

**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
2014-2015 Executive Budget Health/Medicaid

Presented by
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Good afternoon Chairman Farrell, Chairman DeFrancisco, members of the Senate Finance Committee, Assembly Ways and Means Committee and the Health Committees. Thank you for your ongoing support for people with disabilities and for the opportunity to speak with you today regarding Governor Cuomo's 2014-2015 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.

CP of NYS has a long history of providing Early Intervention and Article 28 clinic services under the auspices of the New York State Department of Health (DOH). But, our Affiliates are probably best known for the wide range of Office for People With Developmental Disabilities (OPWDD) programs that they operate, which include IRAs, ICFs, CRPs, Residential and Day Habilitation, Family Support and Respite Programs, Article 16 clinics and Community Residences.

Our Affiliates depend upon Medicaid funding for almost 80% of their operating revenue, and now find the rates for these critical OPWDD supports and services set by the Department of Health. These supports and services were developed over many years as New York State made a commitment to support the vulnerable individuals and families that we serve. This recent shift in fiscal authority raises many concerns about the knowledge and understanding within DOH of the services and the impact of their decisions on vulnerable New Yorkers with developmental disabilities. The separation of program and fiscal responsibilities is troubling. While observers are open to draw their own conclusions on whether there is a larger plan in place for people with disabilities with the Medicaid program in New York, we believe that there are numerous policy shifts and initiatives already in place that will undo much of the progress New York has made to ensure inclusion and access for people with disabilities.

We seek the Legislature's support in working with us to prevent any further harm to individuals with disabilities and families and the supports that New York has had such a proud history of providing. We have come too far as a State and we must all continue to honor the promises made in the New York State Constitution and by the Governor in his campaign materials.

Access to Medicaid Services for People with Developmental Disabilities

There have been significant funding reductions taken in services for people with developmental disabilities funded through OPWDD. According to the transformation agenda that OPWDD submitted to the Federal Centers for Medicare Medicaid and Services (CMS), the enacted budgets for 2011-12, 2012-13 and 2013-14 contained more than \$593 million (\$296.5 state share) in savings from cuts to not-for-profit supports and services for people with developmental disabilities. These cuts included elimination of the trend factor and COLA, reduced funding for certain day programs and transportation, moving people from certified residences to non-

certified settings, moving people from day programs to employment and cuts to agency administration.

At the same time, DOH has segregated its treatment of funding for people with disabilities and has allowed spending for all Medicaid programs funded under the global spending cap for enrollment and services to expand by nearly 4% overall. Further, our State budget projections for growth in the OPWDD system seems to be a prime area to take yet another hit and as much as \$330 million is recommended to be eliminated from OPWDD service investment spending over the next three years, as part of the Governor's Gap closing. 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 urge the Legislature to provide funding so that individuals with developmental disabilities and their family members in the community do not continue to be denied access to these Medicaid funded services. In addition, we strongly urge that the Global Medicaid cap be expanded to include OPWDD services funded through Medicaid as the best way to address the issue. Alternatively, the same level of support could also be achieved outside of the Medicaid cap by establishing similar protocols and controls on spending growth in the OPWDD Budget.

DOH and OPWDD Coordination of Medicaid Services

CP of NYS has long supported the idea of including individuals with developmental disabilities in care management programs, and in fact we have established many systems that are being adopted in a care coordination model. While our emphasis has been on meeting the needs of the people we serve, we have made significant progress in incorporating the medical and health needs of the people who live with us in their entire service plan development.

Our Affiliates have been providing Medicaid supports and services largely certified by OPWDD and are now under the fiscal authority of DOH. As such, we are concerned that the Medicaid State Plan considerations of some of the issues we are seeing in OPWDD aren't fully appreciated or understood by DOH and we seek the Legislature's assistance in working with us to ensure that potential OPWDD State Plan and HCBS Waiver Agreement threats are acted upon swiftly. The most recent concern we have is with the policy of the "front door" in OPWDD which has had the effect of denying access to services and prompt or timely decisions in notification of service availability. Specifically, we have had people waiting for as much as eight months to get through the "front door" with no action by OPWDD to ensure that the Medicaid services described in the Medicaid State Plan are provided and the State's obligations met in a timely fashion. CP of NYS submitted an outline of suggested fixes to the failed front door policy in November 2013 and as of January 2014 we have been told it will be another six months before OPWDD addresses the bottleneck in access the front door policy has created. We urge the Legislature to join us in ensuring this failed policy does not further jeopardize New York's agreement with the federal government to implement a Medicaid program that fairly treats recipients as outlined in the State Plan and HCBS Waiver Agreement. The front door is a failed policy that will threaten the New York State Medicaid program's standing with CMS.

CP has been working with DOH for years on our Article 28 clinic issues, and we repeatedly had to work to differentiate high needs Medicaid patients served in our clinics from the typical patients seen by other Medicaid providers. There was good reason our patients were exempt from utilization thresholds of the past and as we progress to capitated payments, the future of those high cost, outlier patients is of paramount importance to us. Not only are we concerned with how we will be managed by the fiscal intermediaries unfamiliar with truly high need people, but more importantly we are concerned that DOH staff do not know enough about the people we serve to develop good public policy regarding their access to care.

We ask that with rate setting and other fiscal decisions now in DOH, that a *Disability Clinician Advisory Group* be created within DOH that staff must consult with and receive direction from in the development of any policy or fiscal action that would affect the role specialty services for people with disabilities play in the health care delivery system. We offer our Medical Directors' Council and experienced staff from across the State as a resource for those within DOH looking to better understand the multiple needs of the people with disabilities we serve.

In addition, particularly with the recent *Jimmo v. Sebelius* decision regarding CMS' improvement standard, we ask that DOH fully incorporate the concept that OPWDD's long term supports and services are habilitative and are valid health services under the federal standard. While DOH knows and understands the medical model, we do not want the progress made in New York State over the past thirty-plus years since the days of Willowbrook to be negated because the systems and supports that have evolved are outside the understanding or consideration of Department staff.

CP of NYS has long supported moving people with developmental disabilities into a care management environment, but it must be done thoughtfully and in a way that carefully analyzes the impact that it will have on individuals with disabilities and their families.

OPWDD has worked collaboratively with consumers, providers and families. We strongly urge that DOH, as they assume the leadership role in fiscal policy, be required to continue that collaboration. Knowledge of the system and supports in place and understanding of the needs of people with disabilities should not be excluded from policy decisions as care management is implemented in New York.

DOH Rate Rationalization is Anything But Rational

Another example of where we believe DOH does not understand the people we support and serve has been in the development of a new rate setting methodology for services for individuals with developmental disabilities. CP of NYS understands the need for transforming the current system to one that is sustainable and as such has a rational payment system for providers. We also support New York State's efforts to comply with directives from CMS on controls for setting rates and reimbursing service providers. But, we must note that New York State's financial issues with the federal government cannot exact payment from the not-for-profit community who did not receive the funds/reimbursement rates now questioned by CMS.

The development of the proposed rate setting policy has demonstrated that our population's unique needs are not understood by DOH. We have heard throughout that people with

developmental disabilities would receive “managed long-term care with a DD add-on” – this sentiment reflects a lack of understanding of who we support and serve. DOH staff and others continue to tell us that a similar methodology was used for nursing homes and “it worked well”. Aside from the strong disagreement with the nursing home industry that this statement provokes, one cannot compare a 120 bed nursing home with a four or six bed home where Olmstead, CMS and federal regulations require that individuals be integrated into the community, go out every day to either a work or day program and participate fully in society and their community. Cuts to hours and reimbursement for staffing cannot be covered by having staff “float” among houses that are blocks and miles away. The lack of any true understanding of how people’s services will be affected by the proposal needs to be understood before DOH proposes a model that could harm the most vulnerable individuals that these rates are designed to support.

Support Expansion of the Nurse Practice Act Exemption

The Olmstead Mandate

Governor Cuomo has stated that “people with disabilities have the right to receive services and supports in settings that do not segregate them from the community; it is a matter of civil rights.”

Accordingly, one of the areas of focus for Governor Cuomo’s Olmstead Cabinet was the need to increase opportunities for people with disabilities to live integrated lives in the community. One critical legal issue identified by the Olmstead Cabinet identified as inhibiting the community integration is access to health-related task assistance for individuals with developmental disabilities.

These health-related tasks include medication management, medication administration and other home health treatments. Recognizing these barriers, current law only authorizes people with disabilities served by certain programs to receive assistance with these tasks from non-nursing personnel.

We strongly support the Governor’s proposal to expand the exemption from the Nurse Practice Act for medication administration to individuals in non-certified OPWDD settings. This is a positive step to support broader access to support services in less costly settings and to achieve community integration for people with disabilities – this approach is in sync with how other States have successfully supported people in the most integrated community setting possible.

Support Restoration of the MRT 2% and Related Article 16 Cut

The Governor’s budget proposal includes restoration of the MRT 2% across the board cut. We strongly urge the Legislature to adopt this restoration for Article 28 clinics and for Article 16 clinics which serve individuals with developmental disabilities.

While OPWDD’s Medicaid supports and services were supposed to be exempt from the MRT process and are not currently included in the Medicaid Cap or reinvestment, DOH determined that OPWDD’s Article 16 clinics would be cut. Rather than a 2% across-the-board cut, as with other Medicaid providers, DOH decided that in an Article 16 clinic environment where OPWDD had already set utilization limits for clinics and our providers had operated under those

thresholds, DOH would target people with developmental disabilities who received more than the average number of long term therapies in a month, regardless of diagnosis or medical condition. The clinics which provided services to individuals who required more than the average number of therapies were expected to absorb the cut. As a result, the CP of NYS Affiliate clinics and others who serve patients with more complex medical needs and physical disabilities were cut significantly, while Article 16 clinics serving individuals who are physically healthy and whose physical or medical condition do not require long term therapies above the average received no cut at all. Therefore, providers serving the most vulnerable are given the choice of either not providing the services as prescribed by their physician or continue to be penalized and have their clinic payments cut. That sort of public policy does not make sense on many levels, particularly when services provided to maintain function will reduce costs to the Medicaid system so that patients do not regress and present in a higher cost service setting. **Therefore, restoration of MRT #26 is critical.**

We ask the Legislature 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 in New York State.

Thank you.