

Testimony of Laura J. Kennedy President, NYSARC, Inc.

*Submitted to the Assembly Standing Committee on Mental Health and
Developmental Disabilities*

*“Identifying Barriers to Implementing the Office for People With
Developmental Disabilities’ Transformation Agreement”*

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Introduction

Good morning. My name is Laura Kennedy and I am the parent of a young woman with a developmental disability and the president of NYSARC, Inc. On behalf of the families of NYSARC, I want to thank Assemblywoman Gunther for the opportunity to testify today regarding the inadequate services and supports for people with developmental disabilities in New York State.

NYSARC is the nation's largest family governed organization serving people with intellectual and other developmental disabilities and their families. Through our forty-eight operating Chapters we serve approximately 60,000 people, providing a full range of day, residential, clinical and employment services.

Sixty-six years ago, NYSARC was founded by families with children with developmental disabilities. At that time, there were few, if any, opportunities for residential housing and other services. We, in partnership with New York State have worked for over six decades to create the best system in the nation. But now that system is eroding and that must be stopped.

In 1975, Governor Hugh Carey directed New York State to partner with families. That partnership, embedded in a contract called the Willowbrook Consent Judgment, provided for residential opportunities and a host of other services including employment and day programs.

In 1987, at the closing of Willowbrook State School, Governor Mario Cuomo reaffirmed the State's promise to a commitment of care to those with developmental disabilities. And in the late 1990s, the State created New York State Cares, a robust residential program that met the needs of individuals and their families. Unfortunately, New York State's commitment appears to be waning and its promise is in the breach. This must change.

Today I will briefly discuss four important areas that are in crisis and are in immediate need of attention.

1. Programs and services for people living at home

The number of people in acute need of services, especially adults with I/DD who are living at home with aging parents who can no longer provide care, has been rapidly growing. This is a major source of concern and anxiety among thousands of families throughout New York State. They wonder how their child will be cared for once they can no longer perform the role of caregiver.

According to a study compiled by David Braddock of the University of Colorado,¹ 54,309 New Yorkers with developmental disabilities live with family caregivers – usually parents – who are age 60 or older. Many of these caregivers are approaching a time when they

¹ *Braddock, et. al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

can no longer provide a safe and appropriate home.

Parents like New York City resident Jackie Macchia stay awake every night worrying who is going to take care of her 33-year-old daughter Cathy when she's gone. Long Island resident Lynne Brewer worries who is going to take care of her 63-year-old sister when their 88-year-old mother is gone.

Adding to the anxiety of families is that it has not been possible to clearly determine what the State is doing to address this issue. We do not know, for example, how resources are being used to meet the needs of people living at home. Earlier this year, in this very building, Chairwomen Gunther and I both appeared at a press conference with three women who had been waiting years to find residential placements for their adult children.

The past few State budgets have shed little to no light on this issue because no specific goals were set forth for people leaving developmental centers, people aging out of residential schools, or, critically, people living at home.

The Legislature added language to this year's final budget and asked for a report to clarify these matters. I understand that OPWDD is currently working on this report and will report the status of people on the residential request list. The report is due by February 15, 2016 and we look forward to seeing it, but we cannot let another full budget cycle pass without an increase in residential development.

While the exact number of people needing support is not yet known, there is no question that the number is in the thousands. Families across this State are panicking over this issue and we believe the Governor should include significant resources in his upcoming budget to begin to address the lack of services for people living at home. I would respectfully ask the Legislature to ensure that we get both the information we need and, more importantly, the funding we need to address this urgent problem in the SFY 2016-2017 budget.

2. Minimum wage for Direct Support Professionals

For decades the wages we pay to our direct support professionals (DSPs) have been a major issue. This year the issue has only grown in importance.

We applaud Governor Andrew Cuomo for making the minimum wage a priority. We are aware of the \$15 per hour minimum wage recently recommended by the Department of Labor's wage board for fast food employees. We are grateful that the Governor followed with a similar \$15 per hour minimum wage proposal for all employees in New York State and this must include Direct Care Professionals ("DSPs") with fully funded Medicaid rates. A minimum wage proposal must be approved for DSPs, but more importantly, it must be fully funded through the Medicaid rates. Unless it is, the wage increase will constitute a crushing unfunded mandate on the entire developmental disabilities system.

In the field of developmental disabilities, there are no employees more vital than DSPs . Because DSPs provide hands on care twenty-four hours per day, seven days a week, they are the backbone of the entire system of support and are responsible for the health, safety and very lives of tens of thousands of individuals with developmental disabilities throughout New York State. DSP wages have never been equal to their responsibilities. DSPs administer medications and respond to potentially dangerous behavioral episodes. They manage routine dietary, grooming and toileting needs. To do their jobs, DSPs must undergo hours of intensive training in medication administration, behavior management, fire safety, CPR, first aid and incident reporting. They are responsible for many people who are medically fragile and extremely vulnerable. Because of the care they provide, DSPs are closely scrutinized by the State for any oversight, accident or misfortune.

In view of these responsibilities, the Governor correctly realized that a minimum wage increase targeted at only fast food workers is wrong. Nonprofit providers of services for people with developmental disabilities are already in crisis and are experiencing significant challenges recruiting and retaining essential staff due to a tightening job market. NYSARC's Chapters currently have a DSP vacancy rate of 11 percent and are trying to fill more than 2,000 vacancies.

A minimum wage increase only for fast food employees promises to make matters worse. Fast food employers and developmental disabilities providers compete for the

same workers and starting DSP wages throughout the state range from about \$9.50 per hour to just under \$11 per hour. Employees will not want to work for us when they can start at \$15 an hour at a fast food establishment. Many DSPs will quickly give up caring for people in favor of serving fast food. Consequently, vacancies among critical care staff will soar; increasingly new hires, unfamiliar with individual needs, will take the place of seasoned workers; more positions will go unfilled altogether; awake/overnight shifts will be shorthanded; and, the ability to ensure health and safety will deteriorate.

DSPs and other similar workers, such as the teacher's aides and assistants in pre-schools for developmentally disabled children, must be given increases that are commensurate with the incremental wage increases that will be given to fast food workers over the next several years. And, as noted, that wage increase must be fully funded by the State with additional resources or the entire underfunded system will be threatened with collapse.

3. Employment

Few would disagree that the least restrictive, integrated employment opportunity that pays at least minimum wage is the ideal for people of all abilities. However, that ideal is not practical for many people with developmental disabilities given the hard realities of the economy and the inability of many individuals to fully perform each and every task associated with various job opportunities.

The challenge of matching people with appropriate jobs was exacerbated when OPWDD finalized a multi-year commitment on employment transformation with CMS. The commitment, as originally understood, would have eliminated the entire system of sheltered workshops over the next six years; harming rather than benefitting people with disabilities. Many individuals now served by these programs have long relied on them for friendships, fulfillment, learning new skills and a paycheck. When the employment transformation plan was first released, it appeared that it would cause many individuals to lose all of these benefits.

However, NYSARC is now hopeful that a middle ground can be found. NYSARC and the State have been working toward a more realistic understanding of the issues originally raised by the workshop closure plan. This understanding, we believe, has been enhanced by the work of advocates, the Legislature and OPWDD. Today we are working towards the conversion of sheltered workshops into integrated businesses. There are some elements of this plan, however, that still need to be worked out. For example, we must ensure that there is Medicaid funding to pay for the relocation of waiver services that can no longer be housed in the same building as an integrated business and funding for the cost of transporting people to and from the integrated business.

We believe that the introduction of legislation by you ("The Employment First Choice Act," Assembly bill 5955 (Senate bill 3893 by Young) has helped to focus the State's attention on the key role choice should play in the lives of people with developmental

disabilities.

A “meaningful choice” is a personal choice, not one dictated by someone else. The right to choice was affirmed the US Supreme Court’s Olmstead Decision and in the landmark consent decree between the US Department of Justice and State of Rhode Island. That Consent Decree is seen as a national model for minimizing the role of workshops and at the same time recognizes the right of participants to remain in this setting if they so choose.

While the Bill did not pass last session, we believe that the attention it received helped facilitate everyone’s understanding of the central issue of choice. Therefore, the Bill should remain in the forefront of the attention of both houses in the 2016 session until the State, parents and advocates fully agree on an approved plan for meeting the State’s employment transformation goals on sheltered workshops.

Our families believe it is essential for their loved ones to retain the choice to stay in a trusted environment that they believe is safe, productive and emotionally fulfilling.

4. Preschool

Preschool services for children with disabilities ages three-five years offer the youngest members of our society the means to avoid significant disabilities later on in life. The value of preschool in preventing more severe disabilities has been repeatedly proven

through studies and research.

In view of this, the outright neglect of the preschool program and the State's failure to provide even minimally adequate funding is detrimental to at risk preschoolers, their families and society.

Parents are very concerned that without an adequate growth factor, much of New York State's system of 4410 preschools (authorized pursuant to section 4410 of the NY Education Law) will be forced to close within the next two years. Most recently, a Bronx preschool program was forced to close its doors at the end of this year after more than fifty years of educating children with developmental disabilities. A thirty-year-old program on Staten Island closed its doors in June, leaving 70 preschoolers searching for services. Many more programs are at risk of closing their doors during the coming year.

After six years of no increases, the Division of Budget finally approved a woefully inadequate growth factor of only 2 percent for 4410 preschools. This increase is not enough to ensure the survival of even minimally adequate preschool services.

We call on the Legislature and the Governor to provide the necessary resources to sustain a viable system of preschool services. At the very least, pre-schools should receive the same percentage annual increase as the general elementary and secondary education program in the upcoming state budget.

I have highlighted four areas that we believe this Committee needs to address immediately. There are however, several other important issues that NYSARC wishes to draw your attention to and which will be the topic of future testimony:

- 1) The need for the State Budget to include transformation funding to support innovation, efficiency, and quality in services for those individuals with developmental disabilities.

- 2) Rapidly increasing funding to fully implement the START program of behavioral supports in order to address those in crisis.

- 3) Mitigating some of the unintended consequences of Rate Rationalization.

- 4) Better focusing the Justice Center on preventing serious harm and fostering quality improvement.

For over 40 years New York has been a leader in the DD field. We need to reaffirm our commitment to a most vulnerable population and their families. It is the right thing to do and, frankly, the only thing to do.

I thank you for this opportunity to address you and your committee.