



Services to People with Developmental Disabilities in New Jersey 2012

**Testimony
to the
New Jersey State Legislature Legislative Review Panel on State
Psychiatric Hospitals and Developmental Centers
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**by
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A University Center for Excellence in Developmental Disabilities Education, Research, and Service

Senator Van Drew, Assemblywoman Huttler, Distinguished Members, and guests, I am honored to have the opportunity to testify before you today at this meeting of the New Jersey State Legislature's Legislative Review Panel on State Psychiatric Hospitals and Developmental Centers.

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 the federal mandates of The Boggs Center 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

collection, 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 sharing a commitment to well-being and opportunities for individuals with developmental disabilities, their families and those who work on their behalf.

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 its purpose 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,” and that 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.

New Jersey is pursuing a five year Medicaid and Children’s Health Insurance program Section 115 Research and Demonstration Waiver, a “Comprehensive Waiver” to Rebalance the Medicaid program. At the state level this reflects policy oriented to community services, as the waiver seeks to “promote increased utilization of home and community based services (HCBS) for individuals in need of Long Term Care”²

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

The majority of the 43,136 individuals, 70 % of the caseload of the Division of Developmental Disabilities³, live at home with their families. The number of individuals who live at home with their families in New Jersey significantly exceeds the 57% of individuals who live with their families nation-wide.⁴ Also of note is New Jersey’s Waiting List for Waiver Services, comprised of 8,177 individuals living with their families. The Waiting List is classified by two categories: “Priority” on which there are 5, 029 individuals; and “General” with 3,148 individuals.

As demonstrated in Table 1, the same percentage of New Jersey citizens with developmental disabilities and their peers nationwide live in out-of-home placements (“other residential placements”). Fewer NJ citizens with developmental disabilities live in their own homes.⁴

Table 1

Where People with Developmental Disabilities in NJ Live

Percentage of Individuals Receiving Residential Services by Living Arrangement New Jersey and USA (FY 2010)⁴

	Other Residential	In own home	In family home
New Jersey	30.7%	1.6%	67.7%
United States	30.7%	12.3%	57.0%

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: 68.0% compared to 74.6%.⁴ In New Jersey, 2,529 individuals live in state operated developmental centers.³ In NJ, 25.5% of residential service utilization is in settings of 16+ people, in contrast to 12.8% nationally.

Table 2

**Utilization of Residential Settings by Size
New Jersey and USA⁴**

	Percentage of residents in 1-6 sized residential settings	Percentage of residents in 7-15 sized residential settings	Percentage of residents in 16+ sized residential settings
New Jersey	68.0%	6.5%	25.5%
United States	74.6%	12.6%	12.8%

Of additional concern as we look at the range of service settings is the reported increase over the past twelve years, of individuals with developmental disabilities in New Jersey who are living in Nursing Facilities.^{5,9} DDD reports that there are 1,019 individuals who are clients of the Division that are in Nursing Facilities. Nationally, the percentages of individuals with developmental disabilities in Nursing Facilities are decreasing; in New Jersey, the percentages are increasing.

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 10 states (Alaska, Hawaii, Maine, Michigan, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia) plus the District of Columbia, that no longer have any state operated large institutional settings.⁵ Eleven states now have only one state institution.⁷

New Jersey is one of only five states, including California, Illinois, New York and Texas, that have over 2,000 people living in public institutions.⁵ In New Jersey, the 2,529 individuals living in state operated developmental centers³ represent 18.7% of the group of individuals with developmental disabilities who live in out of home placements.⁴ Proportionately this represents two and a half times the percentage of individuals who reside in large state-run facilities across the country.⁴

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.⁸

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.⁶ 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%).⁶

The Experience with Deinstitutionalization in NJ and the US

In 1980, 7,262 resided in New Jersey's developmental centers,⁶ 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%.⁶

New Jersey's 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, which 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 address of needs and access to treatment upon movement to the community.¹⁰

The Role of Medicaid in Funding Long Term Care Services for People with Developmental Disabilities 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,⁶ 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.”⁶ 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).”⁶ In New Jersey, the HCBS waiver for individuals with developmental disabilities is often referred to as the “Community Care Waiver” or the “CCW”.

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%.¹¹

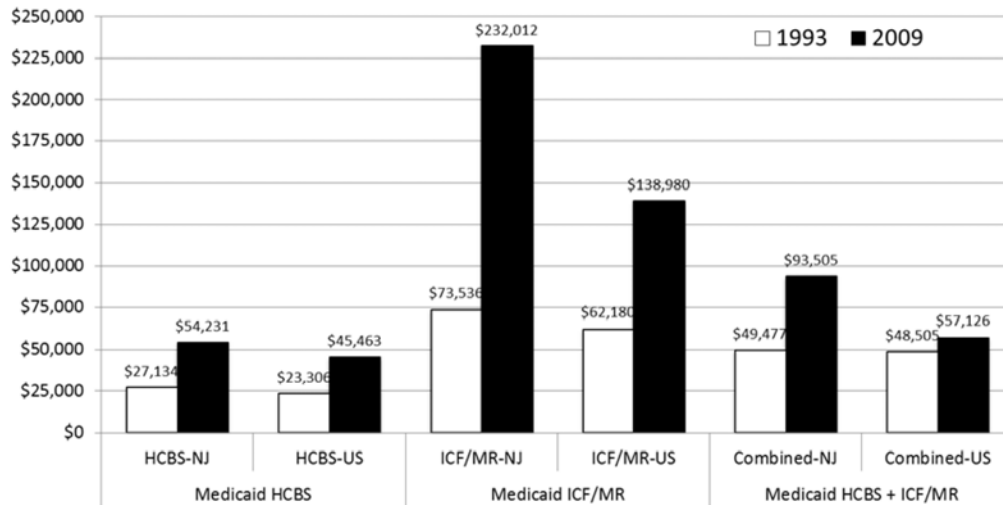
Table 3 presents a comparison of per recipient expenditures for Home and Community Based Services and ICF/MR expenditures for New Jersey and the nation from FY 1993 to FY 2009.⁴ Expenditures have increased within each category during this 16 year period, but it is noteworthy that within categories (HCBS and ICF/MR), expenditures within New Jersey increased at a higher rate than within the US as a

whole. Most notably, expenses in New Jersey more than tripled for ICF/MRs, while for the US, the increase was double.

Also of note is that the level of expenditure for ICF/MRs in New Jersey is four and a quarter times greater than HCBS spending. Nationally, ICF/MR spending is three times greater than HCBS spending.

Table 3

Changes in Per Recipient Expenditures for HCBS, ICF/MR and combined HCBS and ICF/MR Recipient Between 1993 and 2008, New Jersey and the USA⁴



The Funding of Community Services and Supports in New Jersey

Thirty states now direct more than 80% of their total spending on services for people with developmental disabilities for community services; New Jersey does not. New Jersey dedicates 66% of its DD resources to community spending. Figure 1 and Table 4 demonstrate how New Jersey lags behind our neighboring state of Pennsylvania which

dedicates 82% to community spending, the comparison group of Mid-Atlantic States (84%), and the nation as a whole (84%).⁹

Figure 1⁹

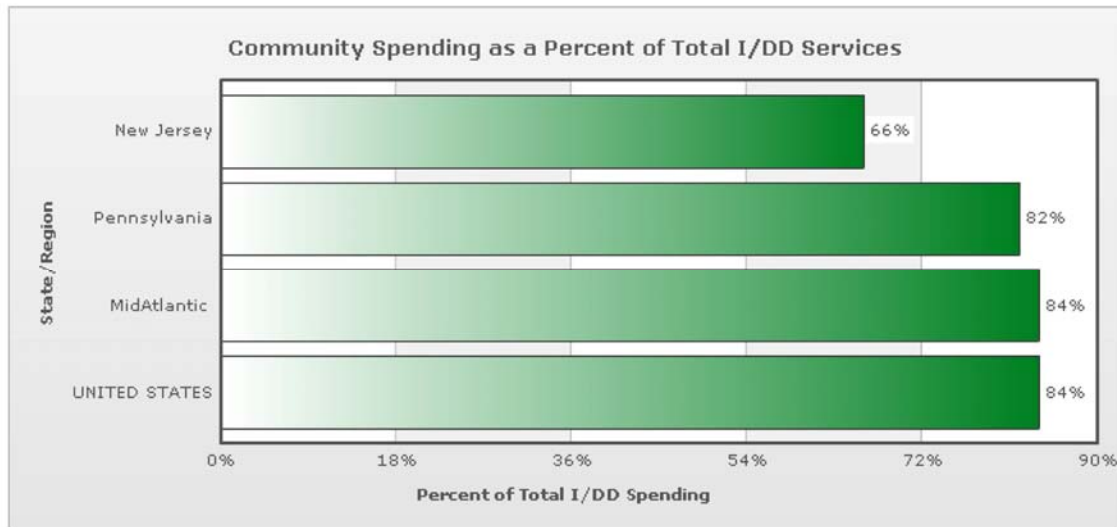


Table 4⁹

Community Spending as a Percent of Total I/DD Services	
State/Region	Percent of Total I/DD Spending
New Jersey	66%
Pennsylvania	82%
MidAtlantic	84%
UNITED STATES	84%

In New Jersey 90% of the individuals served by the Division of Developmental Disabilities live in the community, but we dedicate only 66% of resources to spending in the community.

Approximately two years ago, the New Jersey Division of Developmental Disabilities changed its Waiting List from a Waiting List for Residential Services to a Waiting List for Home and Community Based Waiver, “Waiver” or “CCW” services. The net change in the number of HCBS recipients has been exceedingly low, with only a 0.3% increase from FY 08 to FY 09.⁵ For the 8,177 individuals on the Waiting List, who are living with their families in the community, the hope of access to Waiver services seems very unrealizable.

Opportunities for Enhancing Community Services and Supports

New Jersey has the opportunity and the strong need to avail itself of policy options and build upon the experiences of other states which have enhanced and strengthened community services. There are strong imperatives to create a more intentional and balanced system for the delivery of supports and services to our fellow citizens with developmental disabilities and their families.

➤ Maximizing Enhanced Federal Financial Resources

New Jersey’s application for a Section 115 Demonstration “Comprehensive Waiver” is an important step in moving the state towards a better balance in facility and community care. As expressed in the application:

“[C]onsistent with the requirements of the Olmstead decision, a key objective of the Comprehensive Waiver is to reduce the use of institutional placement for people with intellectual and developmental disorders and increase community placement and support for those individuals” (p. 129) ².

Implementation of a Supports Waiver for individuals living with their family and development of affordable housing alternatives are significant components of this system balancing approach.

The provisions of the federal Patient Protection and Affordable Act, P.L. 111-148, which address long term care, hold great promise for enhancing community based services in New Jersey and improving life quality for individuals with developmental disabilities and their families.

These include:

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

Money Follows the Person, in which New Jersey has been participating, provides an increased Federal Medical Assistance Percentage (FMAP) for individuals moving to the community from an institution. The program allows states to cover institutionalized individuals 90 days before they move to the community

- **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 is in the process of developing an application for these funds. New Jersey is anticipating that we will 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**, in 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), but who still reside in the community. This could provide a 6% additional federal match for CFC services.

➤ **Investing in Community Services**

Investing in a “bridge fund” for the expansion of community services, for individuals moving from Developmental Centers to community would expedite community development and provide for more rapid conversion of ICF/MR funding to HCBS funding.

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

Systemic Planning and Capacity Building, including Information Technology

New Jersey’s supports and services to individuals with developmental disabilities would be enhanced by system-wide planning, including addressing strategies to enhance capacity in the provision of behavioral and medical supports. An essential element in this planning is the development of a functional system of information technology, both to improve service delivery and assure the efficient functioning of the

system and its resources. The lack of such technology persists and is limiting and is a continuing obstacle and major frustration to those who work in the system, those who use services and to the legislature in exercising its policy, fiscal and oversight roles.

➤ **Implement Robust and Accessible Methods of Quality Assurance and Improvement**

Basic Assurances of Health and Safety are a requirement of Medicaid Home and Community Based Services. In the shift toward increasing these services, New Jersey needs to focus on quality improvement that addresses individual outcomes and also system indicators. As a participant in the National Core Indicators Quality effort through the National Association of State Directors of Developmental Disabilities Services, New Jersey can benchmark its service performance against national performance. In addition to dedicated resources for these quality efforts, New Jersey needs to develop mechanisms to utilize these findings in quality improvement activities and in making planning and fiscal decisions. Given the emphasis on self-direction and choice, both within HCBS waivers and New Jersey's enunciated policy directions, these findings also need to be available and accessible to consumers and their families to assist them in their decision-making about the services and supports that would meet their needs and preferences.

➤ **Strengthen Case Management and Service Coordination**

The clear trend in improving service provision in long term care for people with disabilities and other chronic conditions is coordination of care. Coordination of care is associated with enhanced personal outcomes and fiscal efficiency. Robust, focused case management/service coordination also provides continuity for individuals and families over time and across settings.

➤ **Investing in Families**

Given that the majority of individuals with developmental disabilities live with their families, it is essential to invest in families. Earlier investments in services for and to families, whether addressing behavioral or other support needs before they become crises or emergencies, will maximize the length of time families can care for their family member and also prevent or delay more extensive or larger service needs, including requests for out-of-home placement.

➤ **Implement the Supports Waiver**

As referenced in the Comprehensive Waiver application and conceptualized by DDD, the Supports Waiver, if approved by CMS and implemented, would provide a meaningful level of resource and service to adults with developmental disabilities living with their families. The administrative support necessary to bring this Waiver into being must be put in place and the Waiver needs to extend to a larger group of

individuals who are living with their families in the community.

➤ **Continue to Develop the Direct Support Professional Workforce**

New Jersey has begun to identify significant strategies for reducing direct support professional staff turnover, improving staff competence and enhancing the delivery of quality services in the community. The NJ DSP Career Path Pilot 2008 through 2010, funded by the NJ Council in Developmental Disabilities, demonstrated that on-line learning combined with on-the-job mentoring and portfolio development decreased staff turnover in the eight participating agencies. In portions of the participating agencies where the Career Path was made available to staff, turnover decreased from 38% (2007) - 12% (2009). Given that the median cost of turnover in NJ per DSP is \$9500, this investment in the workforce which reduces turnover, yields a significant cost savings. This outcome further stresses the need for investment in staff education and career paths that lead to stable, quality supports. The Career Path also provides educational and economic mobility, having been evaluated by The Community Consortium for Workforce and Economic Development and recognized as nine (9) credits toward an Associates Degree in Human/Social Services. The Boggs Center is currently working with Thomas Edison University to create another statewide option for college credit.

In September of 2010 the New Jersey Department of Human Services created the “New Jersey Partnership for Direct Support Professional Workforce Development”, making the College of Direct Support available to all community providers, DDD Developmental Center and other employees, and care givers and families involved in self-directed community supports. College of Direct Support courses have been introduced at Vineland Developmental Center; more than 100 direct support professionals have signed up to take courses, expressing the felt need for “expanding their career options in the community.”

The professionalization of the direct support workforce in addition to being essential for the well-being of people with developmental disabilities is also an important employment issue, and an employment option that needs to be promoted by the Department of Labor.

Policy attention is needed to:

- Build competitive wages and benefits;
- Enable educational opportunities and promote career paths that promote economic mobility and a stable work force;
- Encourage the Department of Labor to include direct support as a focus in health care jobs

➤ **Encourage the Development of Employment Opportunities and Self- Advocacy**

The federal entitlement for educational services that prepare students with disabilities for adult life, including employment, can

make for lives of opportunity as well as the effective utilization of mandated, dedicated resources. The power of employment as an underpinning of community participation, a source of natural supports and potential asset development has not been central to the work of the Educational or the Adult Services system and that needs to be realigned, and be a focus of our collective efforts.

Thank you for the opportunity to appear before you and your consideration of these issues.

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