



**Cerebral Palsy Associations
of New York State**

Real people. Realizing potential.



2013-2014 ANNUAL REPORT

A Call To Action

The CP of NYS story is one that started almost 70 years ago and includes a rich tradition of family support and activism to ensure that services for people with cerebral palsy and other significant disabilities were part of the community fabric throughout the State. Until recently, our efforts had been successful and we enjoyed a strong system that allowed for those in need to find the supports and services to reach their personal goals. From the '70's and '80's through today, the security of knowing that options were available for people with disabilities grew and our Affiliates evolved to meet those growing and changing needs. Sadly, our world is changing and we no longer can assume that all that we thought to be in place will be there for future generations, much less in the next year and coming years.

As an organization, CP of NYS has worked hard to influence decisions in Albany and Washington regarding funding, regulations, and statutes that impact the quality of lives of people with disabilities. But we have lost much ground in the past few years. Today, there are unnecessary regulatory obligations and reductions in funding based on averages rather than individual need. As we move to a State mandated managed care program, the inequity of policy making by averages will have a more pronounced negative impact on those who require more supports and services. And those are the people supported by the CPs throughout the State. As history has shown, managed care does not work well for those with significant multiple disabilities. Yet the State has continued to move in this direction regardless of potential negative ramifications.

As the Centers for Medicare and Medicaid Services (CMS) audited New York State and its practices for overbilling for state services, the reduction in reimbursement has been passed down to the providers. This was the reason we supported a PR campaign last year that called for no further cuts in funding for people with disabilities, and we, with our Affiliates and other disability providers, were successful in this effort. We also were successful in our work within Metro Services to streamline our operations and explore development of different housing supports. Our clinic operations continue to serve a patient population other providers have failed to serve, yet we must reconfigure our clinic services over the next year to ensure we can continue to operate these vital health services. Similarly, the State's movement to transform the ICF program has presented a challenge which we have embraced, yet it will take time and resources to successfully transition our residents to locations and settings that fit with newly identified federal and State standards. A pervasive problem of lower funding and a growing need confronts us in all service lines. This challenge must be met with creativity and resolve, developing new models for supporting those with the most significant needs.

*The front and back cover of this year's Annual Report feature photos taken by
Progressive Visions Photo Club members:
Frank Ferebee, David Horsham, Robin Jones, Angel Rodriguez and Cissy Stavropolis.*

Our Affiliates have similarly made great progress in their efforts to establish strategic alliances that will ensure that needed supports and services are in place around the State. Our Affiliate Services Office staff has worked with State representatives on the State Medicaid waiver, education standards and reimbursement, clinic and health services changes, and the intricacies of proposed reimbursement strategies for OPWDD's key services. All have generated some success, yet much work needs to be done. The policy makers have implemented a reimbursement system for our OPWDD programs that is irrational at best and which will negatively impact providers serving those with highest needs. Expediency to establish a new system has replaced thoroughness or an understanding of disability supports.

Just as we did in the early days of the disability movement, we must call on our partners and forge new alliances to ensure people with disabilities are not left out. It is time once again to act and renew our commitment to the vision and mission of all CP Affiliates.

Join us over the next year as we fight to rekindle the passion in the State to honor their constitutional responsibility to people with disabilities and their families.



Thomas J. Caserta Jr.
Thomas J. Caserta, Jr., Esq.
Board Chair



Susan Constantino
Susan Constantino
President & CEO

METRO SERVICES

COMMUNITY LIVING SERVICES

- 369 people live in 78 certified Individual Residential Alternatives (IRAs).
- 76 people live in 6 certified Intermediate Care Facilities (ICFs).

DAY SERVICES

- Day Programs provide supports to over 400 people in inclusionary programs where they are integrally involved in their immediate communities.
- Metro Options for Independence provides work related services to 150 people, providing Office for People With Developmental Disabilities (OPWDD) and ACCES-VR sponsored Supported Employment and related vocational services, Career Exploration/Volunteer Services and Community Habilitation Services.
- We support 107 people on work sites through various programs and have developed 25 new paid work opportunities this year.



HEALTH CARE CENTERS

Article 28

- Metro Services operates four full-time health care centers providing care to over 2,500 patients. We provide primary care services and specialty medical services including cardiology, gastroenterology, neurology, ophthalmology, physiatry, podiatry, audiology and psychiatry.
- Dental services are provided in Staten Island, Brooklyn and The Bronx.
- Our team of health care professionals includes 23 physicians, 5 dentists and 2 nurse practitioners.

Article 16

- There are 232 people receiving long-term physical, occupational and speech therapy services as well as counseling in our Article 16 Clinic.

COMMUNITY AFFAIRS AND VOLUNTEER SERVICES

- Metro Services has trained 96 individuals under a \$300,000 three-year contract with the MTA to provide travel training to qualified Access-A-Ride participants. The contract was extended through February 2015. In addition, a video promoting Travel Training and the MTA's new free Metro Card for Access-a-Ride customers was produced in partnership with the MTA. This video will be shown throughout NYC.
- Parent/Advocate meetings were held on a quarterly basis to share information including the proposed changes to the State's service delivery system, among other topics.
- Eight students are currently enrolled in the After School program at the Hungerford School main site on Staten Island and an additional seven students at an offsite campus. Plans are underway to start a new after school program at another Staten Island school.

METRO SERVICES

- We continued to have volunteers from the New York School of Urban Ministry, Summer Youth Employment Program and South Richmond High School. Volunteers provided enhanced support to residential and day programs.

COMMUNITY SUPPORT SERVICES & SERVICE COORDINATION

- Metro Services provides Medicaid Service Coordination (MSC) to 465 people, including 260 people living in IRAs operated by CP of NYS. In the past year, 20 new individuals chose to begin receiving MSC from CP of NYS.

STAFF DEVELOPMENT AND TRAINING

- Members of the Training Department are part of the OPWDD Direct Support Professional Talent Development Work Group. The DSP Core Competencies, along with accompanying performance evaluations, were finalized over the past year. The group continues to work on finalizing the Frontline Supervisor Competencies.
- OPWDD has adopted the Council on Quality and Leadership (CQL) Personal Outcome Measures (POMs) as a tool to assess what matters most to each person served. Two members of the Quality Management (QM) Department have been trained in Personal Outcome Measures interview techniques and have trained a core team of six additional QM staff. A pilot program is underway to train staff in all Metro Services programs.
- The second year of our Leadership Development Program has produced 42 more employee graduates.
- Working in partnership with 1199 SEIU Labor Management Project, a total of 41 staff participated in two-day workshops on Conflict Resolution: Managing and Problem Solving Conflict.



DEVELOPMENT

- Foxhurst Apartments: The property has been purchased and design work has commenced for the HUD Section 811 Independent Living project to construct 14 independent living units for people with disabilities in The Bronx. An application is being processed with NYC for \$1.75M in Special Needs Housing.
- Planning is underway to develop 13 residential opportunities to serve individuals “aging out” of residential school placements. Construction is expected to commence in the fall of 2014.
- Plans to reconstruct the Astoria and Medina Group Homes are being implemented. It includes temporary relocation of the residents and constructing two additional homes in Queens and Staten Island.
- We were awarded funding in response to an RFS to develop two new IRAs to place a total of eight individuals being repatriated from the Brooklyn Developmental Center. Site search is underway.
- Metro Services has engaged in discussions with two low-income housing developers to form a joint venture to develop an affordable housing tower over the West Farms – Metro Community Health Centers facilities in The Bronx. The plan includes 103 apartments with 20 set aside for people with disabilities.

METRO SERVICES

ENERGY CONSERVATION

- The design of Foxhurst Apartments will incorporate the Enterprise Green Community energy efficiency standards which are specifically designed for low-income housing.

HEALTH MANAGEMENT PROJECTS

- The transformation of CP of NYS's Article 28 Diagnostic and Treatment Centers into Federally Qualified Health Centers (FQHCs) is nearly complete. The Board of Directors of Metro Community Health Centers is operating in accordance with the US Health Resource Services Administration (HRSA) compliance standards and the Health Centers have adopted HRSA-compliant Policies and Procedures. The FQHC is expected to be operational in 2015.
- A number of Affiliates are collaborating to develop a network of FQHCs across the State. The goal is to create a financially sustainable Health Center model which improves health services to patients with complex needs.
- Metro Services and five Affiliates are founding members of the Accountable Care Coalition of Greater New York, a Medicare Shared Savings Program of Accountable Care Organizations (ACO). ACCGNY is one of the nation's first ACOs to focus on the needs of adults with I/DD. ACCGNY is a partnership between Collaborative Health Systems, Queens County IPA and 12 developmental disabilities health services providers across New York.



AFFILIATE ACTIVITIES

ANNUAL CONFERENCE

More than 700 staff, volunteers, people with disabilities and members of their families gathered in Saratoga Springs October 2013 for the CP of NYS Annual Conference. More than 50 educational presentations and meetings were conducted at the Saratoga Hilton Hotel.

The Conference began with a Keynote presentation at the opening luncheon by Laurie Kelley, Acting Commissioner, NYS OPWDD, who offered her vision of the future of supports and services for people with disabilities in a climate of massive change and uncertainty.

Monday and Tuesday were filled with informative sessions. The Conference also included awards dinners honoring and highlighting the contributions and accomplishments of individuals and organizations from around the state.

The Conference concluded on Wednesday, October 23, with a session by sportscaster Jason Benetti. He used humor and personal anecdotes to convey his thoughts of how he uses his forum to change how his audience perceives people with disabilities.

The 54th CP of NYS Annual Conference will be held October 20-22, 2014 at the Hilton Albany Hotel.

CORPORATE COMPLIANCE CONFERENCE

The 7th Annual Corporate Compliance Conference, presented by CP of NYS and NYSARC, Inc., attracted more than 200 people from across New York State. The May 13 event included educational sessions presented by top professionals in the field.



GUARDIANSHIP PROJECT

The Cerebral Palsy Association Guardianship Corporation, which has been operated as a pilot project with the Center for Disability Services over the past four years, is now open and available to any CP of NYS Affiliate wishing to participate. The program provides options for decision making for disabled consumers unable to make life decisions for themselves and who have no active family or legal guardian.

POOLED SUPPLEMENTAL NEEDS TRUSTS BECOMING POPULAR

The CP of NYS “Community Trusts” (pooled supplemental needs trusts) are increasingly being used by people served by CP of NYS Affiliates. These trusts allow them to benefit from assets or income that would otherwise render them ineligible for government benefits. Trusts offer both them and their families significant opportunities for fiscal peace of mind as government policies on payment for disability services shift.

AFFILIATE ACTIVITIES

NYS ELKS ASSOCIATION

The New York State Elks Association continued its support for the CP of NYS Home Service Program. The Elks have contributed more than \$20 million dollars to support the program since its inception in 1964. Despite declining membership, the Elks again provided nearly \$500,000 to support Home Service Directors across the state. CP of NYS conducted two regional meeting of Home Service Directors and the Elks in April as well as an annual statewide meeting in October.



AFFILIATE ACTIVITIES

CP of NYS STATEWIDE COMMITTEES

- Assistive Technology
- Corporate Compliance
- Development/Public Relations
- Education/Early Intervention
- Emerging Leadership
- Employment/Vocational/Day Services
- Finance
- Guardianship
- Health & Clinical Services
- Human Resources
- Medical Directors Council
- Quality Assurance
- Residential Services
- Service Coordination
- Traumatic Brain Injury

TECHNICAL ASSISTANCE

CP of NYS provided technical assistance, information and direct assistance to Affiliates regarding program development, reimbursement and other critical issues including:

Rate Appeals (tuition, clinic, residential, day, SED, DOH, OPWDD) – Changes to Day Program – Residential Program Oversight and Development – Respite Programs – Medicaid Service Coordination – Implementation of Special OPWDD Initiatives – New State Provider Agreements for Early Intervention – Transition to State Fiscal Agent for Early Intervention Billing – New Regulations and Rate Methodologies – New DOH and CMS Guidelines for DME – Assistive Technology/Durable Medical Equipment – APG Billing Issues – Fiscal and Program Audits and Surveys – Office of Medicaid Inspector General Audits and Surveys – OMIG Effectiveness Reviews – Required Documentation and Training for “Medicaid in Education” – Preschool Re-Approval Process – New Applications and Regional Need Process for Expansion of SED Programs – Comptroller’s Audits of Preschool Programs – Implementation of Justice Center Requirements – Application for Corporate Practice Waivers – Approval of New and/or Expansion of Special Education Program Models – Re-Configuring SED Program Models to Eliminate the Need for 1:1 Aides – Article 16 MRT Cuts – Article 28 Certificate of Need – Health Homes and Care Coordination Initiatives – DSRIP and BIP Initiatives – Medicare “Improvement Standard” Settlement – Capital Recalculation Recoupment and Appeals

GOVERNMENT NETWORKING

Staff members from CP of NYS and its Affiliates represent the organization and its constituents on statewide advisory councils, task forces, committees, advisory groups, as well as at public hearings, including the following:

OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES (OPWDD)

Provider Associations
Employment Training Internship Program Advisory Council
Workforce Recruitment & Retention Work Group
Real Choice Grant Committee
Electronic ISP Subcommittee
Quality Indicators Subcommittee
Housing Subcommittee
Provider Efficiency Work Group
Fiscal Sustainability Design Team
People First Waiver Steering Committee
Medicaid Managed Care Advisory Council

DEPARTMENT OF HEALTH (DOH)

Early Intervention Coordinating Council (EICC)
EICC Executive Committee
EICC Developmental Group Task Force
Work Group on Early Intervention Standards for Children with Autism
Provided Testimony at Assembly Hearing on the Early Intervention State Fiscal Agent
DOH/OPWDD Clinical Services Provider Council
AHCF Cost Report Work Group

STATE EDUCATION DEPARTMENT (SED)

Special Education Financial Advisory Group
SED Preschool Rate Methodology Work Group
Attended Assembly Roundtable on School-Age Rate Methodology

GOVERNMENT RELATIONS

2014-2015 NEW YORK STATE BUDGET

The New York State Senate, Assembly and the Governor came to a final 2014-2015 state budget agreement and the Legislature passed an on time final budget. For the first time in four years, there were no new budget cuts and there were a number of highlights including:

- DSP and Clinical Salary and Benefit Increase – A targeted 2% wage and fringe benefit increase for Direct Support Professionals beginning on January 1, 2015 and an additional 2% beginning on April 1, 2015. Another 2% increase for clinicians will begin on April 1, 2015. These increases are permanent and include \$110 million built into the OPWDD voluntary program base going forward.
- Expansion of Nurse Practice Act Exemption – The prior exemption from the Nurse Practice Act for appropriately trained and certified direct care staff is extended to staff working in non-certified settings funded, authorized or approved by OPWDD. The tasks must be under supervision of a nurse and other appropriate safeguards are included.
- Integrated Employment Plan – Requiring the Commissioner of OPWDD to develop an “Integrated Employment Plan” in consultation with the Developmental Disabilities Advisory Council. The plan would outline individualized integrated employment



options to increase employment opportunities for people with developmental disabilities. The plan is to be developed with input from individuals with developmental disabilities, advocates, parents, guardians and providers.

- Tax Credit for Hiring Individuals with Developmental Disabilities – A new tax credit allows employers to get a credit of 15% of a person with a developmental disability’s salary for at least 30 hours per week and 10% of a person’s salary for as little as 8 hours per week.
- Credentialing Report – OPWDD is required to issue a report to the Governor, Senate and the Assembly, no later than January 1, 2016, making recommendations for the establishment of a Direct Support Professional (DSP) credentialing pilot program.

FAMILY ADVOCACY MONTH

In order to fend off further funding cuts, CP of NYS worked with five other advocacy groups to promote Family Advocacy Month from mid-February to mid-March. Families, staff and volunteers visited their legislators in their districts. This was effective since legislators in Albany respond well to family members’ concerns.

ALBANY LOBBY DAY

CP of NYS, NYSARC and The Alliance of Long Island Agencies held an Albany lobby day on March 3. Executive Directors and senior staff from each of the associations around the state came to Albany to meet with legislators, the Governor’s Office, Division of the Budget and key staff. There were meetings with Senate Majority Leader Dean Skelos, Assembly Ways and Means Chairman Herman Farrell, Deputy Secretary for the Governor Courtney Burke and others involved in the budget negotiations. It was a successful and productive day.

GOVERNMENT RELATIONS

TESTIMONY AT LEGISLATIVE FISCAL HEARING

CP of NYS presented testimony in January at the Joint Legislative Fiscal Hearing on Health and Medicaid. CP of NYS was the only association representing developmental disability providers to present testimony at the hearing. Testimony advanced our concern that the Department of Health, which now sets all rates for OPWDD programs and services, does not have staff who understand either the needs or supports and services of people with developmental disabilities.

We also stressed DOH was moving people into mandatory managed care without any understanding of the impact on people or any plan to pay for administrative costs. We made several proposals, including that a Clinical Advisory Council be established within DOH, comprised of clinicians and physicians with expertise in individuals with developmental disabilities, which was included in the final budget. The testimony asked legislators to ensure that people with developmental disabilities are not harmed and the success of the past is not reversed by continuing the cycle of annual cuts in funding.

STATEWIDE MEDIA COVERAGE

CP of NYS spearheaded and coordinated an advocacy campaign which included a coalition of seven regional and statewide associations of providers. This advocacy coalition worked together to enlist media outlets across the state to join with us in asking Governor Cuomo not to propose or support cuts to services for people with developmental disabilities.



Our coalition had success in securing newspaper placements and radio interviews regarding our request that Governor Cuomo not propose or support any additional cuts to funding for supports and services for people with developmental disabilities. There were editorials, op-ed pieces, radio interviews, letters to the editor, news pieces and other media placements.

Additionally, we started a petition, Honoring the Promise (<http://www.honoringthepromise.org/>) which asked the Governor not to propose or support cuts in funding. The petition had nearly 10,000 signatures reinforcing the message that New York cannot cut funding for its most vulnerable citizens.

SIGNIFICANT LEGISLATION

A number of bills important to people with disabilities and their families passed both Houses of the New York State Legislature and are awaiting Governor Cuomo's signature. CP of NYS supported and advocated for passage of the following bills:

1. OPWDD Services Under Managed Care – A.9766-A (Gunther)/S.7400-B (Carlucci) – CP of NYS wrote this bill and was instrumental in getting it passed in both Houses to ensure those entities that provide supports and services for individuals with developmental disabilities must be public or non-profit entities with experience providing those services under OPWDD regardless of the type of managed care entity, i.e., DISCO, MCO or MLTC program.

GOVERNMENT RELATIONS

2. Justice Center Interviews – S.7232-A (Carlucci)/A.9605-A (Gunther) – This bill requires the Justice Center establish protocols and procedures for evaluation of an individual with a disability/vulnerable person prior to an interview. It also requires the notification of personal representatives of an impending interview and notification to the individual with a disability/vulnerable person that a Justice Center interview is voluntary.
3. Front Door – S.6641-C(Carlucci)/A.8846-C(Weisenberg) – Requires the Commissioner of OPWDD develop a plan to overhaul and improve the front door process.
4. Updated Accessibility Signage – A.9934-A (Galef)/S.6846-A (Carlucci) - Replaces the outdated term “handicapped accessible” with “accessible” and change the icon symbol for all new signage for accessibility with a new international symbol of access.
5. Task Force on Adults with Developmental Disabilities – A.8835-A (Gunther)/S.6659-A (Carlucci) – Creates a Task Force on adults with developmental disabilities, charged with studying, evaluating and developing recommendations relating to specific actionable measures to support and meet the needs of adults with developmental disabilities. These include vocational, residential and social needs. The recommendations will comprise the basis for a comprehensive plan for meeting the needs of adults with developmental disabilities and will be submitted to the Governor and the Legislature on or before January 1, 2016.
6. People First Act of 2014 – A.8452 (Gunther)/S.1109-D (Maziarz) – Requires the Commissioner of OPWDD conduct a geographic analysis of the supports and services available in a community setting to people with developmental disabilities and to identify gaps in supports and services by region. The Commissioner is also directed to develop a web-based data base which will permit the prioritization of needs for those facing emergency or immediate need and planned need.

FINANCIAL REPORT

CEREBRAL PALSY ASSOCIATIONS OF NEW YORK STATE
STATEMENTS OF SUPPORT, REVENUE AND EXPENSES
FOR THE YEARS ENDED JUNE 30, 2013 AND 2014

(In Thousands)

	<u>6/30/14</u>	<u>6/30/13</u>
SUPPORT AND REVENUE		
Support from the public:		
Contributions		
NYS Elks Association Major Projects, Inc.	\$ 457	\$ 429
Total Support	<u>\$ 457</u>	<u>\$ 429</u>
Government Fees/Grants for Program Services:		
Medicaid Fees	\$ 108,803	\$ 108,758
Grants/Fees: Education, Training and Direct Consumer Services	<u>485</u>	<u>\$ 392</u>
Total Grants and Fees	<u>\$ 109,288</u>	<u>\$ 109,150</u>
Other:		
Affiliate Support	\$ 730	\$ 730
Other Revenues	<u>2,301</u>	<u>3,850</u>
Total Other	<u>\$ 3,031</u>	<u>\$ 4,850</u>
TOTAL SUPPORT AND REVENUE	<u>\$ 112,776</u>	<u>\$ 114,159</u>
EXPENSES		
Program Services		
Day Services	\$ 15,397	\$ 15,214
Residential Services	80,445	81,136
Clinic	7,286	7,736
NYS Elks Association Major Projects, Inc.	457	429
Affiliate Clinics	538	592
Affiliate Services and Conference	1,427	1,780
Transportation	<u>\$ 55</u>	<u>\$ 286</u>
Total Program Services	<u>\$ 105,605</u>	<u>\$ 107,173</u>
Administrative/Supporting Services	<u>\$ 7,135</u>	<u>\$ 6,806</u>
TOTAL EXPENSES	<u>\$ 112,740</u>	<u>\$ 113,979</u>
EXCESS (DEFICIENCY) OF SUPPORT AND REVENUE OVER EXPENSES	<u>\$ 36</u>	<u>\$ 180</u>

*Copies of complete audited financial statements are available upon request from
CP of NYS, 330 West 34th Street, New York, NY 10001

MISSION STATEMENT

The mission of Cerebral Palsy Associations of New York State is to advocate and provide direct services with and for individuals with cerebral palsy and other significant disabilities, and their families, throughout New York State in order to promote lifelong opportunities and choices for independence, inclusion and enhanced quality of life.

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