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# Cerebral Palsy Associations of New York State

### TESTIMONY SUBMITTED TO THE NEW YORK STATE LEGISLATURE

Joint Hearing of the Senate Finance and Assembly Ways and Means Committees

> 2015-2016 Executive Budget Mental Hygiene

Presented by
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Good morning Chairman DeFrancisco, Chairman Farrell, members of the Senate Finance Committee, Assembly Ways and Means Committee and the Mental Health and Developmental Disabilities Committees. Thank you for your ongoing support for people with disabilities and for the opportunity to speak with you today regarding Governor Cuomo's 2015-2016 Budget proposal. I am Barbara Crosier, Vice President of Government Relations for the Cerebral Palsy Associations of New York State (CP of NYS) – founded almost seventy years ago by parents seeking services for their children with disabilities. Since that time, 24 CP of NYS Affiliates throughout the state have been offering a wide array of services for children and adults with disabilities and their families. While originally focused on children with cerebral palsy and other physical disabilities, our services have expanded to include children and adults with all types of disabilities and a variety of supports and services throughout their life span. Today CP Affiliates offer a variety of programs and services to over 90,000 people and their families across the state, and we employ over 18,000 New Yorkers.

We appreciate the decades of support and leadership that New York State has provided which has enabled CP of NYS and our Affiliates to move people with developmental disabilities out of institutions and into a community-based system of care. In the 1970s, with the Willowbrook Consent Decree, New York State asked CP of NYS to assist in bringing individuals out of Willowbrook and into the community. Today, CP of NYS is both a statewide association and provides supports and services to more than 2,000 individuals with developmental disabilities through our residential, day, employment, clinic and other programs.

OPWDD's recent Statewide Comprehensive Plan for Services, says that the mission and vision for implementing the transformational agenda and supporting people with developmental disabilities is to ensure that they "enjoy meaningful relationships, experience personal health and growth, live in the home of their choice and fully participate in their communities." CP of NYS heartily endorses this mission and vision but we are concerned that the current path will not allow it to come to fruition and we ask the Legislature for support in ensuring that this will plan will be realized for individuals with developmental disabilities.

# Making the necessary investment in Supports and Services

Because of this dual role and our rich history, CP of NYS is acutely aware of the challenges facing New York State in allocating resources and balancing the needs and priorities of competing interests. But, the field of developmental disabilities has done more than its share of belt tightening during the past four years. According to the transformation agenda that OPWDD submitted to the federal Centers for Medicare and Medicaid Services (CMS), the enacted budgets for 2011-12, 2012-13 and 2013-14 contained more than \$692 million (gross) in savings of which approximately \$346 million were cuts in the New York State enacted budget to supports and services for people with developmental disabilities. In addition, the 2014-2015 state budget included the elimination of \$330 million from OPWDD service investment spending over the next three years which reflect a lowering of the State's investment in supports and services for people with developmental disabilities for years to come. The Governor's proposed budget for 2015-16 does little to alter this picture. This funding would have supported critical new services for individuals with developmental disabilities. Essentially, this elimination of funding represents another 2% to 3% reduction in OPWDD resources each year. As a result, thousands of New Yorkers with developmental disabilities either are being or will be denied supports or are only receiving limited supports that do not fully meet their needs.

We appreciate that the Governor has included \$60 million (state share when fully annualized) in his 2015-16 Executive Budget proposal, for new opportunities for individuals with developmental disabilities. But, after so many years of funding reductions, even the most optimistic allocation is woefully inadequate to begin to meet the needs of the thousands waiting for services or to provide the support necessary to serve all the individuals with high priority needs who live at home with their families. The need for services including day, at home support, out of home residential and other services, far surpasses any funding amounts that have been suggested, particularly for those who are aging out of the education system or can no longer live safely with their families.

In order to begin to address the demand for acutely needed services, especially for those living at home with aging family members, we urge you to add \$30 million (state share at 50% phase in) to fund opportunities for people living at home in need of additional supports including out of home residential supports.

# Restore the Cost of Living Increase for OPWDD Supports and Services

While we greatly appreciate that the Governor and the Legislature has fully funded the 2% increase for direct support professionals (DSP) beginning on 1-1-15 and another 2% beginning on 4-1-15, this increase does not begin to address the erosion that has occurred over the past five years. The State is in a strong financial position and is can no longer afford to defer the cost of living for those who support New York's most vulnerable individuals with developmental disabilities.

The costs of providing community based supports and services has grown significantly due to the rising cost of living, health insurance, workers compensation, liability insurance, minimum wage and other factors beyond an agency's control. Over the past five years, nonprofit agencies and Direct Support Professionals have seen their purchasing power eroded by over 16% once the impact of the consumer price index (CPI) is taken into account. This erosion has left nonprofit agencies struggling to make ends meet, recruit and retain staff and cover all of their expenses.

Rather than continuing to defer the cost of living increase for yet another year (until the 2016-2017 budget), it is critical that it be restored (\$60 million State share) in the 2015-16 Budget so that the OPWDD providers and continue to recruit and retain qualified staff and ensure the health, safety and quality of care for individuals with disabilities.

# **OPWDD System Transformation**

We applaud the Cuomo administration for putting in place an OPWDD Transformation Panel. As Acting Commissioner Kerry Delaney has said, their task will be challenging, but vitally important. The panel will be charged with examining the challenges we face in implementing the Transformation Agenda, offering managed care in our system and ensuring its long-term fiscal sustainability for people currently receiving services and those who will need to access our services in the coming years.

On behalf of the individuals and families that we support we look forward to participating and working with OPWDD, individuals, families, the legislature and our colleagues in this effort.

# People who live in community based Institutional Settings

Part of the OPWDD Transformation Agenda and commitment to CMS includes a transition "plan" to close or convert institutional settings called Intermediate Care Facilities (ICFs). This "plan" actually has no plan or infrastructure to support it, at least that we have seen, and is merely a very aggressive timeline or chart without any specific plan to guide this transition. There are numbers on a chart with no explanation of how individuals will be moved from the ICF to a supportive or supervised IRA or even what moving an individual to "non-traditional residential housing and person controlled housing" or what they means for individuals and families.

As New York State transitions individuals to more individualized services in the community, the transition must be based on the individuals' choice and needs and must be carried out within a reasonable timeframe. There must be a valid assessment of an individual's needs and a person centered plan to meet those needs. Individuals and families should not be steered toward and only offered what is available, regardless of their needs.

If OPWDD's mission and vision is supporting people with developmental disabilities to enjoy meaningful relationships, experience personal health and growth, live in the home of their choice and fully participate in their communities, then the supports and services must be provided in a timely manner, even if it requires additional resources.

In order to ensure that every individual's rights and that their needs are met, we urge you to include \$5 million in State funds to initiate the downsizing of non-profit run Intermediate Care Facilities to meet the State's agreement with CMS and to ensure compliance with CMS' new HCBS settings regulations.

## Conclusion

We would like to thank the Legislature for your ongoing support for people with developmental disabilities. But there is much more to do. We ask that you to help us to ensure that people with developmental disabilities are not harmed and the success of the past is not forsaken.

CP of NYS has gotten to where we are by partnering with NYS for almost seventy years, and we hope to be there for another seventy years for people with disabilities. With your support, we can work together to redesign the system without losing critical supports and services for people with disabilities. We are eager to redesign the system and supports for people with developmental disabilities. But it must be done by building on our past success with a New York State partner that understands and is committed to the needs of individuals with disabilities.

We appreciate your consideration of our comments and look forward to working with you as we look to continue our work on behalf of people with disabilities and their families in New York State.

Thank you.