**Remarks by Laura J. Kennedy**

**January 14, 2016**

My name is Laura Kennedy. I am the president of NYSARC, Inc., a family governed organization of over 100,000 members statewide and I am the parent of young woman with a developmental disability. I am proud to be a citizen of this State, proud that New York had the courage and determination 40 years ago to address a failed system of institutional care that was exposed during the abysmal days of Willowbrook and change to a system of care that has been a model for our country and the world. Families, professionals and advocates collaborated with government to develop community based services of housing, day programs, supported employment, and family supports in a planned way. We went from a government that was ignorant, arrogant and indifferent to one that has supported and provided an array of supports so that people could be included and be valued members of their communities. But that is now all changing.

That system of innovation and supports is unraveling before our eyes. I am angry and frustrated, as I know many of your are. And why?

We need a governor whose actions clearly demonstrate that he values those with I/DD, their families and care givers and works to preserve services and programs for our most vulnerable people. The difficulties that families have in securing needed supports, particularly housing in a timely manner, speak volumes to his indifference to our issues. A clear example of this is the slow dismantling of OPWDD, an agency created in the aftermath of Willowbrook, to protect and oversee services and supports for people with I/DD.

For several years we have been told that the present system of services is unsustainable, that it is too expensive, that it must all be transformed in order to meet the needs of a growing population and a population with more intense needs due to aging and those with severe behavioral challenges. Residential development has come to a gradual halt.

The voluntary agencies have not been able to offer appropriate wages to our DSPs for many years. Why are we told that are our programs are “unsustainable”?

What are the financial projections that have caused this governor to change the course in providing reasonable resources to OPWDD? Unsustainable? The families and dedicated providers deserve answers to this question.

Governor Andrew Cuomo prides himself on being a doer, a transformer. He’s working hard to transform the landscape in New York. Replacing the Tappan Zee Bridge, a project costing $4 billion. And Governor Cuomo will do this without raising tolls--forgoing $700 million in toll revenue. He plans on spending billions to fix up LaGuardia Airport and he’ll spend billions more for a new Penn Station and Hudson River tunnel.

He wants to help the workers in New York. He’s mandated an increase to the minimum wage for fast food workers, workers in State Government, SUNY workers and many others. Beneficiaries of his focus must be the DSPs—those dedicated individuals who perform the crucial and critical tasks of caring for those with I/DD.

They have their own families to care for as well. No mention that they should be guaranteed the $15 minimum wage. Why?

Three years ago, Governor Cuomo came to the College of Staten Island, the place that was once the site of Willowbrook State School. He came to talk about his vision and his ideas of building a better New York. I had been invited to listen to his presentation. Outside of the auditorium our disability community was protesting his budget cuts to OPWDD. After his remarks I approached him and mentioned that he needed to amend his presentation to include people with disabilities in his vision for New York. He was silent in his response and I then handed him a copy of our position on his budget cuts and a copy of the promise his father, Governor Mario Cuomo made when he closed Willowbrook in 1987. He told me he would review the matter. His father’s promise, inscribed on a bronze tablet not 20 feet from where his son spoke reads, in part:

The end of this institution symbolizes the success and appropriateness of New York State’s commitment to provide an extensive and comprehensive program of community living opportunities for its citizens with mental retardation and developmental disabilities.

Where is this commitment today?

Today, by our count, there are at least 6,000 people waiting for community residences and that number could very well be higher. We don’t know the exact number because OPWDD did not have reliable data. We are grateful that the legislature passed a law mandating OPWDD come up with a number by next month. In the end, regardless of the number, the question will remain: will this Governor provide the necessary resources to expand residential opportunities? Will this Governor provide peace of mind to elderly parents who have at home their adult child with I/DD and need to ensure appropriate long term care?

Twenty years ago, then Governor George Pataki created a program called, New York State Cares. That program guaranteed a residential opportunity for all New Yorkers with I/DD. This governor must do the same.

Yesterday the Governor presented his budget. Overall the budget doesn’t come close to meeting the needs of individuals who have been waiting too long for services. There is some reason to believe that the Executive Branch understands the need for immediate relief to address pressing issues. That is encouraging news but the reality is such that we as family advocates must continue to persevere with continued strong advocacy voices.

We must continue to do all we can to convince this Governor that our community is hurting and that he is has it within his power to change it for the better.

It is always easy to blame others for denying supports: the Feds, Medicaid, CMS, Managed Care, Supreme Court decisions and the like.

But the bottom line is that he is the one in charge and it is his decisions that matter. We must work to ensure that this Governor understands that those with I/DD, their families and care givers deserve to be included in his vision for New York.

Continuing to provide appropriate levels of resources for people with I/DD to live meaningful lives in their communities, has to be as important as a bridge, tunnel or airport. It matters to us.

Thank you.

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