

The Future of Individuals with Developmental Disabilities and New Jersey's Developmental Centers

Executive Summary

The Arc of New Jersey believes that all individuals with intellectual and other developmental disabilities have a right to live, and be fully included, in communities of their choosing. There must be an array of diverse, high quality community resources available to ensure the opportunity for community living, as well as a spectrum of residential options from which individuals with developmental disabilities can choose. Adults with developmental disabilities, in conjunction with their families, should have the opportunity to self-direct and individualize their services to the extent possible and should not be “placed” into a program or facility. The Arc of New Jersey also holds that any individual currently residing in a developmental center who has an expressed desire and ability to move into the community must be given that opportunity without further delay. Resources must be made available to ensure that individuals experience a smooth transition from developmental centers to community living, and large congregate facilities should eventually be eliminated. While they continue to exist, however, the health and welfare of the residents and the quality of services delivered, including staffing ratios, must remain priorities. This white paper outlines the key issues relevant to institutional closure and makes specific recommendations regarding the successful closure of five of New Jersey's developmental centers.

Over the past several decades, there has been an abundance of national and state-specific planning, legislation and litigation geared toward significantly reducing the number of individuals with developmental disabilities served in large congregate institutional settings. Unfortunately, New Jersey has lagged seriously behind national trends in providing community-based supports and services to individuals with developmental disabilities. For most other states, it is not a matter of “if,” but “when and how” they will close their institutions. While New Jersey has made some efforts to begin changing the way supports and services are provided, there has not yet been a true philosophical or fiscal commitment to eliminating state-operated institutions.

The Arc of New Jersey calls upon the state to immediately implement the following recommendations:

1. Review and strengthen the *Path to Progress* plan (see page 6) and fully fund its implementation to ensure that individuals can continue to move out of institutions without delay if they desire to do so.
2. Ensure that a full array of medical, mental health, behavioral and related services are available to those leaving institutions by implementing the recommendations from The

Arc of New Jersey's white paper, *Community Infrastructure Needs for People with Developmental Disabilities Who Are Leaving Developmental Centers: Medical, Mental Health, Behavioral and Ancillary Service Areas* (see Appendix A).

3. Create a bridge fund to cover the dual costs that will exist prior to actual closure.
4. Reform case management to ensure continuity and support as individuals transition from developmental centers to community living.
5. Fully fund The 10% Solution (see page 9) to ensure no new admissions to developmental centers occur unless absolutely necessary.
6. Collect, update and disseminate critically-necessary data on people with developmental disabilities in New Jersey.
7. Form a task force to develop and oversee the implementation of a plan to close five of New Jersey's seven developmental centers over the course of 12-15 years. Two developmental centers should remain open to ensure that individuals who have lived in an institutional setting for many years and prefer to remain there can choose to do so. The task force's plan should include:
 - a. A plan to close two of the five centers over the course of the first four years, followed by one every three years until all five have been closed.
 - b. An individual plan for each developmental center closure.
 - c. Well-planned and targeted placements for individuals currently residing in developmental centers.
 - d. An order of developmental center closures based, at least in part, on the age and condition of the structure.
 - e. The examination and monitoring of community infrastructure.
 - f. A system for evaluating each closure.
8. Assist developmental center staff to become Medicaid qualified providers to ensure their ability to continue to provide services after an individual transitions into the community.
9. Reinvest all savings realized from developmental center closure into community-based services for people with developmental disabilities.
10. Direct all federal funds received through the Community Care Waiver and the ICF/MR program back to the New Jersey Division of Developmental Disabilities.
11. Ensure an appropriate annual cost of providing care increase for community providers based on the CPI-Urban Wage Earner Index for the Northeast.

The Future of Individuals with Developmental Disabilities and New Jersey's Developmental Centers

Background

Institutions for individuals with intellectual and other developmental disabilities are known in New Jersey as developmental centers. While any facility housing more than 16 individuals with developmental disabilities is considered an institution, most of New Jersey's developmental centers house closer to 500 individuals.

The first state-operated institutions for individuals with developmental disabilities in the United States were opened in the 1850s.¹ New Jersey's first developmental center was Vineland State School which was established in 1892. The national trend toward the institutionalization of individuals with developmental disabilities increased after World War II and throughout the 1950s.² In 1967, the nation's institutional census peaked with 240 state facilities serving 195,000 residents.³ Since 1968, however, the number of individuals served in state institutions has declined nationally by an average of 4% each year for 39 consecutive years.⁴

Current trends promoting community-based services over institutional settings evolved out of parent advocacy movements in the 1950s and 1960s.⁵ In the 1970s and 1980s, segregating individuals with developmental disabilities in large institutions became a national civil rights issue.⁶ By 1980, many states had begun implementing community services initiatives involving the development and funding of group homes, supervised apartments, family support programs and supported employment in an effort to integrate individuals with developmental disabilities into their communities and support their independence.⁷ In 1981, the part of the Social Security Act dealing with Medicaid was amended, creating the 1915 (c) option for states. This option allowed states to apply to the federal government for "waivers" of some of the Medicaid rules and gave states the option to provide Medicaid services in community settings rather than institutions. The waiver program for individuals with developmental disabilities, known in New Jersey as the Community Care Waiver, caused a substantial push toward the development and utilization of community-based services in New Jersey during the 1980s.

In this day and age, it is widely believed that institutions enforce an unnatural, isolated and regimented lifestyle that is neither appropriate nor necessary. Studies show that community living increases the quality of life of individuals with developmental disabilities. Furthermore, two of New Jersey's developmental centers, New Lisbon and Woodbridge, were investigated in 2002/2003 by the Department of Justice and found to have patterns of abuse and neglect, as well as conditions and services that did not meet generally accepted professional standards of care.⁸ Finally, while the cost of providing services to individuals with developmental disabilities is not always less expensive in the community than the cost of providing services in an institutional setting, national data shows that when an institution is closed there is a savings of anywhere from 9% to 45%.⁹

National Efforts to Move Individuals out of Institutions

The nation's reliance on the use of residential settings for 16 or more persons has been declining since 1968.¹⁰ The trend toward closing institutions for individuals with developmental disabilities gained momentum during the recession of the early 1980s and has continued since then.¹¹ The creation of the Medicaid waiver program in 1981 as well as strong advocacy from the developmental disabilities community resulted in developmental center depopulation during the 1980s through present day. From 1990-2006, the number of residents in institutions housing 16 or more people declined 41% from 171,821 people to 101,416.¹² Dr. David Braddock, the Executive Director of the University of Colorado's Coleman Institute for Cognitive Disabilities and a nationally recognized expert in the field of developmental disability research and policy, predicts that this trend will continue, "As the nation's institutional census continues to fall and average daily costs increase, there will be continued pressure on states to close institutions."¹³

States continue to close developmental centers each year and there are only ten states left that have never closed an institution, with five of those states operating only one institution.¹⁴ The majority (70%) of the 7% decline in the national census of state institutions from 2004-2006 occurred in ten states: California, Indiana, Wisconsin, Louisiana, Georgia, Missouri, Ohio, Florida, Illinois, and North Carolina.¹⁵ In 1991, New Hampshire became the first state to provide services to individuals with developmental disabilities exclusively in community settings.¹⁶ Now New Hampshire, Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii, Maine, Indiana and the District of Columbia provide services to individuals with developmental disabilities without utilizing any state-operated institutions.¹⁷

Currently, three states are in the process of closing institutions: Florida, Massachusetts and Tennessee. The most recent developmental center closure was that of the Fort Wayne Developmental Center in Indiana in April of 2007, making Indiana the most populous state in the nation without any institutions for people with developmental disabilities.¹⁸ Fort Wayne Developmental Center had 120 residents at the time its closure was announced in October 2005.¹⁹ It took Indiana one year and six months and \$95 million to close Fort Wayne Developmental Center.²⁰

Developmental Center	Location	Date of Closure	Number of Residents	Cost	Length of time from announcement to closure
Fort Wayne	Indiana	2007	120	\$95 million contract to manage transition	October 2005 – April, 2007 1 ½ years
Agnews	California	2009	350	\$170 million*	July 1, 2004 – March, 2009 5 years
Gulf Coast Center	Florida	2010*	306	Unknown	January 1, 2005 – present > 4 years

Rosewood Center	Maryland	2009	153	\$14.4 million*	January 2008 – June 30, 2009 1 ½ years
1. Fernald 2. Monson 3. Templeton 4. Glavin	Massachusetts	2010* 2012* 2013* 2013*	162 136 123 55 Total of all four developmental centers is 476	\$40 million for all four developmental centers*	December 2008 – present Estimated 5 years for all four developmental centers
Arlington Developmental Center	Tennessee	June 30, 2010*	128	Unknown	June 30, 2007 – present > 2 years

* Projections according to state plans

David Braddock was also commissioned to do a study for North Dakota in 2006 where he reported on the possible closure of Grafton Developmental Center. In this report, Dr. Braddock estimated “dual costs” of \$10.4 million for a three-year implementation period to move the 150 residents of Grafton and close the center.²¹ Dual costs are the costs of maintaining an institution while at the same time serving individuals from that institution in the community as the institutional population is reduced prior to closure.

New Jersey Efforts to Move Individuals out of Institutions

Unfortunately, New Jersey lags significantly behind national trends in rates of community placements of individuals with developmental disabilities from institutions. New Jersey continued to develop additional institutional capacity through 1969, with the opening of Hunterdon Developmental Center, and the state’s institutional census did not peak until 1980 with 7,317 individuals living in developmental centers throughout the state.²² While there has been some improvement, New Jersey still falls seriously behind national progress and currently ranks 49th nationally in terms of utilization of state-operated institutions to serve people with developmental disabilities.²³ In FY 2006 New Jersey’s average daily spending per person in state-operated institutions reached \$494, an increase of 9% from FY 2004.²⁴

There are currently 2,747 individuals with developmental disabilities living in seven developmental centers throughout New Jersey.²⁵

Developmental Center	Location	Date Founded	Capacity	Number of Residents²⁶
Green Brook Regional Center	Green Brook Somerset County	1981	118	83
Hunterdon Developmental Center	Clinton Hunterdon County	1969	652	553

New Lisbon Developmental Center	New Lisbon Burlington County	1916	690	414
North Jersey Developmental Center	Totowa Passaic County	1928	450	392
Vineland Developmental Center	Vineland Cumberland County	1892	556	427
Woodbine Developmental Center	Woodbine Cape May County	1921	591	477
Woodbridge Developmental Center	Woodbridge Middlesex County	1965	608	381
		Total	3,665	2,738

The Division of Developmental Disabilities is attempting to implement the *Path to Progress* plan, a State plan to move 1,850 individuals out of developmental centers and into community placements by state FY 2015. However, no developmental center closure or consolidation is currently proposed in the *Path to Progress* plan. Additionally, *Path to Progress* has not been fully funded and is not being fully implemented.

State Fiscal Year	Total cost (per <i>Path to Progress</i>)	Dollars allocated	Number of people to move (per <i>Path to Progress</i>)	Actual Number of people moved out of developmental centers	Number of people admitted to developmental centers
2008	\$33.6 million	\$30 million	100	121	47 (from January 2008 - June 2008)
2009	\$61.8 million	\$30 million	250	112	41 (in calendar year 2009)
2010	\$44.3 million	\$9.3 million	250	42 (thus far)	

The *Path to Progress* plan calls for \$44.3 million in FY 2010 to move 250 people into the community. The Governor's proposed FY 2010 budget provides \$9.3 million to move 62 people from developmental centers into the community. Currently, New Jersey faces significant fiscal problems in the face of the global economic crisis. It is unclear how this will affect individuals with developmental disabilities in the FY 2010 budget and future state budgets.

Another obstacle in reducing the number of individuals with developmental disabilities residing in developmental centers is that individuals are continuing to be admitted. The current policy of the Division of Developmental Disabilities is that admission to the developmental centers is permitted only when an emergency exists, as defined in Division regulations N.J.A.C. 10:46B 3-3, and no community placement is available. Unfortunately, due to the lack of funding for residential supports and services for people living at home with aging caregivers, the unmet

support needs of individuals living in the community and the lack of infrastructure to serve individuals in the community, the only placements that occur are emergencies. In an emergency, with no community placements available, individuals are being admitted to developmental centers from the community. Without funding to begin serving the over 8,000 people in the community on a waiting list for services, there will continue to be emergency placements and New Jersey will never be able to truly close the front door to its developmental centers.

Developmental Center Closures in New Jersey

Only three developmental centers have been closed in New Jersey: Edison, Johnstone and North Princeton.²⁷ In 1988, New Jersey closed Edison developmental center, with a population of 70 residents at the time the closure was announced.²⁸ In 1992, New Jersey closed Johnstone Training and Research Center, which had 229 residents at the time its closure was announced in 1991.²⁹ Most recently, in 1998, New Jersey closed North Princeton Developmental Center, which had 512 residents at the time its closure was announced and took three years to shut its doors.³⁰

There has been significant follow-up on the quality of life of the former residents of North Princeton, including three reports by the Developmental Disabilities Planning Institute (DDPI) at the New Jersey Institute of Technology (NJIT). According to these reports, nearly 75% of those who left North Princeton are residing in community settings including group homes, supervised apartments and skill development homes while about 25% ended up in a developmental center, nursing home, or other institutional setting.³¹

The studies done by the DDPI show no evidence of an increase in mortality or any other negative consequences of deinstitutionalization.³² Despite opposition to the closure of North Princeton by some family members, the DDPI studies show that there is now strong support for community living by a clear majority of family members.³³ Additionally, the DDPI reports show that consumers living in the community are doing “equal to or better than” their institutional counterparts, with strong empirical evidence linking community living with a better quality of life in the areas of community participation, family contact, self-care, freedom via lower social controls, utilization of mental health care, productivity, personal choice and autonomy, and safety of the person and their possessions.³⁴

Olmstead v L.C.

On June 22, 1995, the United States Supreme Court issued a landmark decision for individuals with developmental disabilities, recognizing community living as a civil rights issue. In *Olmstead v. L.C.*, the Court determined that the unjustified institutionalization of people with disabilities violates the Americans with Disabilities Act of 1990 (ADA). Specifically, the Court ruled that states are required to provide community-based services for individuals with disabilities who are residing in institutions if the appropriate professionals determine that the individual is capable of residing in the community, the individual does not oppose community living, and the placement can be reasonably accommodated by the state.

Governor’s Task Force

In November 2001, a Governor’s Task Force on the *Olmstead v. L.C.* Decision was convened to guide New Jersey’s efforts to shape a comprehensive plan for the community integration of

people with disabilities. In December 2002, the Department of Human Services, in conjunction with the Governor's Stakeholder Task Force on Olmstead issued a report titled "Achieving Community Integration for People with Disabilities." This report contained 62 recommendations addressing issues and barriers to community integration, and emphasized the need for a sustained commitment in the State budget to support the diversion of people with disabilities from institutions and the transition of people with disabilities from these settings to their communities with appropriate supports. Unfortunately, the recommendations contained in this report were not implemented and many of the issues identified by the Task Force, and the recommendations contained in its report, reappear in the 2007 *Path to Progress* plan.

Public Law 2006, Chapter 61

On August 2, 2006 Governor Corzine signed into law Senate bill 1090/Assembly bill 2947, now P.L. 2006, c.61. This law required the Division of Developmental Disabilities to develop a plan with established benchmarks to ensure that within eight years (State FY 2008 through State FY 2015), each resident in a developmental center who expresses a desire to live in the community and whose individual habilitation plan so recommends, is able to live in a community-based setting. In developing the plan, the Division of Developmental Disabilities was required to 1) establish criteria to identify those who are appropriate candidates for community-based living 2) identify the resources needed to provide those individuals with community-based services and supports and 3) set forth how the necessary funding, services and housing are to be provided.

Additionally, this law required the Division of Developmental Disabilities to solicit public input in developing the plan, including four public hearings which were held throughout the state in January, 2007. This plan was completed and released by the Division of Developmental Disabilities under the direction of Assistant Commissioner Kenneth Ritchey on May 2, 2007, and is called Olmstead Plan "Path to Progress." Public involvement continues through an Olmstead Implementation and Planning Advisory Council that includes a variety of stakeholders who advise the Division of Developmental Disabilities on various aspects of the *Path to Progress* plan and its implementation.

Path to Progress

The DDPI has already assessed all individuals living in New Jersey's seven developmental centers and the Division of Developmental Disabilities has a statewide database which includes information regarding the abilities, preferences and support needs of each resident of the seven developmental centers. The Division of Developmental Disabilities has identified 2,303 individuals who are eligible to move from a developmental center into a community placement. This includes 1,005 individuals whose families/guardians do not oppose such a move, and 1,298 whose families/guardians do oppose a move even though the interdisciplinary team and the individual do not. *Path to Progress* proposes moving the 1,005 individuals whose move is unopposed first, while providing education and preparation to the families of the other 1,298 individuals for movement thereafter.

The *Path to Progress* plan outlines the individual planning and transition process, methods for assessing and expanding community infrastructure and capacity, and the cost of implementing the plan. The *Path to Progress* plan covers State FY 2008 through State FY 2015 and involves moving 100 individuals the first year and 250 individuals each of the following seven years, for a

total of 1,850 individuals in eight years. It is important to note that *Path to Progress* does not discuss the closure of any developmental centers.

Litigation

In 2004, Disability Rights New Jersey (formerly New Jersey Protection & Advocacy) filed suit against the New Jersey Department of Human Services, charging that the State has long failed to provide community-based services or to develop an adequate assessment tool for identifying individuals who are appropriate for living in non-institutional settings. The complaint further charges that the State has unnecessarily and illegally segregated individuals with developmental disabilities in institutional settings such as developmental centers. The lawsuit cites violations of mandates and requirements of the Americans with Disabilities Act (ADA), the Rehabilitation Act (Section 504) and the Social Security Act Title XIX (Medicaid).

With the lack of full funding and implementation of the *Path to Progress* plan, Disability Rights New Jersey has amended and re-filed the complaint. The purpose of the lawsuit is to get a permanent injunction that stipulates that community residential services will be provided within a reasonable timeline and that places a stringent burden of proof upon anyone seeking to commit and retain an individual to a developmental center. This case is ongoing and has not yet been heard by the court.

Conclusion & Recommendations

As evidenced by the above discussion, there has been a great deal of national and state level litigation, legislation and planning in an effort to begin significantly reducing the number of individuals with developmental disabilities served in institutional settings, and toward the elimination of institutions altogether. The *Olmstead* decision and subsequent state efforts to comply have moved us into an era where services can, and should, be provided in one's community. Unfortunately, New Jersey has not yet made the philosophical and fiscal commitment required to ultimately eliminate the need for large congregate institutions. **The Arc of New Jersey believes that the time for this change is long overdue, and calls upon the state to immediately implement the following recommendations to ensure that individuals with developmental disabilities in New Jersey have the opportunity to be full participants in their communities:**

1. Review and strengthen the *Path to Progress* plan and fully fund its implementation to ensure individuals can continue to move out of institutions without delay if they desire to do so. This means moving no less than 250 individuals into the community each year at an average cost of \$150,000 per person. This will require allocating at least \$37.5 million in New Jersey's FY 2011 budget. *Path to Progress* explicitly states that "It is important to note that the ability to properly execute this plan is contingent upon the availability of appropriated funding over its lifetime." (p. 58)

2. Ensure that a full array of medical, mental health, behavioral and related services are available to those leaving institutions by implementing the recommendations from The Arc of New Jersey's white paper, *Community Infrastructure Needs for People with Developmental Disabilities Who Are Leaving Developmental Centers: Medical, Mental Health, Behavioral and*

Ancillary Service Areas (see Appendix A). In order for developmental center closure to occur safely and effectively, medical, mental health, behavioral and ancillary service infrastructure must be developed in the community. We have detailed information on the support needs, and preferences which clearly shows the need for additional infrastructure and community-based supports and services to serve individuals from developmental centers in the community. For example:

	All People Living in the Developmental Centers³⁵
Average age (years)	49.2
% female	40
% with a psychiatric diagnosis	53
% tube fed	8
% with catheters	4
% who use wheelchairs	47
% needing physical therapy	52
% needing speech therapy	60
% needing occupational therapy	70
% needing a behavioral specialist	56
% needing counseling	27
% needing nursing	95
% receiving special food preparation	65
% fed by staff	23
% with intensive behavioral supports	31.6
% who bang their head	12
% who run away/wander	15
% who hit others	32

Given these needs, the lack of professional infrastructure in the community to meet the medical, mental health, and behavioral support needs of the individuals currently living in New Jersey's developmental centers is a critical problem and there must be substantial efforts to expand these vital services in order to ensure the health and safety of individuals as they move into the community. A robust community support system with a wide array of supports and services is needed in order to appropriately and successfully serve individuals with developmental disabilities in the community. In May, 2006 The Arc of New Jersey released a white paper titled *Community Infrastructure Needs for People with Developmental Disabilities Who Are Leaving Developmental Centers: Medical, Mental Health, Behavioral and Ancillary Service Areas*. This paper provides a series of health-related recommendations that should be implemented in order to adequately serve individuals from developmental centers in the community.

3. Create a bridge fund to cover dual costs that will exist prior to actual closure. Additional funding will be needed to maintain an institution while at the same time serving individuals from that institution in the community as the institutional population is reduced prior to closure. Advocates believe that dual costs will be approximately \$15 million per year per institution

leading up to closure. Once the first two institutions are closed, assuming the savings are reinvested, there should be sufficient funds available to cover the dual costs of the remaining institutional closures.

4. Reform case management to ensure continuity and support as individuals transition from developmental centers to community living. Case managers should be the lifeline of information and services from the Division of Developmental Disabilities. Currently, the Division of Developmental Disabilities has caseloads of hundreds of individuals being served by one case manager. This is unacceptable. Individuals transitioning out of developmental centers need their case manager to be an active presence in brokering and linking them to the services they need. The support of a case manager is paramount to the individual's achievement of his/her desired outcomes and the safety and success of his/her transition into the community. In addition, quality case management could serve to prevent many of the emergency admissions to developmental centers by assisting individuals in obtaining the supports and services needed to avoid an emergency, as well as plan for foreseeable life changes in a way that keeps individuals supported in their communities even when their circumstances change. Knowledgeable case managers with suitable case loads and the time to understand and meet the individual needs of their clients are key to the implementation of any initiative of the Division of Developmental Disabilities. Specifically, The Arc of New Jersey recommends that the Division of Developmental Disabilities: 1) clearly define and communicate the role of case managers, 2) utilize adequate, up-to-date information technology (IT), 3) put in place clear guidelines for case management, 4) put in place mechanisms for evaluating the success of case management, and 5) where feasible, allow consumers choice in determining their case manager. More detailed information on this issue and these recommendations can be found in The Arc of New Jersey's fact sheet on reforming the Division of Developmental Disabilities' system of case management.

5. Fully fund The 10% Solution to ensure no new admissions to developmental centers occur unless absolutely necessary. The only way to prevent future admissions to developmental centers is if there is capacity in the community to serve not only individuals with significant medical, mental and behavioral health needs, but also those needing emergency placements. New Jersey must develop the capacity to deal with emergencies by utilizing community services rather than developmental center placements, and the waiting list for the Community Care Waiver must be addressed in order to *prevent* emergencies. There are currently 8,170 individuals in New Jersey on the Community Care Waiver waiting list for services because there is neither the funding nor the capacity to provide these individuals with services. Additionally, in 2006 there were an estimated 22,658 individuals in New Jersey with intellectual and developmental disabilities living with a caregiver age 60 or older.³⁶ For many of these individuals waiting for services and/or living with aging caregivers, it is simply a matter of time before their situation becomes an emergency. The Division of Developmental Disabilities consistently places approximately 350 individuals each year who are in emergency situations. When there is truly a crisis (such as the primary caregiver dying or a situation of neglect) and someone needs a place to go, they will be placed in a developmental center if there are no services available for them in the community. In 2007, The Arc of New Jersey proposed The 10% Solution to address the Community Care Waiver waiting list and increase the community capacity to serve individuals with developmental disabilities. The 10% Solution proposes

serving 10% of the priority category of the waiting list each year; in FY 2011 this would mean providing services to 499 individuals at an approximate cost to the State of \$20.6 million.

6. Collect, update and disseminate critically-necessary data on people with developmental disabilities in New Jersey. It is impossible to create any sort of successful plan without accurate and up-to-date data. There should also be an ongoing review of the current assessment tool used for data collection to ensure that it accurately reflects the support needs of the individuals being assessed. In 2007 the DDPI released a report “Descriptive Characteristics of All Consumers Residing in New Jersey’s DD Centers.” This report contains very specific data on the needs and preferences of every individual living in a developmental center in New Jersey. Unfortunately, as far as we know this data is not being tracked over time or updated as individuals move in and out of the developmental centers. Also, while *Path to Progress* states that there has been an assessment of available community resources, including the quality of those resources and their capability for meeting the demand, we have been unable, despite requests, to obtain this data. This information is critical in order to create and implement a responsible, fact-based plan for developmental center closure. It is also imperative that aggregate data be easily accessible and available to the public so that planning can be done, progress can be monitored, and stakeholders can provide informed input with regard to the process and outcomes.

7. Form a task force to develop and oversee the implementation of a plan to close five of New Jersey’s seven developmental centers over the course of 12-15 years. Two developmental centers should be identified at the outset as the ones that will remain in operation at the end of the 12-15 year period. Leaving two developmental centers open will ensure that individuals who have lived in an institutional setting for many years and prefer to remain there, can choose to do so. The task force developed to oversee and implement a plan for closure should include:

- Chair, or designee, of the Senate Budget and Appropriations Committee
- Chair, or designee, of the Senate Health, Human Services and Senior Citizens Committee
- Chair, or designee of the Assembly Budget Committee
- Chair, or designee of the Assembly Human Services Committee
- The State Treasurer, or designee
- The Commissioner of Human Services
- The Assistant Commissioner of Human Services in charge of the Division of Developmental Disabilities
- Two self-advocates
- A representative from a developmental center family organization
- Two family members of people who have transitioned to community living from a developmental center
- A representative from a labor union
- A medical consultant/expert
- A national expert on developmental center closure
- A behavioral consultant/expert
- The Arc of New Jersey
- The New Jersey Council on Developmental Disabilities
- The Boggs Center on Developmental Disabilities
- Disability Rights New Jersey
- Two appointees of the Commissioner of Human Services’ choosing
- Alliance for the Betterment of Citizens with Disabilities (ABCD)
- The New Jersey Association of Community Providers

The task force's plan for developmental center closure should include:

- a. **A plan to close two of the five centers over the course of the first four years, followed by one every three years until all five have been closed.** This is in line with national timeframes for developmental center closures when the number of residents is taken into account. David Braddock suggests a conservative timeframe and a date range for closure because it eliminates or invalidates a significant amount of the opposition to closure.
- b. **An individual plan for each developmental center closure.** Every developmental center is slightly different. Because of this, there needs to be an individualized plan for closure for each developmental center. These individualized plans need to take into consideration the residents and their needs, the staff, the services provided by the developmental center, the community capacity to serve individuals from the developmental center, the physical structure and the community where the developmental center is located. The task force should develop and oversee the implementation of these individual developmental center plans for closure.
- c. **Well-planned and targeted placements for individuals currently residing in developmental centers.** There must be 250 community placements from developmental centers each year. All those eligible for community placement in the developmental center targeted for closure next should be moved into the community first. If there are not 250 or more individuals remaining in the developmental center targeted for closure who are eligible for community placement, individuals from one of the two developmental centers that will remain open at the end of the 12-15 year period who are eligible for community placement should be served next. Those not currently eligible for community placement should be transferred to one of the two developmental centers slated to remain open after the 12-15 year closure period. Every person who moves, regardless of where they are moving to should have an individualized transition plan outlining when and where they will be moving and how their transition will be supported. If the individual chooses, current developmental center staff serving that individual should be a part of the transition plan and process and continue to be a regular part of the individual's life for a period of time after they move into the community. The amount of disruption of individuals' lives should be minimized to the extent possible and no individual should have to move more than once. As much as it is practicable, resident groups, friends, and staff should be kept intact when an individual moves.
- d. **An order of developmental center closure based on, at least in part, the age and condition of the structure.** In determining which developmental centers to target next for closure, the task force should consider the necessity for capital improvements, cost of maintenance, needed repairs, and any other foreseeable building or grounds maintenance and repair costs. Developmental centers with greater repair needs should be considered for closure first to avoid sinking additional money into institutional infrastructure costs.
- e. **The examination and monitoring of community infrastructure** to ensure that the supports and services needed by those transitioning out of developmental centers are available and appropriate. The community infrastructure and its ability to support individuals leaving developmental centers should be consistently monitored to make certain that the development of community supports and services keeps pace with the needs of individuals moving into the community. There should be a reassessment of the community infrastructure after each closure to ensure that there is the capacity to continue moving individuals into the community and a plan to create additional capacity

in areas where insufficient capacity is anticipated. The availability of community services to meet the support needs of those leaving developmental centers is imperative to the health, safety and successful community living for all individuals transitioning out of developmental centers.

- f. **A system for evaluating each closure.** Each closure should be evaluated systematically and longitudinally as was done with the closure of North Princeton Developmental Center. The evaluation of developmental center closures should include the perspectives of residents, their families, impacted staff, and the local community. Evaluation should begin at the time the closure is announced and continue for at least two years after the last resident has moved out. The evaluation and assessment information should be utilized by the task force to modify the plan or implementation as appropriate based on this data.

8. Assist developmental center staff to become Medicaid qualified providers to ensure their ability to continue to provide services after an individual transitions into the community. Currently, those leaving developmental centers are given an individual budget which they can use to purchase services and supports from any Medicaid qualified provider, whether that is an individual or an agency. If staff of the developmental centers become Medicaid qualified providers, they can be hired using the individual budgets of those transitioning into the community from developmental centers. This would allow individuals who have developed a close relationship to their staff to bring them into the community and would allow staff to maintain their employment and relationships.

9. Reinvest all savings realized from developmental center closure into community-based services for people with developmental disabilities. These funds are desperately needed to expand services to individuals with developmental disabilities and their families. The developmental disabilities community has a wide range of unmet needs due to lack of funding. The overall lack of community-based medical, behavioral and psychiatric supports is a consistent impediment to individuals with developmental disabilities in New Jersey being able to move out of large institutions and off long waiting lists. Any savings realized from developmental center closures should be used to strengthen and expand the infrastructure in place to ensure the needs of individuals with intellectual and other developmental disabilities are appropriately met and to develop capacity to serve additional individuals and support future developmental center closures.

10. Direct all federal funds received through the Community Care Waiver and the ICF/MR program back to the New Jersey Division of Developmental Disabilities. Currently, when surplus federal matching funds are received by the State of New Jersey under the Community Care Waiver or the ICF/MR program, those funds are allocated to the State's General Fund. This allows the State to utilize these funds for other areas of the state budget that do not necessarily benefit people with intellectual and other developmental disabilities. Given the dire needs of the developmental disabilities community in New Jersey, all federal revenue brought in under the Community Care Waiver or the ICF/MR program must be reinvested into community based supports and services and used to expand community infrastructure and serve additional individuals from developmental centers and the waiver waiting list.

11. Ensure an appropriate annual cost of providing care increase for community providers based on the CPI-Urban Wage Earner Index for the Northeast. The only way that the community infrastructure can fully support people moving out of developmental centers with quality supports and services is if there is an annual cost of providing care increase built into the funding for community based supports and services. Although the costs associated with providing services, such as health insurance, transportation, utilities, and worker's compensation, have increased dramatically; community provider agencies have not received an adequate contract increase in nearly 15 years. New Jersey gives its State Departments increases every year to address the mandatory increase in costs associated with providing services; however community providers, which provide the actual community services on the State's behalf, do not receive an annual increase. In order to sustain and grow the community infrastructure to serve additional individuals with developmental disabilities in the community, the cost of providing care must be fully funded with mandatory yearly increases commensurate with the CPI-Urban Wage Earner Index for the Northeast.

Notes

1. Braddock (March 7, 2006). *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines*.
2. *Ibid.*
3. *Ibid.*
4. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities*. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
5. Braddock (March 7, 2006). *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines*.
6. *Ibid.*
7. *Ibid.*
8. The Department of Justice began their investigations of the New Lisbon and Woodbridge developmental centers in March, 2002 and April, 2003 respectively. In their investigations into the conditions and practices of the two developmental centers they reported that the conditions and services did not meet generally accepted professional standards of care. Specifically, that the residents were not adequately protected from harm or appropriately supervised, that there was a pattern of abuse and neglect, that restraints were being used unnecessarily in lieu of proper mental health and behavioral supports and services, and that residents were not provided with adequate medical care or nutritional, medication and physical management.
9. Braddock (March 7, 2006). *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines*.
10. *Ibid.*
11. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities*. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
12. *Ibid.*
13. *Ibid.*
14. *Ibid*
15. *Ibid*
16. *Ibid.*
17. *Ibid.*
18. Indiana Family and Social Services Administration. Retrieved April, 2007 from www.fwsdc.com.
19. *Ibid.*
20. *Ibid*
21. Braddock (March 7, 2006). *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines*.
22. New Jersey Department of Human Services, Division of Developmental Disabilities (May2, 2007). *Olmstead Plan "Path to Progress."*
23. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities*. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
24. *Ibid.*

25. New Jersey Division of Developmental Disabilities, Records Custodian (February 2, 2010). Obtained via OPRA Government Records Request, #W48348.
26. *Ibid.*
27. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities*. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
28. *Ibid.*
29. *Ibid.*
30. *Ibid.*
31. Hall Apgar, Lerman, Jordan, Carter, Christenberry, Gaboda, Hessler, Lee, Madden, Shresta, Siligato, and Tansug (November 2003). *Life After North Princeton Developmental Center: Final Outcomes, A Follow-up of Former Residents*. New Jersey Institute of Technology, Developmental Disabilities Planning Institute.
32. *Ibid.*
33. *Ibid.*
34. *Ibid.*
35. New Jersey Institute of Technology, Developmental Disabilities Planning Institute (April, 2007). *Descriptive Characteristics of All Consumers Residing in New Jersey's DD Centers*.
36. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities*. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.

Theodore Stieve
President



Thomas Baffuto
Executive Director

Community Infrastructure Needs for People with Developmental Disabilities Who Are Leaving Developmental Centers: Medical, Mental Health, Behavioral and Ancillary Service Areas

The Arc of New Jersey Planning White Paper

May, 2006

I. HEALTH CARE AND MEDICAL NEEDS

Research, current experience in New Jersey, and a recent U.S. Surgeon General's Report demonstrate that access to health care, especially specialized primary health care, is restricted for individuals with developmental disabilities. Additionally, extreme access problems exist in relation to various specialty practitioners (such as dentists, psychiatrists, gynecologists, cardiologists, and others) as well as for ancillary services such as occupational, physical, and speech therapies. The barriers to care are many and can be considered together as deficiencies in the professional *infrastructure* that exists in community settings. To begin to address these issues, The Arc of New Jersey has identified a number of actions designed to enhance and expand this service infrastructure.

Recommendations:

1. ***Discharge Planning Process.*** A comprehensive, interdisciplinary, and documented pre- and post-discharge process needs to be established to provide appropriate transition services to individuals leaving New Jersey developmental centers (DCs). This process should begin well before discharge and continue well after initial placement. Transitional waiver funding should be explored (see # 5, next page).
2. ***Medical Records.*** As individuals leave DCs, they should be accompanied by a complete medical record and medical history that includes: (1) a comprehensive, standardized summary document, (2) necessary original source documents, (3) a history of specific procedures and illnesses and (4) complete information on current medication/therapies, as well as on-going health care needs. The process of compiling the record should be integrated with the discharge planning process; the Division should empanel an expert committee, including community providers, to develop the format of this record.
3. ***Integrated Nursing-Health Care Specialist Model.*** Workable, community-based, provider-centered, DDD-funded nursing/health care specialist or support models and/or networks should be developed to provide residential support for health care. Nurses and similarly credentialed providers need to be made available as staff positions in residential providers of size and through other network arrangements as needed for groups of small providers or skill home providers. Nurses working in this model should be included in the discharge planning process to link with health care managers in Medicaid managed care.

4. ***Service Expansion.*** The Division needs to promote efficient, broad-based, and entrepreneurial primary health care delivery models by providing market analyses, technical assistance, training assistance, business planning, access to Division of Medical Assistance and Health Services (Medicaid) expertise and programs and, possibly, pilot project support to enhance the capabilities of existing providers and engage new providers. The Division should avoid purchasing services that are available through Medicaid.
5. ***Transition Waiver and Strategic Planning.*** The Division needs to explore “transition waiver” possibilities for the discharge and placement of DC individuals into adequate community settings. Furthermore, the Division needs to develop and formalize interdisciplinary, expert, strategic planning groups that include appropriate constituent representatives, in order to develop integrated, long-term, appropriate, efficient, and effective health care networks and system components for individuals with developmental disabilities. These efforts need to include assessment and re-examination of existing funded models, opportunities for pilot programs with needed start-up funding, and potential for integration into current Medicaid managed care market structures.

II. MENTAL HEALTH AND BEHAVIORAL SERVICES

It is well known that 30% to 40% of individuals with developmental disabilities also exhibit mental health disorders according to DSM criteria. Furthermore, studies in New Jersey have shown that up to 50% of individuals remaining in developmental centers live in so-called “behavioral cottages.” Unfortunately, in community settings there have never been sufficient numbers of mental health professionals with experience in co-occurring disorders (i.e., “dual diagnosis”). This problem will be exacerbated in future transfers of DC individuals to community settings. Additionally, there is no well-established system of mental health supports that welcomes and well-serves adults with developmental disabilities and even fewer supports for children with developmental disabilities. Medicaid fee-for-service mental health providers have been generally unresponsive to this population.

Recommendations:

1. ***Integrated MH Service Delivery Teams.*** Develop multidisciplinary, community-based mental health teams (e.g., mental health practitioner, behaviorist, health care manager) with 24/7 responsiveness that are integrated into the developmental disabilities community (i.e., DDD providers) as well as existing mental health structures (via DMHS providers). Explore existing reimbursement structures and potential inclusion under Home and Community Based Services (HCBS) waiver (e.g., as service alternative under traditional targeted case management program) and/or as part of other services under the waiver (e.g., family support).
2. ***Integrated Behavioral Model.*** The Division needs to explore and establish workable, community-based, provider-centered behavioral models and/or networks to provide residential supports for behavioral plan development and implementation. Behaviorists need to be made available as staff positions in residential providers of size and in other network arrangements as needed for groups of small providers and skill home providers. Behaviorists working in this model need to be included on integrated teams as well as in the discharge planning process for former DC residents, and need to link with health care managers in Medicaid managed care.
3. ***CPST Linkage.*** The Division should explore the potential linkage between above teams and existing CPST program consultants with the goal of adapting CPST as required to allow it to function seamlessly with integrated teams (#1 above) and integrated field behaviorists (#2 above).

4. ***Service Expansion.*** The Division needs to explore service expansion strategies in this area including additional contracting and/or network development opportunities, expanded training supports, and personnel development. To the extent possible, services should be funded under waiver structures. Services need to include specialized therapy and counseling opportunities in addition to traditional psychiatry and behavioral interventions.
5. ***Highly Specialized Settings.*** A limited number of highly specialized, time-limited placements need to be developed, outside of traditional mental health settings, for complex mental health and behavioral cases (often with co-occurring mental health disorders) and those inpatient mental health discharges that require step-down transition. These settings need to have system components that foster integration with general DDD community residential and health care providers.
6. ***Strategic Planning.*** The Division needs to develop and formalize interdisciplinary, expert strategic planning groups including appropriate constituent representatives to develop integrated, long-term, appropriate, efficient, and effective mental health care and behavioral support networks and system components for individuals with developmental disabilities. These deliberations need to include assessment and re-examination of existing funded models, opportunities for pilot programs, and potential for integration into current or expanded HCBS waivers or Medicaid managed care.

III. ANCILLARY SERVICES NEEDS

As a group, people with developmental disabilities exhibit more co-occurring disabilities than the general population and often have specialized treatment needs even in typical services. For example, people with developmental disabilities exhibit proportionally more sensorimotor and ambulation problems and more speech and hearing and visual disabilities. Additionally, this group requires more complex dental procedures than the general population with many procedures needing to be accomplished in surgical settings. Additionally, some ancillary service needs are either not available in fully integrated settings or difficulties are encountered in adapting the settings to serve this group because of the dearth of providers or complex system and payment barriers. Thus, in developmental center settings some of these services are routinely available through the ICF/MR (intermediate care facility) model, but are exceedingly difficult to access in community settings under current waiver and/or Medicaid provisions, a problem perhaps exacerbated in New Jersey due to the lack of numerous small ICF/MR settings.

Recommendations

1. ***Service Continuity.*** Ways must be found to duplicate the range of ancillary services (such as occupational therapy, physical therapy, speech therapy, counseling, nutritional services) that were available to individuals in developmental center settings. Although the current Community Care Waiver is intended to provide such needed services, it has fallen short. Regardless, the levels of needed services should be identified in the integrated discharge planning process to assure service continuity for all individuals.
2. ***Service Expansion.*** The Division needs to explore service expansion strategies in these areas including additional contracting opportunities and/or network development, expanded training supports, and personnel development. To the extent possible, services should be funded under waiver structures. Services need to include specialized therapy and counseling opportunities in addition to traditional psychiatry and behavioral interventions. The Division needs to empanel an expert, interdisciplinary workgroup to explore these models, including possible inclusion or adaptation of the current CPST program. A critical goal of such a work group is to provide

financial and other business incentives to expand the market to attract providers to work with individuals who have developmental disabilities.

3. **Waiver Review.** The Division needs to seek competent waiver consultants with unique capabilities who are able to bring fresh ideas to current New Jersey developmental disabilities waiver programs. One focus would be to identify waiver-funded opportunities to enhance the delivery of ancillary therapies and services (including, for example, clarifying rules and definitions *vis a vis* habilitation vs. rehabilitation).

IV. Conclusion

In its advocacy role, The Arc of New Jersey has identified and collected information and perspectives from a diverse group of providers across the state in regard to the upcoming so-called Olmstead initiatives to move individuals from state-run developmental centers to community-based settings. The consensus of expert opinion is that the present programs of the NJ Division of Developmental Disabilities are not sufficient to assure the success of this relocation process going forward. Of concern in this white paper is the level, or general lack of, professional *infrastructure* to provide adequate health care, mental health care, behavioral services, and ancillary support services as well as competent individuals to carry out such services. It is the position of The Arc of New Jersey that the Division must directly address infrastructure issues at the time it embarks on the relocation of individuals from developmental centers. In doing so, The Arc of New Jersey urges the Division of Developmental Disabilities to consider the recommendations contained in this white paper.