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Empowering People: Providers Shaping Policies

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Testimony of Lowell Arye, Executive Director

To

Joint Hearing on the Care Options for People with Developmental Disabilities

Senate Committee on Health, Human Services and Senior Citizens

And

Assembly Committee on Human Services

May 7, 2010

Lowell Arye
Executive Director

**Testimony of Lowell Arye, Executive Director
at the Joint Hearing on the Care Options for People with Developmental Disabilities**

I want to thank the Chairs, Senator Weinberg and Assemblywoman Huttle, and the other members of the Senate Health, Human Services and Senior Citizens and Assembly Human Services Committees for providing me with the opportunity to testify today. Discussion about the future options of care for people with developmental disabilities, including the future of the Developmental Centers, is an important issue to people with developmental disabilities, families, and providers.

My name is Lowell Arye and I am the Executive Director of the Alliance for the Betterment of Citizens with Disabilities (ABCD). ABCD is an association of non-profit organizations in New Jersey whose mission is to affect the development and implementation of public policy and to support the member organizations whose specific purpose is to improve the lives of people with multiple physical and neurological developmental disabilities so that they have the opportunity to attain the highest level of purpose and dignity. ABCD's member agencies provide a broad array of community-based services to more than 10,000 people with complex developmental disabilities and their families.

ABCD's vision is for people with complex developmental disabilities to have significant relationships, access to full participation, and inclusive options in their communities, with quality supports. ABCD is committed to empowering people with complex developmental disabilities through the advancement of beneficial public policy and successful supports. Our core values demonstrate that we are here to serve the best interests of the individuals and their families who do not always have a voice in the policy development process. ABCD's core values are: 1) Person-Centered Thinking: Persons with complex developmental disabilities will continue to develop personal competencies, gain and maintain satisfying relationships, and have opportunities to fulfill valued roles and live with dignity; 2) Inclusion: Individuals with complex developmental disabilities will be present and fully participate in community life; and 3) Choice: Persons with complex developmental disabilities will express preferences and make choices in everyday life.

The individuals served by ABCD's member agencies in the community have similar or more complex disabilities than people who currently reside in the State's Developmental Centers. Specifically, most of the individuals served by ABCD members in community-based settings are in wheelchairs, need assistance in bathing, feeding and toileting, many of these individuals are unable to communicate verbally and have behavioral and complex medical issues such as trachea tubes. Later in my testimony I will provide specific information related to assessments which were done on behalf of the Division of Developmental Disabilities (DDD) on the people who live in the Developmental Centers. As you will see, the people served by ABCD member agencies have needs as complex as those living in the Developmental Centers.

For more than 30 years, federal and state disability policy changes have been implemented that break down the barriers of exclusion, dependency, and segregation. The 1999 Olmstead Supreme Court decision interprets the most recent of these changes, the Americans with Disabilities Act, and provides a framework for developing comprehensive plans for community integration for people with disabilities. The goal of community integration is that no one should have to live in an institution if they can live in the community with the proper supports. According to the Supreme Court, people with disabilities have the right to receive benefits and supports in the most integrated settings appropriate to their needs. By issuing this decision, the Court gave legal weight to accelerating policy and systems changes to expand opportunities for people with disabilities to live with dignity and on an equal basis with others in their homes and communities.

New Jersey continues to serve more people with developmental disabilities in state institutions than almost every other state in the country. Studies show that, proportionate to its population, New Jersey serves more individuals with developmental disabilities in large, state institutions than all but three states. Approximately 2,800 individuals with developmental disabilities live in seven Developmental Centers in New Jersey. New Jersey needs to move forward on ensuring the rights of individuals to live in the most integrated setting appropriate to their needs.

With this in mind, ABCD calls upon the Governor to announce that a Developmental Center will be closed within the next two years. We look forward to working with the Administration and Legislature to adequately fund a plan, build the necessary community infrastructure, and fully utilize all federal funds to ensure that people may move into the community.

Background

In 1999, the US Supreme Court ruled in *Olmstead v. L.C.* that people had the right to live in the most integrated setting appropriate to their needs. The decision provides a process that a state can take if it does not wish to be sued for violating an individual's rights to live in the community. The process includes having a "comprehensive, effectively working plan for placing qualified persons in less restrictive settings..."

Path to Progress

ABCD joined with The Arc of New Jersey to propose, draft and advocate for a bill that mandated the State move forward on a plan in compliance with the Olmstead Supreme Court decision. In 2006, P.L. 2006, C. 61, was enacted into law in New Jersey, and mandated that the Division of Developmental Disabilities (DDD) develop an Olmstead plan. The plan, entitled *Path to Progress*, established benchmarks to ensure that any individual wishing to move from a Developmental Center into the community would have the right and access to do so within eight years.

In May of 2007, *Path to Progress* was published by DDD, with public input, which explained how the Division would take more than 1,850 individuals out of the Developmental Centers over an eight-year period, ending by Fiscal Year 2015. The plan called for moving 250 people per year out of the Developmental Centers, beginning in Fiscal Year 2009. Despite the calls from ABCD and others within the community, the plan did not call for closure of any of the Developmental Centers. Given the costs associated with maintaining seven large Developmental Centers and the civil rights issues, it is critical that New Jersey decide to close and consolidate the Developmental Centers. The plan did provide an implicit acknowledgement that every two years 500 people would move into the community, in effect the size of one Developmental Center, but an explicit statement to close these institutions is needed.

As I explained earlier in my testimony, the characteristics of the individuals in the Developmental Centers are identical to the individuals already served by ABCD members in the community. According to the plan, the individuals left in the Developmental Centers have the following characteristics: on average 50 years old, 57% with a psychiatric diagnosis, 24% with cerebral palsy, 18% with autism, 39% with visual impairment, 40-60% with health conditions; 39% using a behavioral specialist, 45% using a wheelchair, 40% taking psychotropic medication; 14-21% could benefit from environmental modification.

The plan has never been fully funded. In FY'09, there was only funding for 125 individuals. In FY'10, funding was included in the budget for 62 individuals. In the Governor's proposed FY'11 budget there is again funding for 62 individuals. ABCD believes that the State simply needs to commit to providing the funding for moving 250 people out each year and then follow the Plan.

Need for Community Infrastructure

In 2007, the Developmental Disabilities Planning Institute at the New Jersey Institute of Technology (NJIT) performed a study for DDD. The study demonstrated that community infrastructure must be increased significantly in order to advance the rights of people with developmental disabilities and enhance their ability to live in the community.

For many of us in the community one issue of particular concern is that the front doors of the Developmental Centers remain open. Continuing to admit people into the Developmental Centers on an emergency basis cancels out the positive gains made when moving people into the community. The primary reasons for individuals from the community being admitted for non-respite purposes into the State's Developmental Centers are: 1) lack of barrier-free housing opportunities; 2) significant behavioral and psychiatric problems; and 3) medical needs that are not currently being met in the community. Clearly the NJIT study showed that rather than increasing admittance rates among individuals into the Developmental Centers, the State should expand community resources and create alternatives and other living options, including emergency options, for consumers with significant mental and physical needs or other profound disabilities.

From 1997-2007, on average, there were more individuals admitted into Developmental Centers from the community than people moving out of the Developmental Centers. Fortunately there has been a significant change in the past few years. In FY 2009 only 43 people were admitted into the Developmental Centers and as of March of this year only 28 people were admitted in this fiscal year. In this fiscal year alone, if the Plan had been fully funded to move 250 people there would have been a net reduction of 222 people in our Developmental Centers. If there had been full funding of the Plan since FY2009, we would have had a net reduction of 429 individuals in the Developmental Centers. That means that the net number of people moving out of the Developmental Centers would have equaled to or been close to the number of people in either Woodbridge (410 residents), North Jersey (400 residents), or New Lisbon (440 residents) Developmental Centers.

For years, ABCD has been at the forefront of advocating that funds from the Community Care Waiver must be reinvested back into community services. Literally millions of dollars of federal funds from the Community Care Waiver have been used by the State for other purposes. For example, in FY 2007, the State received more than \$194 million in retroactive funds from the federal government. Over a three year period, only \$50 million of those funds were provided for the Division of Developmental Disabilities; meaning that \$144 million were used by the State for other purposes.

Last year, the Division of Developmental Disabilities amended the federal Home and Community-based services Waiver, called the Community Care Waiver, to allow the State to claim for federal funding for additional services. The Division assumed approximately \$6-\$9 million in additional federal funds. The Treasury sequestered these funds for governmental purposes other than community services to people with developmental disabilities.

Budget language has been in place for the past six years which caps the amount of funds from the Community Care Waiver that the State can use for community services. This budget language must be eliminated and replaced with language that reinvests all federal dollars from the waiver and any savings from consolidating/closing Developmental Centers (including the selling of the land of the Developmental Centers) back into community services.

Closure of A Developmental Center in Two Years

Earlier in our testimony we stated that ABCD calls upon the Governor to announce that a Developmental Center will be closed within the next two years. This request is based upon our view that New Jersey should support the civil rights of individuals with developmental disabilities as expressed in the Supreme Court's decision on Olmstead and in ABCD's core values of Person Centered Thinking, inclusion and choice.

The request for the Governor to announce that a Developmental Center will be closed within the next two years is also based upon an ABCD analysis of how long it has taken other states to close Developmental Centers as well as New Jersey's history with North Princeton Developmental Center.

Based upon this analysis we believe that it will take approximately two years to close Developmental Centers with 400 to 500 residents. For example, we learned from discussions with the provider association in Maryland that it took approximately 17 months from the date of announcement to closure of a facility with 153 individuals eligible to live in the community. Massachusetts is estimating that it will take approximately five years to close four institutions with a total of 476 residents. California estimated that it will take 5 years to move 350 people into the community from one of its Developmental Centers. Indiana took 18 months to move 120 residents from its Developmental Center into the community. The announcement to close North Princeton Developmental Center with approximately 488 people was in 1995 and its doors did not close until 1998. Announcing that a Developmental Center will close within the next two years falls well within these estimated and documented timeframes of already closed or closing Developmental Centers.

Conclusion

ABCD supports the right of all individuals with developmental disabilities to live in the most integrated setting appropriate to their needs, as laid out in the U.S. Supreme Court decision.

ABCD's member agencies serve some of the most medically and neurologically complex individuals with developmental disabilities in the community. We believe that individuals currently living in the Developmental Centers, all of whom have similar characteristics to those already served in the community, can and should live in the community.

We urge the Governor to announce that a Developmental Center will be closed within the next two years.

Thank you for the opportunity to testify. I am happy to answer any questions which you may have.