

THE ELIZABETH M. BOGGS CENTER
ON DEVELOPMENTAL DISABILITIES

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Where New Jersey Stands in Services to People with Developmental Disabilities and National Policy Trends

**Testimony
to the
New Jersey Senate Health, Human Services and Senior Citizens
Committee and the
New Jersey Assembly Human Services Committee
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**by
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Senate Vitale, Assemblywoman Huttler, Distinguished Members, and guests, I am honored to have the opportunity to testify before you today at this joint meeting of the Senate Health, Human Services and Senior Citizens Committee and the Assembly Human Services Committee.

My name is Deborah M. Spitalnik, Ph.D. and I am a Professor of Pediatrics at UMDNJ-Robert Wood Johnson Medical School, where I am also Executive Director of The Elizabeth M. Boggs Center on Developmental Disabilities. The Boggs Center, as New Jersey's University Center for Excellence in Developmental Disabilities Education, Research and Service, is a third party reviewed program, funded under the Developmental Disabilities Assistance and Bill of Rights Act.

One of our federal mandates is to advise policy makers on issues of importance to individuals with developmental disabilities, their families, and service systems. It is in that capacity that I come before you today. My goal is to place our experience, our concerns, and our opportunities for supporting individuals with developmental disabilities in New Jersey in a national context.

The information I am sharing with you today comes from national data bases and state sources, and is referenced. There may be slight variations in actual numbers due to variations in the time frames of data bases but all the trends are constant.

It is also my deeply felt goal to contribute to a dialogue that acknowledges and affirms that we are all people of goodwill with a shared

commitment to the well being and opportunities for individuals with developmental disabilities and their families.

The Direction of Federal and State Policy

There is, and has been for over 30 years, a clear direction in federal and state policy toward community living for individuals with developmental disabilities. The first major movement in deinstitutionalization occurred under President Nixon, although the nature of data gathering at that point did not make these shifts visible until later. It is been clear over time that these issues and the needs of people with developmental disabilities are bipartisan concerns.

This orientation towards community is apparent in the DD Act, in that Individuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, and States, and the Nation; ¹

The thrust of national policy toward the community is also seen in the evolution of Medicaid funding for long term services, as reflected in the growth of Home and Community Based Services waivers (HCBS). The findings of the US Supreme Court in *Olmstead v L.C.* that “unnecessary institutionalization is a form of discrimination,” the activities of the Office of Civil Rights, and the federal declaration in 2009 of “The Year of Community Living” in recognition of the 10th anniversary of the *Olmstead* decision, lend further evidence to the strength of this policy trend.

The long term care enhancements that are part of health care reform, embedded in the Patient Protection and Affordable Care Act, P.L. 111-148,

unequivocally support increased development and reliance upon community services. These provisions (referenced in the final section of this testimony) also hold the promise of increased federal funding for New Jersey and other states, but only for community based services and supports.

Where Do People with Developmental Disabilities in NJ and the US live?

The majority of the 41, 645 individuals,² 70% of the caseload of the Division of Developmental Disabilities, live at home with their families. The number of individuals who live at home with their families significantly exceeds the 57.4% of individuals who live with their families nation-wide.³ Also of note is New Jersey's Waiting List, comprised of 8,170 individuals living with their families. The Waiting List is classified by the following categories: "Priority" 4,994 individuals; "Priority Deferred" 249 individuals; and "General" 2,927 individuals.

As demonstrated in Table 1, more New Jersey citizens with developmental disabilities live in out-of-home placements (22.1%), compared to their peers nationwide (16.1%). Fewer NJ citizens with developmental disabilities live in their own homes.³

Table 1

Where People with Developmental Disabilities in NJ live

**Percentage of Individuals Receiving Residential Services by Living Arrangement
New Jersey and USA ³**

	Out of home	In own home	In family home
New Jersey	22.1%	7.8%	70.1%
United States	16.1%	26.5%	57.4%

For people who utilize residential placements in New Jersey, in contrast to the US as a whole, we have a smaller percentage of people who live in smaller community living arrangements of 1-6, such as group homes: 60.4% compared to 74.5%.³ In New Jersey, 2,725 individuals live in state operated developmental centers.² In NJ, 32.2% of residential service utilization is in settings of 16+ people, in contrast to 13.2% nationally.

Table 2

**Utilization of residential settings by size
New Jersey and USA ³**

	Percentage of residents in 1-6 sized residential settings	Percentage of residents in 7-15 sized residential	Percentage of residents in 16+ sized residential settings
New Jersey	60.4%	7.4%	32.2%
United States	74.5%	12.2%	13.2%

Of additional concern as we look at the range of service settings, is the 500 person increase, over the past ten years, of individuals with developmental disabilities living in nursing homes.³ DDD reports that there are 984 individuals who are clients of the Division who are in Skilled Nursing Facilities.²

New Jersey and the National Trends in Large State Institutions

The clear nationwide trend is to decrease reliance on large state institutions for the provision of residential services. There are now 11 states that no longer have any state operated large institutional settings: Alaska, the District of Columbia, Hawaii, Maine, Michigan, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia. ³ Eleven states now have only one state institution.⁴

New Jersey is one of only ten states that have over 2,000 people living in public institutions.⁴ In New Jersey, 2,725 individuals live in state operated developmental centers.² Proportionately, this represents three times the percentage of individuals who reside in large state-run facilities across the country.

Table 3

**Percentage of total residents in 16+bed state-run facilities
New Jersey and USA³**

	Number of residents in 16+ state-run	Total residents	Percentage of residents in 16+ state-
New Jersey	2,897	11,485	25.2%
United States	35,035	436,866	8.0%

In addition to having a large number and high percentage of individuals residing in state facilities, New Jersey has a high rate of institutionalization from a population perspective: 33.4 persons per 100,000 of population, in contrast to 11.8 persons per 100,000 nationally.⁵

The level of intellectual disability of the residents in New Jersey's developmental centers is generally comparable to the level of intellectual disability of individuals in large state institutions nationwide. There are a larger percentage of individuals, 65.6%, classified in the profound range of intellectual functioning, which is higher than the US average of 51%, but comparable to Pennsylvania's population at 68%. Functionally, the group of individuals in NJ's developmental centers has similar needs and abilities in understanding verbal requests, toileting, and transferring [from wheelchair] compared to the institutional population nationally. A smaller percentage of NJ residents in developmental centers cannot communicate verbally or need assistance with walking or eating compared with the national averages, but the percentage in NJ who need assistance or supervision with dressing is higher.³ There is a slightly higher percentage (36.5 %) of individuals age 55 years or older in NJ's developmental centers, compared to the US as a whole (30.6%).³

The Experience with Deinstitutionalization in NJ and the US

In 1980, 7,262 resided in New Jersey's developmental centers,³ then called "State Schools and Hospitals." In the period between 1980 to 2008, the population living in developmental centers decreased by 59.4% while the population in large state facilities nationally decreased by 72.8%. Our

neighboring state of Pennsylvania, whose institutional population in 1980 was comparable to ours at 7, 290 people, from 1980 to 2008 decreased the number of people in large congregate settings by 82.4%, while we in New Jersey only decreased our population by 59.4%.³ New Jersey pace of reducing the numbers of people living in state run institutions has consistently been below the national rate. In the period 2005-2008, New Jersey decreased its institutional population by 4.8%, while nationally, the institutional population decreased by 11.8%.

Of the three state institutions closed by the Department of Human Services, North Princeton Developmental Center, which closed in 1998, was the largest with 512 residents. (Edison opened in 1981 and closed in 1988, housed 70 individuals; Johnstone Training Center, closed in 1992, housed 239 individuals.) Extensive documentation of the impact of the closing of North Princeton Developmental Center (NPDC) was conducted by the Developmental Disabilities Planning Institute at NJIT. Through measurement of individuals' status prior to closing and at regular interval up to two and a third years after closure, and in comparison to individuals continuing to reside at other developmental centers, the Planning Institute demonstrated: 1) positive outcomes; 2) no evidence associated with increased mortality or other negative consequences; and 3) despite initial opposition, eventual strong support of community living by a clear majority of NPDC family members. For psychiatric and behavioral needs, often identified as areas of concern about the community living, important positive findings were demonstrated. The increased numbers of individuals who received a psychiatric diagnosis, the increased use of

antipsychotic medication and decreased use of medication to control behavior, suggest a pattern of more appropriate and individualized, person centered addressing of needs and treatment upon movement to the community.⁷

How We Utilize Available Resources in New Jersey

Medical Assistance (Medicaid) Title XIX of the Social Security Act is the federal financial underpinning for Developmental Disabilities services in New Jersey and for all other states. How we utilize Medicaid for long term care services has both a unique history in New Jersey, and is reflective of how we have structured supports and services for individuals with developmental disabilities. In 1971, the Intermediate Care Facilities program of Title XIX was amended to serve individuals with mental retardation/intellectual disabilities and became the ICF/MR program. By 1977, 40 states had one ICF/MR certified facility,³ which enabled the state to draw down partial federal reimbursement for institutional services. New Jersey did not enter the ICF/MR program until 1978, considerably later than most other states. Entrance into the ICF/MR program was the impetus for New Jersey's significantly reducing its institutional population by 1,557(21%) in the five year period between 1980 and 1985, and developing a system of community residential and day services.

Home and community based services(HCBS) waivers came into being through the 1981 Omnibus Budget Reconciliation Act which gave the "Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow state to finance 'non-institutional' services for Medicaid eligible individuals."³ HCBS waivers were designed to provide community services to people with ID/DD "Who, in the absence of

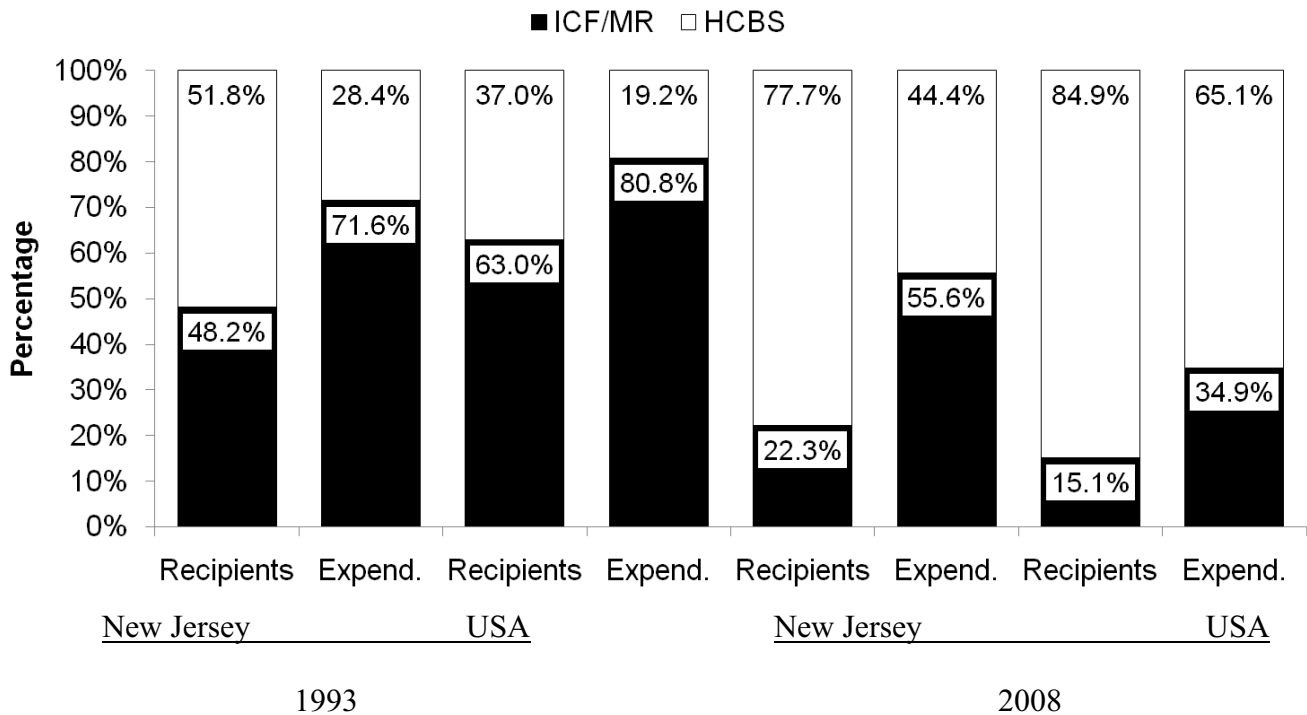
alternative non institutional services, would remain in or would be at risk of being placed in a Medicaid facility (i.e. a Nursing Facility or an ICF-MR)(p.87).”³

The national trend toward community supports is powerfully demonstrated by the historical changes in Medicaid expenditures. From 2002 to 2008, ICF-MR expenditures increased nationally by only 5%, while HCBS waiver expenditures increased 70%.⁸

In the 15 year period between 1993 and 2008, there was a decrease in the number of Medicaid recipients served in large institutions (ICF-MRs) and an increase in those served through HCBS waivers. In New Jersey the DDD Home and Community Based Services waiver is often referred to as the “Community Care Waiver” or “CCW.” Although this progression is seen in both New Jersey and nationally, as presented in Table 4, significant disparities persist in the rate of change as well as the pattern of expenditures for community services and for large institutions between New Jersey and the rest of the nation. The change in the percentage of Medicaid recipients receiving HCBS nationally increased more than the percentage of Medicaid recipients receiving HCBS services in New Jersey. The percentages of expenditures for community (HCBS) services also increased more nationally than in New Jersey.

Table 4

**Percentage of Total Medicaid ICF/MR and HCBS
Recipients and Expenditures
in HCBS and ICF/MR, 1993 and 2008
New Jersey and USA ³**

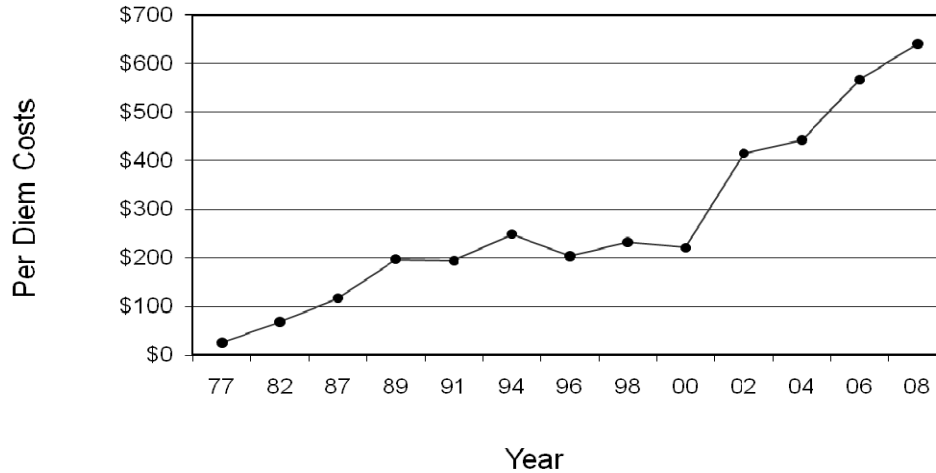


The decrease in the percentage of Medicaid recipients served in large institutions (ICF/MRs) were more dramatic for the nation than New Jersey. New Jersey’s expenditures for ICF-MR services continued to remain higher.

In New Jersey per diem costs in developmental centers have risen dramatically, especially since FY 2001, as demonstrated in Table 5.³ New Jersey’s per diem costs in FY 08 were \$641 as compared with the US weighted average of \$514.35.³ It is noteworthy that there is a significant variation in costs across NJ’s developmental centers, from Hunterdon Developmental Center’s cost of \$390 per diem, to Woodbridge Developmental Center’s cost of \$803 per diem.³

Table 5

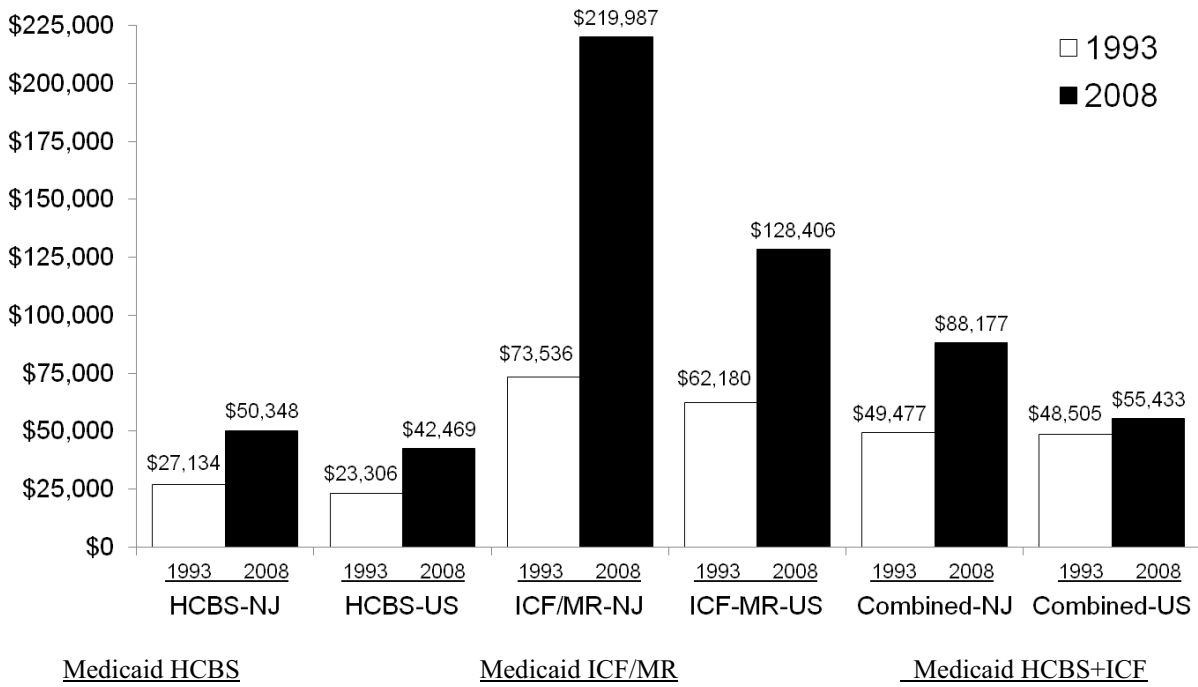
Average Per Diem of NJ State Institutions ³



There are significant disparities in our spending in New Jersey for Medicaid recipients depending upon whether they are receiving ICF/MR services or HCBS services, as demonstrated in Table 6. Average annual spending for ICF/MR recipients in New Jersey is \$219,987; for HCBS recipients it is \$50,348.³ ICF/MR per recipient spending has tripled in the past 15 years while HCBS spending has less than doubled. Our costs in each category of Medicaid long term care expenditures are higher than the US average costs, with New Jersey's ICF/MR spending dramatically higher.

Table 6

Changes in Per Recipient Expenditures for HCBS, ICF/MR and combined HCBS and ICF/MR Recipient Between 1993 and 2008, New Jersey and the USA ³



The Challenge of Waiting Lists and Choice Across the System

The DDD Waiting List, formerly a “Waiting List for Residential Services,” has now become a “Waiting List for Waiver Services,” with the HCBS Waiver now providing in-home supports in addition to community residential and other services. A “supports” waiver, an additional HCBS waiver, is being planned by the Division of Developmental Disabilities. The increased reliance on HCBS waivers to provide services to individuals living with their families, especially those on the waiting list, creates a more urgent imperative to address the disparities in the availability and utilization of Medicaid funds for services to individuals with developmental disabilities in New Jersey.

The issue of choice and its importance to and for individuals with developmental disabilities and their families is an issue of import to all families, independent of the services they have, or want, or need, and an issue of equity. Families of individuals who live with their family, who are on waiting lists, have long been deeply concerned about the wait for community service. For these families their long term interest, and their deepest fears, are that community services will not be available for their family member when they are no longer able to provide care because of the family's aging, illness, or death.

These concerns were addressed by the New Jersey legislature through P.L. 1997, Chapter 17 which required the Department of Human Services to develop a “plan to eliminate the waiting list for community residential services from the Division of Developmental Disabilities (DDD) by the year 2008.”⁹ The resulting plan recognized the need to realign the use of resources to address the disparity in access to community services. A compromise, reached through the dedicated efforts of the late Leila Gold – a parent leader in the developmental center parents group – with community parent leaders, was the proposal to close three developmental centers to be able to utilize those resources more broadly in the community. That recommendation was embedded in the 1998 “Plan to Eliminate the Waiting list.”⁹

The issue of choice is resonant for all individuals and families across the system: for those who choose HCBS services as well as those who choose ICF/MR services.

Moving Forward: The Possibilities for Enhanced Federal Resources

Of great benefit to individuals with developmental disabilities, states, and service systems are the provisions of the federal Patient Protection and Affordable Care Act, P.L. 111-148, which address long term care.

These include:

- **The New State Balancing Incentives Payments Program, Section 10202**, to be in effect 10/1/11 – 9/30/15.

This will provide a temporary increase in the federal Medicaid matching rate for states that make structural reforms to increase community services over ICF services

New Jersey should be eligible for a 2% increase, given that our level of Medicaid expenditures for HCBS is 44%, below the minimum federal target of 50%.

- **Community First Choice (CFC) Option, Section 2402**, will take effect 10/1/11.

A new Medicaid state plan option for comprehensive home and community based services for people eligible for an institutional level of care (including ICF)

This could provide a 6% additional federal match for CFC services

- **Extension of Money Follows the Person Rebalancing Demonstration Program, Section 2403** through 2016

Provides an increased Federal Medical Assistance Percentage (FMAP) for individuals moving to the community from an institution

Allows states to cover institutionalized individuals 90 days before they move to the community

It is essential that New Jersey monitor the implementation of these provisions to ensure that the state is prepared and well positioned to comply with the requirements of these funding sources and to aggressively pursue these federal resources.

It is also essential that there be continued reinvestment of federal resources drawn into the state to permit the expansion of services to individuals with developmental disabilities who are on the waiting list.

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