



**Cerebral Palsy Associations
of New York State**

Real people. Realizing potential.

Testimony

Before the

NYS Senate Finance and NYS Assembly Ways & Means Committees

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 2013 budget. I am Barbara Crosier, Vice President, Government Relations for the Cerebral Palsy Associations of NYS (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 and school-based clinic services under the auspices of the NYS Department of Health (DOH) and more recently have established federally qualified health centers (FQHCs), Traumatic Brain Injury (TBI) and consumer directed personal assistance programs. Our Affiliates are probably best known for the wide range of NYS 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, and Community Residences – an alphabet soup of supports and services that are critical to the very vulnerable individuals that we serve. In addition, our Affiliates have Preschool, School-Age Programs, Article 16 and 31 Clinics, and we provide IEP-mandated Medicaid services billed by the counties. Our programs are approved under: DOH, OPWDD, SED, OMH and OASAS.

ALL MEDICAID AUTHORITY AND ADMINISTRATION IN DOH

CP of NYS has long supported the idea of including individuals with developmental disabilities in care management programs, and we in fact 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. Further, during the Administration of Mario Cuomo, CP of NYS had a grant to develop managed care rates for people with developmental disabilities – a key finding of which was that the high cost people we serve didn't fit in the managed care model of that time. As the world has evolved and we once again consider care management as a means to find efficiencies in the multiple services the people we support receive, we fully support the notion that when people's care is coordinated thoughtfully and with a full understanding of their need there can be better health outcomes and cost savings. However, we are extremely concerned with the Governor's proposal to fold all Medicaid authority and administration into DOH while simultaneously moving all of the OPWDD supports and services into managed care. In our experience, DOH does not have the staff who understand both the specialized needs and supports of individuals with developmental disabilities.

CP of NYS has worked with DOH for years with 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 the Department staff do not know enough about the people we serve to develop good public policy regarding their access to care.

As recently as with the implementation of MRT #26, we saw how a lack of understanding can negatively affect the people we serve. 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 should 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.

We ask that as this transition of rate setting and other fiscal decisions move over to DOH, that there be a concomitant agreement from DOH that the staff in policy making decisions will gather information so that they fully understand 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 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 over the past thirty-plus years, since the days of Willowbrook, in New York State 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. Moving all administration of Medicaid services for people with developmental disabilities into DOH may disenfranchise service recipients and their families while jeopardizing the supports and services that they depend on to care for their vulnerable family members. OPWDD must maintain a leadership role in re-designing the supports and services for people with developmental disabilities, particularly as they interact with the traditional health care delivery system in New York. They cannot and should not operate alone, but OPWDD's institutional knowledge of the system 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.

Therefore, we look to you to help ensure that people 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 an agency that is committed to the needs of individuals with disabilities.

EARLY INTERVENTION PROGRAM

The Early Intervention Program (EIP), authorized under the federal *Individuals with Disabilities Education Act* (IDEA) Part C, provides critical services for children with disabilities and developmental delays from birth to three years of age and their families. Research has shown that EI services which are provided in a comprehensive, coordinated and collaborative manner, as intended by law, are cost-effective and successful in improving long-term prognoses and minimizing the need for life-long services.

INSURANCE PROVISIONS

The Governor's Early Intervention proposal includes provisions to ensure commercial insurance support, which CP of NYS has historically supported, in concept. We believe that commercial insurers should contribute to the program, when EI services are included as part of their plan, as was intended in the initial EI legislation. However, we feel the integrity of the developmental EI program must not be compromised in order to meet the requirements of the medically-based insurance industry. Earlier versions of insurance proposals, put forth several years ago and strongly supported by CP of NYS, utilized the agreed upon IFSP and approved EI provider status to satisfy any insurance requirements for medical necessity, prior authorization and network participation and set payment at the state established rate.

Several components of the current proposal are problematic as they would, in fact, compromise many of the key principles of the state's early intervention system: family choice of evaluators, IFSP decision-making, family input/preference for service provider, and a statewide system of consistent reimbursement rates. The proposed provisions would further restricts families' options for evaluators and providers, would allow decision-making by health insurance representatives and would subject providers to additional cuts in reimbursement, many of which are struggling financially due to historical stagnant reimbursement rates as well as cuts in recent years.

In order to ensure the continued availability of high-quality, effective services for children and families statewide, we recommend consideration of the earlier versions of insurance proposals and/or specific changes to this proposal:

Recommendations:

- ***Remove the Health Insurance representative from the IFSP team membership.*** The health insurance industry operates on very different assumptions from the EIP, which focuses on working with families to enhance each child's development. The IFSP decision-making process should not be influenced by the health insurance perspective or by whether or not the insurer agrees to pay for services.
- ***Ensure that providers are paid at the state-established rate rather than a lower negotiated rate.*** Many providers are struggling financially to continue to provide EI services, while many others have already discontinued their services due to significant financial losses in recent years. Any additional cuts to reimbursement will likely result in more providers opting out, compromising the availability of services for children and families.
- ***Remove requirement for providers to enter into contracts with insurers.*** This requirement would be particularly problematic for multi-service agencies that operate Article 28 or 16 health clinics, which currently have the flexibility to decide whether or not to participate in health insurance networks, without impact on Medicaid billing. Mandatory participation for EI would negatively impact the clinic operations of these agencies, discouraging their ongoing participation in the EIP.
- ***Allow availability of all approved evaluators/providers, regardless of participation in a family's insurance network.*** Recent changes to the EIP in regards to "conflict of interest" have already significantly restricted families' options for evaluators/providers. Further restrictions relative to network participation would result in even more limited options, thereby disenfranchising families.
- ***Clarify responsibility of the State Fiscal Agent for insurance denial appeals.*** The proposed budget language places responsibility on the provider to exhaust all appeals of denials by insurers. We believe the plans to establish a State Fiscal Agent included procedures for these appeals, with information submitted by the provider, to be processed by the State Fiscal Agent.

REVISED ELIGIBILITY DETERMINATIONS AND SCREENING/EVALUATION PROCEDURES

The Governor's Proposal would eliminate the requirement for a full multidisciplinary evaluation (MDE) for children referred with a diagnosed condition and for children "re-referred" following a previously completed and recent MDE. The proposal would also require an initial screening for children referred with a suspected developmental delay, with a full MDE conducted only if screening results indicate concerns or the family requests it. We support these proposals, in concept; however, we would want to ensure that a child and family's entitlement to services are not restricted by these changes and that evaluators are properly reimbursed for their services.

- ***Children with a diagnosed condition:*** Since these children are automatically considered eligible, a full MDE may not always be necessary. However, the program must ensure that children are considered for all available services and that supplemental evaluations are authorized and paid for in order to determine appropriate and necessary services. In addition, DOH should establish a mechanism for payment for the required "record review" by the approved evaluator.
- ***Children referred with a suspected delay:*** Current reimbursement rules provide for payment of a screening only when it does not result in a subsequent MDE. If screening becomes mandatory for all children without a confirmed diagnosis, DOH must establish a revised mechanism for these screenings to be reimbursed, even when followed by a complete MDE. In addition, families must be fully informed of their right to continue with a MDE, regardless of the screening results, if their concerns persist.

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.