Considerations in Rebalancing the System of Services and Supports to People with Developmental Disabilities in New Jersey 2012

Testimony to the Task Force on the Closure of Developmental Centers April 2, 2012

by

Deborah M. Spitalnik, Ph.D.
Professor of Pediatrics, Executive Director of The Boggs Center University Center for Excellence in Developmental Disabilities Education, Research, and Service
Chairman Domalewski, Distinguished Members, and guests, I am honored to have the opportunity to testify before you today at this meeting of the Task Force on Closure of Developmental Centers, established under S 2928.

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 the experience, concerns, and 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.

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 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 the clear policy
orientation towards 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”

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

The majority of the 43,438 individuals, 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 in New Jersey significantly exceeds the 57% of individuals who live with their families nation-wide. 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.
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)\(^4\)

<table>
<thead>
<tr>
<th></th>
<th>Other Residential</th>
<th>In own home</th>
<th>In family home</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Jersey</td>
<td>30.7%</td>
<td>1.6%</td>
<td>67.7%</td>
</tr>
<tr>
<td>United States</td>
<td>30.7%</td>
<td>12.3%</td>
<td>57.0%</td>
</tr>
</tbody>
</table>

For people who utilize residential placements in New Jersey, in contrast to the US as a whole (see Table 2), 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.
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. DDD reports that there are 1,035 individuals who are clients of the Division that are in Skilled Nursing Facilities. This represents an increase of 16 people with developmental disabilities placed in Nursing Homes in the past two months. 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 2,509 individuals living in state operated developmental centers\(^3\) represent 19.0% 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, then called “State Schools and Hospitals.” In the period between 1980 and 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%. 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.

Although New Jersey has lagged behind other states and the nation in institutional closures and the movement of individuals to community living, we have empirical data on the impact of institutional closure in New Jersey. Extensive documentation of the impact of the closing of North Princeton Developmental Center (NPDC) was conducted by the Developmental Disabilities Planning Institute at NJIT.\textsuperscript{10} 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 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.\textsuperscript{10}

\textbf{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,\textsuperscript{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.”\textsuperscript{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).”\textsuperscript{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\%.\textsuperscript{11}
The Need to Rebalance toward Community Services and Supports

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.\footnote{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.
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%).

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 USA
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% net increase from FY 08 to FY 09. 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. This and all other Medicaid waivers will be folded into the Section 1115 Comprehensive Waiver

**Enhancing Community Capacity to Support the Movement of Individuals from Developmental Centers to Community**

It is recommended that the Task Force consider the following areas for strengthening the capacity of community 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 enhancement of community infrastructure and capacity, as well as the expansion of services to individuals with developmental disabilities who are on the waiting list and at risk for institutionalization.

➢ **Systemic Planning and Capacity Building, including Information Technology**

New Jersey’s supports and services to individuals with developmental disabilities must be strengthened by data-driven system-wide planning, including implementing strategies to enhance capacity in the provision of behavioral and medical supports. The expansion and operation of the existing system and the necessity to conduct data-driven decision-making and planning, is seriously impeded by the lack of a functional system of information technology. The lack of such technology persists, 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.
The ability to measure progress on the policy recommendations made by this Task Force will be greatly diminished if those recommendations do not include and result in resources dedicated to a robust system of informational technology.

- **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.

Planning for the closure of Developmental Centers must include case management/service coordination that is continuous, person-centered, ensures an intentional process of transition for the individual and coordinates the range of needed services in the community, making adjustments and enhancements over time. This must be an accessible and trusted source of support to the individual and family over time-through the transition and beyond. It will be important to cut down on discontinuities and multiple
“hand-offs” and transitions in case management/service coordination.

- **Evoke and Coordinate the Range of State Government Services to Facilitate Movement to the Community and Effective Community Living**

The need to ensure a productive life in the community for people with developmental disabilities will be enhanced by coordinating the efforts of the Division of Developmental Disabilities with the services of the Division of Vocational Rehabilitation of the Department of Labor and Work Force Development.

As part of the restructuring of New Jersey state government, the long term care programs that serve older adults are being transferred to the Department of Human Services from the Department of Health and Senior Services. These long term services and supports are being restructured to emphasize the provision of supports in the community. This expertise in senior services should be brought to bear in assisting with the transition to the community of the aging population in Developmental Centers.

Opportunities for housing should continue to be promoted in coordination with the Department of Community Affairs and the Housing Mortgage Finance Administration (HMFA). The need for
housing that incorporates barrier-free design for physical accessibility and that is integrated, not segregated, needs to be elevated as a policy and fiscal priority.

Access should be enhanced to these, and other state programs, for individuals moving from Developmental Centers to the community. Recommendations from the Task Force should include a mechanism for evoking and monitoring efficient and expedited interagency coordination to promote this movement to the community.

➢ **Strengthen the Provision of Health Care**

Utilize the individual health care entitlement through Medicaid and the service delivery principles embedded in the Comprehensive Waiver to innovate models of medical care, including patient-centered health homes for individuals moving from Developmental Centers to the community. The contract between the Department of Human Services Division of Medical Assistance and Health Services (DMAHS) is the vehicle for creating expectations and requirements for the Managed Care Organizations (MCOs). Collaboration with DMAHS and MCOs should be utilized to ensure the provision of comprehensive, coordinated health care services, including
preventive care, for individuals transitioning from Developmental Centers to the community.

➢ **Enhance Capacity in Positive Behavior Supports**

Through training and technical assistance in Positive Behavior Support (PBS), the capacity to support individuals with challenging behaviors and mental health needs can be expanded, as successfully demonstrated by DDD’s Children Placement Enhancement Project (CPEP). Youth and young adults, who formerly would have been placed in out of state placements, are now being served successfully by community agencies in both out-of-home and in-home placements. A targeted approach to implementing these approaches, with adequate funding, staffing ratios and mental health supports that will address the needs of individuals with behavioral health needs should be part of the Task Force’s recommendations. Coordination with the developing Accountable Services Organization for Behavioral Health under the Section 1115 Comprehensive Waiver will be essential, and should also be a component of the Task Force’s recommendations addressing the importance of interagency coordination in supporting the movement of individuals to the community.
Continue to Develop the Direct Support Professional Workforce

Enhancing the Direct Support Professional Workforce will increase capacity in the community system. By finding ways to honor the relationships between the staff who have provided care to individuals moving to the community, continuity and stability can be maintained for individuals and families, and employment opportunities can be maximized.

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) to 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 State College 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. In recognition of the planned movement of individuals from Vineland Developmental Center, College of Direct Support courses were 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 and Work Force Development, as part of the recommendations of this Task Force.

Policy and budgetary attention is needed to:

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

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

Robust, transparent and clearly communicated strategies and results of Quality Assurance and Quality Improvement must be in place as part of the recommendations about Developmental Center closures.

Basic Assurances of Health and Safety are a requirement of Medicaid Home and Community Based Services, as they are for the
ICF/DD program. In the movement from Developmental Centers to community, 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 data-driven 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, and also serve as documentation for system performance.

In New Jersey’s original Olmstead Plan, *Path to Progress*, quality indicators had been separate from the NCI process. Quality indicators need to be continuous across settings and the DD system as a whole, and provide longitudinal information to both
demonstrate compliance with Medicaid requirements and the
efficacy of improvement processes over time.

**Policy Opportunities for Enhancing Community Services and Supports: Maximizing Enhanced Federal Financial Resources**

The development of a plan for the closure of Developmental Centers provides New Jersey with the opportunity and the imperative to avail itself of federal policy options, as well as build upon the experiences of other states which have enhanced and strengthened community services.

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-based 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.

The provisions of the federal Patient Protection and Affordable Care 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.
In Conclusion

Thank you for the opportunity to appear before you and your consideration of this information and these recommendations.

Please let us know how The Boggs Center, New Jersey’s federally designated University Center for Excellence in Developmental Disabilities, can be of further assistance to the Task Force as it moves forward in developing its recommendations.
References

1. Public Law 106-402, October 30, 2000
Developmental Disabilities Assistance and Bill of Rights Act of 2000
TITLE I Subtitle A, (c), 8

2. State of NJ, Department of Human Services in cooperation with
Department of Health and Senior Services and the Department of
Children and Families. (2011) Section 1115 Demonstration
Comprehensive Waiver. Submitted to the Centers for Medicare and
Medicaid Services, September 9, 2011.

3. NJ Division of Developmental Disabilities, Department of Human
Services (1/03/2012 and 3/20/12) Residential Population Statistics
for DDD as reported from December 31, 2012 and February 29,
2012. Hamilton, NJ

Report of the National Residential Information Systems Project on
Services for People with Developmental Disabilities: Status and
Trends Through 2010. Minneapolis: University of Minnesota,
Research and Training Center on Community Living.

Residential Services for People with Developmental Disabilities:
Status and Trends Through 2009. Minneapolis: University of
Minnesota, Research and Training Center on Community Living.

Residential Services for People with Developmental Disabilities:
Status and Trends Through 2008. Minneapolis: University of
Minnesota, Research and Training Center on Community Living.

2011. An Analysis of Medicaid for Americans with Intellectual and
Developmental Disabilities. Washington, DC: UCPA


