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Elaine Buchsbaum, *Chair*  
Alison M. Lozano, Ph.D., M.P.A., *Executive Director*

## ***Major Arguments Supporting the Closure of Developmental Centers in New Jersey***

In sharing their support for the closure of developmental centers in New Jersey, advocates need to have tools available to express their views effectively. To help individuals and family members better convey the importance of scaling back New Jersey's costly and outdated institutional system to lawmakers and others, the NJCDD has compiled a list of major arguments, which explain why these closures are necessary and long over-due.

In bold, advocates will find five key statements that can be touched upon during conversations around closing the institutions. Each point is backed up with supporting statements, statistics, and other vital information, which explain each argument further.

### **1. Keeping seven New Jersey developmental centers open results in less available funding for community-based supports and housing.**

There are over 28,000 adults registered with the NJ Division of Developmental Disabilities (DDD). The vast majority of these individuals, including people with the full range of disabilities, live in the community with family caregivers or state monitored support services.

Researchers estimate there are more than 26,000 people in New Jersey living with family caregivers who are aged 60 or older, a figure which takes into account thousands who are not yet known to the state because they are not yet registered with DDD.

As aging caregivers become unable to support loved ones with developmental disabilities at home, their family member will need services and supports to continue their lives the community. Thousands may seek government resources for the first time over the next ten years.

In addition to this rising demand, over 600 people who live in our developmental centers are waiting for housing and support services in a community setting.

Thousands of people in the community and in the institutions have been waiting for well over a decade to receive community services. Even families on the "urgent" waiting list often wait years for appropriate supports for their loved ones.

We must prepare to meet the needs of individuals who, together with their families, are committed to the vision that they will live as full members of their neighborhoods, workplaces and communities, and not be confined to large institutions.

## 2. New Jersey is out of step with the nation.

New Jersey has more people living in large state run ID/DD institutions than every other state beside Texas.

In 2011, New Jersey devoted a smaller percentage of its ID/DD budget on community services than every other state in the nation except Mississippi (Braddock et al. 2013)<sup>1</sup>.

In 2011, New Jersey spent 34% of its I/DD budget, --nearly \$600 million dollars-- to maintain seven large developmental centers for approximately 2,700 people (Braddock, et al. 2013)<sup>1</sup>. Vineland Developmental Center was to close by July 2013. Following Legislative opposition leading to an indefinite delay, this facility may cost taxpayers \$20 million dollars in facility repairs.

The money spent to operate these seven institutions dramatically affects the state's ability to provide medical care, transportation, housing, and other services for individuals with ID/DD in the community.

## 3. The United States Supreme Court has explained why states must offer community services:

*"Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." Olmstead v. L.C., 527 U.S. 581, 600-01(1999).*

The Court further noted that, *"segregation perpetuates unwarranted assumptions that institutionalized people are incapable or unworthy of participating in community life."*

The Court ruled that if a state's service system, in practice, forces people to move into institutions to get services, then the state commits unlawful discrimination under the ADA. Therefore, states must operate their service systems in a way that provides people reasonable opportunities to receive services in integrated community settings.

## 4. It has been demonstrated repeatedly that individuals with ID/DD can do just as well – and in most cases better – in community-based housing as they do in an institutional setting.

Numerous studies and reports over the past 30 years have clearly demonstrated the benefits of community living for people with the full range of developmental disabilities. Even those with the most significant physical or intellectual disabilities --including those who require round-the-clock caregiving-- can be found living successfully in the community.

The benefits of transitioning people to the community from institutions have been shown through decades of evidence about what works in the real world. For example, a peer reviewed

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<sup>1</sup> "The State of the States in Developmental Disabilities: 2013;" Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., & Wu, J., Washington, DC: American Association on Intellectual and Developmental Disabilities (In collaboration with the Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado and the Department of Disability and Human Development, University of Illinois at Chicago).

study of the closing of North Princeton Developmental Center in New Jersey,<sup>2</sup> found that people who transitioned out of the institutional setting had more friends, exhibited less challenging behaviors, perceived their life to be better, and demonstrated significant increases in self-care skills over time.

The study also produced “convincing evidence” that the multi-cognitive scores of people who remained in institutional settings, including social skills, significantly *decreased* from 1994-2001.

Numerous peer-reviewed studies are available with similar findings about individuals who transition to the community. In fact, a review of the literature concluded,

*“Thirty years of research demonstrates there is a benefit to the adaptive behavior (daily living skills) and challenging behavior of individuals with developmental disabilities moving to community settings from institutions.” Behavioral Outcomes of Deinstitutionalization for People with Intellectual and/or Developmental: Third Decennial Review of US Studies. 1977-2010 (Lakin, Larson, and Kim 2011)*

**5. No matter what the setting, we need to ensure that housing, medical, and other support services are safe, effective, regulated, and readily available for those who need them.**

Regardless of where any of us stand on the issue of whether or not to close one or more of New Jersey’s institutions, we can all agree that the highest priority should be to ensure that people with developmental disabilities are able to receive a level of caregiving that is appropriate to their needs. Public oversight, proper staff training, and respect for the individual should be the norm in all cases.

This also means that the state must use effective and safe practices to transition individuals from developmental centers to integrated community settings such as group homes or supported apartments and townhomes. The state has outlined in detail their plans to prepare individuals and families for transition, to support them as they move, and to monitor satisfaction and outcomes following their relocation.

Safety and medical care are insured by establishing high standards for service providers and direct care staff, and by requiring ongoing staff training and regular monitoring and accountability for health, safety and other measures of quality.

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<sup>2</sup> “Longitudinal Changes in Adaptive Behavior of Movers and Stayers;” Lerman, P., Apgar, D., Jordan, T. Mental Retardation Journal, American Association on Mental Retardation. February 2005, pp. 25-42.

**Note: Some people oppose closing institutions because they believe individuals who transition to the community are at a higher risk of dying when they live in the community. You can respond as follows:**

- There are a handful of mortality rate studies based on people who transitioned before 1995.
- These studies have little or no value in predicting outcomes in New Jersey two decades later.
- The methods and findings of the studies were criticized by other researchers.
- Regardless of the reliability of the studies, the authors did not believe that higher mortality rates in the community were inevitable. Instead, they recommended quality assurance practices be implemented to ensure appropriate medical care and staff training.
- We certainly agree that safety and quality medical care must be a priority for people in all settings, including those moving to the community from developmental centers.
- The vast majority of peer-reviewed research demonstrates beneficial outcomes for people who move to less restrictive environments. Decades of research also includes numerous peer-reviewed surveys showing a majority of families report satisfaction with services following transition, including families who had initial objections to the move. (see point 4 above)
- In New Jersey, as we move forward with plans to transition interested developmental center residents to the community, DDD has put many precautions and quality assurance measures in place. Many are outlined in great detail in the Path to Progress publication at <http://nj.gov/humanservices/ddd/programs/olmstead/>
- Significantly, DDD has established three teams to bear responsibility for individuals transitioned throughout the state. Each team will specialize in one key area for ensuring that individuals who transition have effective services that meet their needs. These focus areas are medical services, behavioral supports, and daily life management.