid eligibility requirements, and 3) seeking a greater contribution toward services from consumers living in group homes. Maximizing federal revenues would enable the State to serve more New Jerseyans in need with the same level of State resources.

New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Their Families lays out an ambitious, yet workable, plan to provide better, more appropriate services to individuals and families – services that are truly oriented around their needs. Together, working with consumers, families, providers, and other partners, New Jersey can build and sustain a system of care that provides more options and greater choice, is fiscally sound, and results in high quality institutions and community programs.

“We can accomplish a lot together.” – Leila Gold, Family Member

Services Today

INSTITUTIONAL CARE

The Division operates seven large and aging developmental centers, housing more than 3,300 consumers. Centers include North Jersey, Woodbridge, Green Brook, Hunterdon, New Lisbon, Vineland, and Woodbine. It is difficult to manage and retain appropriate levels of qualified staff to ensure the provision of good care at these centers. Moreover, the physical infrastructure of these centers suffer from years of deferred maintenance. Deteriorating conditions have largely gone unaddressed over the years, with exceptions occurring during periods of failed federal government inspections and threats of sanctions.

During the past two years, the federal Centers for Medicare and Medicaid Services conducted inspections of New Jersey's developmental centers, along with our counterparts across the country. Since March of 2001, five of New Jersey's developmental centers have undergone these reviews. Continuation of federal funding and certification has been threatened each time. Federal certification not only insures a consistent standard of care, but also provides half of the cost of providing services for consumers.

Two facilities, Woodbridge and New Lisbon, were decertified. Recently, certification was restored to New Lisbon due to efforts to replace outdated equipment and increase staffing. Woodbridge, however, remains decertified and anticipates a review in the late fall of this year.

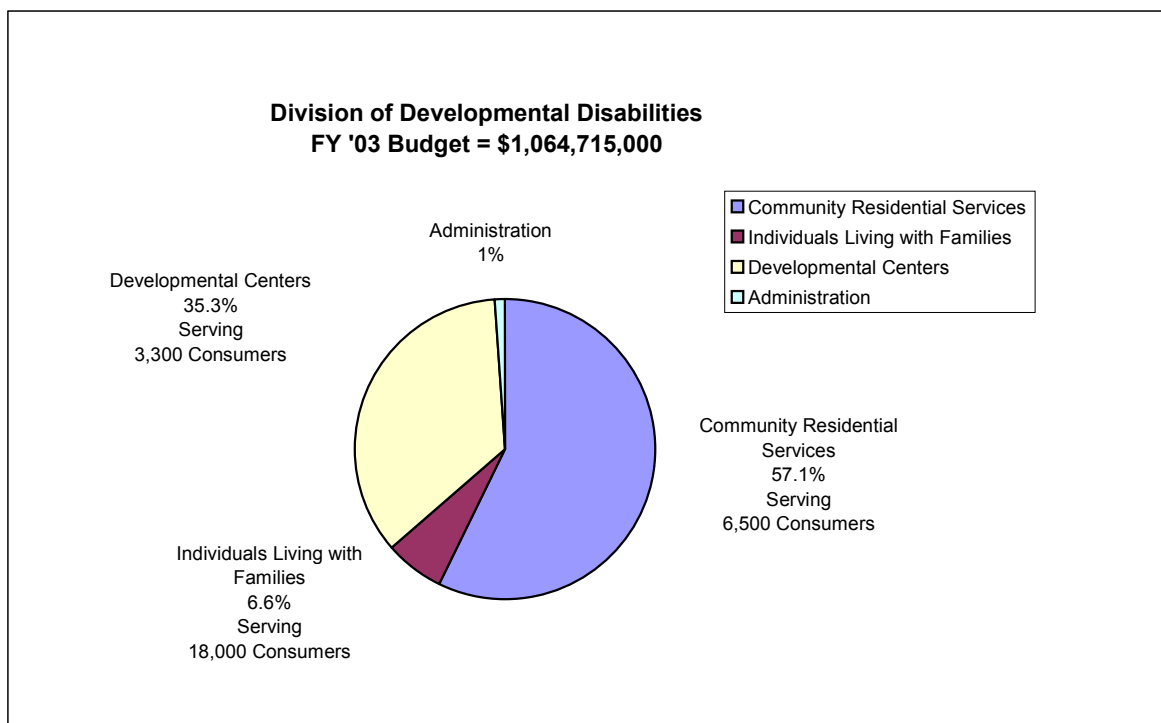
Governor McGreevey's FY'03 budget provided \$27 million in new funding to improve services to individuals in the developmental centers. The administration remains committed to serving people with disabilities and providing a high standard of care.

The Division has funded initiatives in the last two years to expedite and support the movement of eligible consumers to the community complying with the Olmstead decision. This federal mandate stipulates provisions be made for residents capable of living in the least restrictive community settings.

COMMUNITY SERVICES

For the past twenty years, the Division has been moving from a system of institutional care to one based primarily in the community. Currently only 10% of the caseload lives in Developmental Centers. This mirrors the national trend: moving away from large institutional settings to the integration of individuals with developmental disabilities into community life.

New Jersey, similar to elsewhere in the nation, began its evolution to community services with an emphasis on residential placements. It was a familiar service model since it provided 24-hour care for individuals. Over the last decade, the Division has invested heavily in its residential services' budget, primarily group homes. In 1996, the community services budget was \$357M. The community services budget is now \$677 million, a 90% increase.



The Division uses a waiting list to place individuals in group homes and other residential services. The waiting list remains the primary way people access services. Initially intended to categorize individuals according to need and respond to a growing demand for residential placement, the list has only expanded over the years. Unfortunately, the waiting list is not an effective mechanism for organizing a system of services in a timely fashion, nor does it allow families to request supports more tailored to their needs, especially while the individual is at home. Most services are delivered based on the chronological order of the waiting list. There is no comprehensive assessment conducted to determine actual need or consumer preference for types of services that might be most appropriate.

As increasing numbers of individuals have been added to the list, the Division has sought to respond to this growing demand through funded

“Many parents of developmentally disabled adults have told us they would prefer to keep their loved one at home rather than have them live in a group home.” - Commissioner Gwendolyn L. Harris

residential initiatives since FY '99. The Division planned to eliminate the waiting list by placing 500 people each year. However, the Division has not been able to achieve its annual placement goal. Three major barriers have been identified:

1. Regardless of the number of consumers that are placed, 600 new consumers have been added to the waiting list each year;
2. Agencies face community hurdles in designing and planning for facilities, (e.g. site acquisition, cumbersome zoning requirements, local community opposition, and exorbitant costs);
3. Providers report that current Division requirements are too rigid and limit their ability to look at the needs of families at home, or to offer broader options to serve families. As currently structured, agencies are not permitted the flexibility to plan and create alternative non-residential services.

Despite these three major barriers, the bulk of resources continue to support an emphasis on the traditional group home model. Eighty-seven percent of the community services budget is allocated to residential services supporting 6,500 consumers.

“All additional revenues need to be reinvested in expanded services.” Tom Buffuto, Executive Director, ARC of New Jersey

Few supports and services are in place to assist families in caring for relatives at home. New Jersey ranks 37th among other states in the amount of money spent on services to families in their own homes. Less than 7% of the total Division budget is dedicated to serving these 18,000 consumers. The Developmental Disabilities Planning Institute of the New Jersey Institute of Technology (June 2002) reports that consumers would choose other options if available:

- 91% view the waiting list as an insurance policy
- 67% reported that when the time came that they could no longer care for their relative, they preferred arrangements be made for that family member to live with another relative
- 60% would delay placement if adequate services at home were available

Families indicate a number of reasons for delaying placement. For example, forty-nine percent of the sample reported that they want to keep their family together. Thirty-eight percent believed that they can provide better care.

Several factors contribute to the continued growth of the waiting list despite consistent efforts by the Division to move people into placement. The list is inaccurate. The study commissioned by the Department showed that out of 1,842 persons on the urgent portion of the list, 34% were not waiting for residential services. It was found that some individuals had already been placed, or duplicated in the database, or could not be found. Moreover, many people request to be added to the waiting list with anticipation of placement at some time in the distant future. With initiatives occurring each year, however, these individuals may be offered placement before they are ready or willing to accept them. Of the 3, 948 people on the urgent waiting list, 25% of families in each of the last several initiatives have declined placement. Absent other alternatives such as

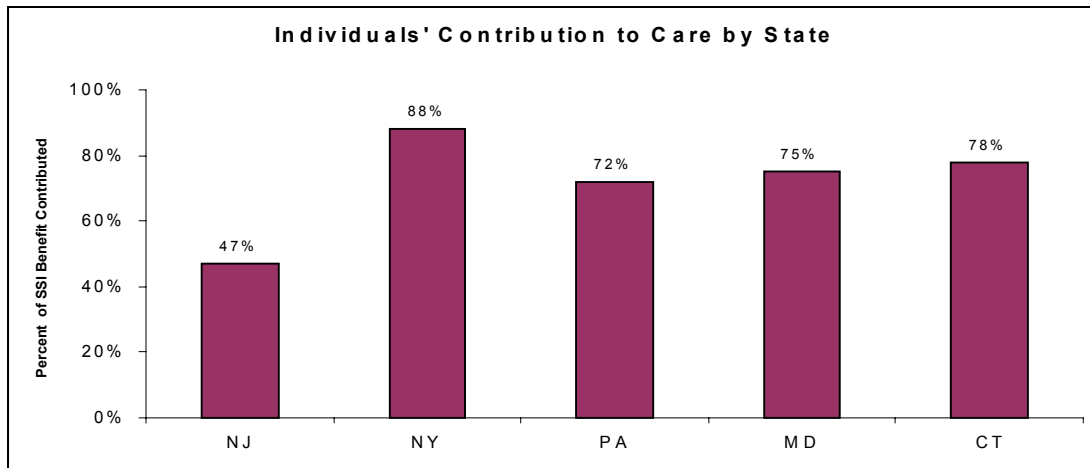
services and supports to individuals living in their own homes, the list often indicates the family's need for a future insurance policy.

RESOURCES AND REVENUES

The Division has not capitalized on the opportunity to draw down the maximum federal reimbursement available through the existing Home and Community Care Waiver. The Waiver authorizes Medicaid reimbursement for residential, day programming and other support services. However, the State does not require that consumers become eligible for Medicaid prior to receiving Division services. For every person who is not made Medicaid eligible, or loses Medicaid eligibility, another person is not served. At any point in time, 10% to 15% of individuals in current Waiver services, primarily residential and day programs, are not Medicaid eligible. Since the federal government reimburses 50% for eligible recipients, New Jersey is losing major resources that could be *reinvested* to serve more people.

For every person who is not made Medicaid eligible, or loses Medicaid eligibility, another person is not served.

Revenues could also be enhanced with a change in the Division's current fee policy. Currently, the Division permits consumers to retain substantial amounts of income from federal benefits, like Supplemental Security Income (SSI) and other income. New Jersey is an outlier in the use of SSI benefits. SSI payments from the federal government are given to individuals with disabilities to support their room and board expenses while the residential programs already



include these necessities. Other states have adopted policies requiring individuals to contribute larger percentages toward their care, while still allowing consumers to retain funds for personal needs.

In New Jersey, most individuals under the current fee structure keep about 50% of their SSI benefit averaging \$700/month despite the fact that they may live in a group home that provides for nearly all of their needs. When an individual accumulates more than \$2000 in cash assets from any source, Medicaid eligibility is lost. The State must then assume 100% of an individual's costs, rather than being reimbursed for 50%. New Jersey must reconsider its current policy. Under revised rules, additional funds could be generated and reinvested in expanded services for more individuals and families.

Our Vision for the Future – An Evolving System

To provide more services and supports to a larger number of individuals and their families, ensuring quality services in both institutions and community settings.

The Division will adopt a service system that recognizes the demographics of its current caseload and creates services based on individualized needs. The current caseload is younger, the needs of residents in group homes are changing, and family caregivers are aging. The current system with its reliance on group home development and placement fails to effectively respond to the majority of individuals and their families and to support families in their care-giving responsibilities.

The system must continue to evolve from developmental centers to community-based services. However, greater attention must be paid to the service needs of individuals living with their families, where the majority of the individuals on the Division's caseload live. Currently, 18,000 individuals on the caseload live at home. The new system will need to assess these individuals earlier and develop service capacity to meet the needs that are identified. This is a direction which has been utilized in other States. The concept of person-centered planning and individualized service planning has been the philosophical direction of developmental disabilities systems across the nation. (Braddock, D., Hemp, R., Rizzolo, M.C., Parish, S. and Pomeranz, A., "The State of the States in Developmental Disabilities: 2002 Study Summary.")

The developmental disabilities system in New Jersey needs to have a fundamental shift in service delivery away from the exclusive development of group homes toward the development of an array of services which support individuals and families in their communities.

FIVE EXPECTED CHANGES

1. Design consumer-oriented information and services.

The Division will expand education and outreach efforts to broaden consumer awareness about services and supports available in their communities. The new system will develop and phase-in an eligibility process which enhances information and supports available to individuals and families. This more consumer-oriented process recognizes that individual and family needs are not static. In partnership with providers, services will be developed in response to the changing needs of consumers.

2. Develop a mechanism that collects information about individuals' and families' needs and preferences.

In order to plan for individualized service needs, it is necessary to gather common information and determine the needs of individuals utilizing a common understanding of the level of individual needs. An assessment tool will be developed which looks at both the individual's abilities to provide for their own self-care needs and the families' care-giving role.

3. Develop a new way of fiscal planning.

The Division has relied on a budget that provided for the development of residential services for 500 individuals on the waiting list each year. This single-focused method of budgeting provided little flexibility to provide an array of services to meet the service needs of these other individuals on the caseload.

The budgeting process in the future needs to support the development of an array of services to different segments of the caseload including:

- Waiting List individuals;
- Individuals leaving special education at 22 and transitioning to adult life activities
- Individuals living with aging family caregivers and individuals currently aging in residential services;
- Individuals living with their families and in need of services to improve their quality of life and support families in their care-giving;
- Individuals and families who have recently become eligible for Division services and who need information and support.

4. Develop a capacity to provide an array of services for individuals living at home.

Once the system has better information and an assessment of the needs of individuals on the caseload, it will be essential to develop and fund an array of services that can meet these needs. It will also be necessary to have an effective case management system which supports individuals living at home. The majority of case management is currently provided to individuals living in residential services.

Surveys of families as well as current requests for family supports provide the best background for the development of needed services. These surveys indicate that to assist an individual in their own home and to provide the needed supports for families, an array of enhanced services needs to be in place. Although many of these services currently exist, we have not assessed the amount of services an individual actually needs to be adequately supported in their own home for as long as possible, nor have we focused on the development of service capacity to meet these needs.

***“This is an admirable start and I look forward to working with all stakeholders to continue to make more improvements.”
Ethan Ellis, Executive Director,
Developmental Disability Council***

Therefore, working with community partners, the Division will develop and fund the increased capacity required to do this. Consideration will be given to include enhanced in- and out-of-home services, special needs and recreational respite, assistive technology, day programming (including employment opportunities) and access to transportation. All of these services are focused on improving the quality of life of the individual and supporting the caregiver.

Recognizing that consumers with disabilities can be supported to live at home if appropriate services are available, the services most often requested will be expanded and enhanced. These include the following:

Respite

Respite is provided when a family member is seeking time away from home or a caregiver needs a break or support. In-home respite is provided in the person’s own home and can vary from several hours, to an evening, to several days. Out-of-home respite is provided out of the family home in a more specialized facility or recreational environment, such as a day or overnight camp or an after-school program.

Day Programming and Employment Opportunities

Provide opportunities for more individuals to develop skills, participate in using community resources and make a contribution to their communities through employment and volunteer work.

Personal Care

This service is for individuals who need physical assistance with bathing, grooming, feeding or transferring to vehicles.

Assistive Devices

These devices assist individuals to remain in their homes and community through the use technology for speech, lifting, mobility, etc.

Access to Transportation

Access to transportation is important for ensuring that individuals can get to and from programs and leisure activities.

Each of these services will be planned and developed in close partnership with community providers, families, advocates and consumers. Several task forces will be formed to incorporate their ideas and best practices into the improvement of these services. As the Division seeks to build capacity to provide more services for individuals living at home, it will also seek to build the capacity of residential provider agencies to ensure compliance with federal standards. Based on the Division's experiences in fulfilling Center for Medicare and Medicaid Services' certification standards, proactive steps will be taken to assist group home and other residential providers in preparing for anticipated federal inspections of our community programs.

5. Support consumers as they transition through various life cycles: transitioning young and aging consumers.

The current system with its residential care emphasis has not focused adequate attention on those individuals with developmental disabilities who have been largely supported by federal education funds while they were eligible for special education. At the age of 22, individuals are no longer eligible for these services. The new system will collaborate with the educational system to assess the needs of these individuals at an earlier point in time and begin to plan services as they move to adult life.

Too often individuals who have been actively engaged in school programming during the day do not have an adequate transition plan. Day programming or employment options have not been put in place or funded and the individual is at home with their families with little or no support. Under these circumstances, families may see the residential waiting list as their only option

The new system will prioritize and fund needed services for individuals transitioning to adult life and will pay special attention to individuals who are aging.

Strategies for Creating Better Services

Governor James E. McGreevey and Commissioner Gwendolyn L. Harris have pledged to improve the way services are delivered to New Jersey citizens, especially vulnerable residents. As such, the Department of Human Services must explore a range of strategies and options designed to strengthen supports to individuals and families in need. For the state's developmental disability community in particular, the Administration has seized on the opportunity to bring to fruition several strategies that can lead to creating a high-quality system of care in both the community and institutions:

- *Maximizing Revenue and Reinvesting in Expanded Services*

- *Designing an Array of Family-Oriented Service Options*
- *Building Upon Investments in Institutions*
- *Working in Partnership*

Maximizing Revenue and Reinvesting in Expanded Services

Difficult economic and budgetary times should not necessarily translate into a loss of services and supports to families in need. Conversely, New Jersey has an opportunity to explore a number of alternative funding strategies including:

Claiming for more individuals under the Community Care Waiver.

The Division's Community Care Waiver authorizes Medicaid reimbursement for individuals, but New Jersey currently fails to require all persons served by the Division to become Medicaid eligible. The State will now require Medicaid eligibility to be determined prior to services being delivered. This will be a significant change, resulting in many more dollars being made available for services. It is estimated that this change could potentially yield an additional \$10 million dollars annually to reinvest in services.

Non-Residential Waiver

The existing Community Care Waiver does not encompass services to families living at home including, personal care, respite care and assistive devices. These services are needed to meet the needs of individuals living with their families. The Division is in the process of 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.

Redesign Consumer Fee Structure

At present, consumers can retain more than 50% of their income from federal benefits, such as Supplemental Security Income (SSI), despite the fact that they may live in a group home that provides for all their needs. The State of New Jersey takes 47 percent of an individual's SSI payment toward the cost of care in a residential placement.

Other states require that between 72% to 88% of an individual's SSI income be contributed toward their costs of care in a community residence. Because New Jersey consumers keep more of their SSI dollars, they often lose Medicaid eligibility when they have more than \$2,000 in assets in the bank.

New Jersey will now seek a higher percentage of individual SSI contributions for residential services provided by the Division. The SSI percentage will be increased to more closely match the national average and could generate an additional \$5 to \$10 million annually.

Design an Array of Family-Friendly Service Options

A *Consumer Assessment Tool* will be developed. This tool will assist the Division in assessing people's actual needs and most appropriate types of services. The utilization of an assessment instrument will provide a more responsive service system.

It will not abandon residential options, but will make them part of a broader menu of services. The lack of services fuels more demand for the more expensive group home option (now estimated at \$60,000 per year vs. \$18,000 for various day and community program services). Enhanced and expanded services as cited above are currently being explored for individuals living at home.

“Creating a more responsive developmental disability system will make it possible for the State to meet the needs of individuals and their families who are currently in the system, and for the first time allow us to reach to those communities who have traditionally been underserved.” – Deborah Spitalnik, Executive Director, Boggs Center on Developmental Disabilities, UMDNJ

Build Upon Investments in Institutions

Despite problems associated with an aging physical infrastructure, New Jersey *has* made progress with improving conditions in its developmental centers. The McGreevey Administration has worked diligently to respond to regulations and other compliance issues mandated by the Federal Centers for Medicare and Medicaid Services. More than 700 staff have been added over the last year as part of an additional commitment of funds totaling \$27 million. These funds were also used to upgrade equipment and technology.

The Division will continue to transition those consumers who are ready for discharge from developmental centers. Any reduction in the current census will result in better consumer-to-staff ratios. The Division will continue to focus its efforts to improve the quality of care offered in all of the State's developmental centers.

Work in Partnership

New Jersey is fortunate to have a strong and vibrant community of consumers, advocates, providers and families concerned about the systems that serve people with developmental disabilities. As the Division moves forward with its efforts to provide more services that speak to the demands and needs of consumers, it will remain committed to work in partnership with every facet of this community.

The Division will also explore inter-departmental and inter-agency agreements to expand available services, especially for the growing portion of the caseload under the age of 22. Since this cohort will constitute 50% of the caseload by the end of the decade, it will be imperative to plan for anticipated needs of this population. Conversations are currently underway with the State Departments of Education (DOE) and Department of Health and Senior Services (DHSS) to achieve inter-departmental collaboration including the pooling of funds where appropriate.

For example, the Division is very interested in working with the DOE to determine how federal funds for students with disabilities can be better utilized for young adults transitioning out of local school districts into the State's developmental disability system.

The Division will also partner with providers as it builds capacity to expand services to support individuals living at home.

Next Steps

Implement a series of components during the remainder of this fiscal year:

- Develop an expanded waiver
- Develop Consumer Assessment Tool (CAT)
- Begin service planning and program development in partnership with consumers, advocates, families, and providers
- Create inter-agency agreements (DOE/DHS/DHSS – MOUs)
- Redesign case management to meet consumer needs
- Design consumer friendly intake process

Moving Forward

A confluence of factors in New Jersey creates an opportunity to continue efforts to improve the system serving people with developmental disabilities. Changing consumer needs and preferences, as well as a national trend supporting individuals living with their families, makes it possible to develop a more responsive system in partnership with our consumers, families, advocates and providers. By taking advantage of new ways to maximize federal revenues, additional dollars can lead to reinvestment in new and expanded services, particularly for individuals living at home. With several promising strategies identified, a commitment to a collaborative multi-year effort will bring this vision to a reality.