2018-2019
Annual Report

Cerebral Palsy Associations of New York State
Real people. Realizing potential.
A New Chapter Begins

Change was the operative word for CP of NYS this past year. On January 1, 2019 the old corporation was split into two distinct entities. What was known as Metro Services became a separate organization called Constructive Partnerships Unlimited (CP Unlimited). The former Affiliate Service Office retained the CP of NYS name but changed its website address to www.cpstate.org. CP of NYS emails now also end in cpstate.org. A great deal of time and effort on the part of the Board of Directors and staff was necessary to ensure a smooth transition, and that is exactly what happened.

CP Unlimited now has the focus and support of a Board of Directors made up of individuals from the communities it serves. CP of NYS has its own Board of people from across the state. The split was preceded by two years of study and planning to ensure that it did not adversely impact the delivery of services in New York City and maintained the continued support of our Affiliates around the state.

CP of NYS has also worked on creating partnerships and coalitions intended to allow our field to speak to government with one voice on issues critical to people with disabilities, their families and the provider organizations that support them. The Coalition Of Provider Associations (COPA) and its Political Action Committee DANY PAC, formerly known as COPA PAC, is well-known and highly respected by the Governor’s Office, key legislators and their staffs.

CP of NYS has secured a regional health improvement grant and a statewide telehealth grant that will help us expand supports and services to more individuals and families, and we will continue to focus on finding new sources of revenue to support our Affiliates as they fulfill their mission. We also continue to work with the New York State Elks Association to raise funds to support the CP of NYS Home Service Program as well as individual grants to support innovative programs at our Affiliates.

With the significant change in corporate structure, CP of NYS remains true to our mission in partnership with and in support of our affiliates.
WHO WE ARE

- 24 Affiliates
- 19,000 employees
- Serve over 100,000 people with disabilities and their families
- Operating budgets of over $1.126B

SERVICES & SUPPORTS

Residential Services:
- 105 of the State’s ICFs, 1,051 people
- 2,081 people in their certified IRAs
- 114 in support IRAs

Day Programs:
- Provide 800,000 units of day habilitation services

Health Services:
- 17 Article 28 clinics
- 14 Article 16 clinics
- 1 Article 31 clinic
- 3 FQHCs

REVENUE BY STATE AGENCY

- $791M – OPWDD
- $165M – SED
- $21M – OMH
- $158M – Other

Total: $1.135B
CP of NYS provides Affiliates with a broad array of supports and services through advocacy on behalf of all or most Affiliates on specific issues, as well as consultative assistance with issues specific to that Affiliate. We develop advocacy efforts to benefit Affiliates, ensuring that the funding and rules for programs and services meet the needs of the people Affiliates support. Our work includes educational programs and ongoing informational support through our statewide committees, which meet throughout the year.

**CP of NYS STATEWIDE COMMITTEES**

- Corporate Compliance/Quality Assurance
- Development/Public Relations
- Education/Early Intervention
- Emerging Leaders
- Employment/Vocational/Day Services
- Finance
- Guardianship

- Health & Clinical Services
- Human Resources
- Medical Directors’ Council
- Regulatory Reform/Streamlining
- 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:

2018 ANNUAL CONFERENCE
The 2018 CP of NYS Annual Conference saw more than 700 people from every corner of the state gather in Saratoga Springs October 15-17 for nearly 50 workshops, educational sessions, and meetings on issues important to people with disabilities, their families and the people and organizations that provide supports and services.

The conference officially began with a keynote presentation by Elaine Angelo at noon on October 15 before more than 300 people in the Saratoga City Center. Her presentation provided insight, results of research and also practical tips on the ever-changing environment of the multi-generational workplace.

The keynote session was followed by a presentation from Kerry Delaney, Acting Commissioner of the NYS Office for People With Developmental Disabilities (OPWDD). Acting Commissioner Delaney offered insight into plans for the future of supports and services for people with developmental disabilities in New York State.

Tuesday, October 16, began with a keynote presentation by former world-renowned fashion photographer Rick Guidotti. For years Mr. Guidotti took photographs of those that others considered the world’s most beautiful people. One day he saw a girl with albinism. She inspired him to begin a process of discovery – about people with differences and about himself. He enthralled the attendees with a story about his determination to transform perceptions of people living with genetic, physical and behavioral differences, both among the public and health care professionals.

Other Tuesday afternoon sessions included a presentation by fitness expert Eric Chessen on the importance of physical fitness to the well-being of people with autism, a special education update from the NYS Education Department and a two-hour training on civilian response to an active shooter event conducted by Ronald Messen, First Sergeant, Albany County Sheriff’s Office. Session attendees received practical information about what to expect during an incident, what to expect from law enforcement, and how to respond to law enforcement.

The 2018 CP of NYS Annual Conference was sponsored in part by the Irwin Siegel Agency; The Beacon Group; BDO USA, LLP; Focused Wealth Management and Total Care RX/Words Fair Pharmacy.

CORPORATE COMPLIANCE CONFERENCE
Quality & Compliance Challenges 2018, the 11th Annual Conference for Providers Serving People with Disabilities, was conducted in May for nearly 200 attendees from across the state.

The corporate compliance conference, presented each year by CP of NYS and The Arc NY, included speakers from NYS Office of the Attorney General, Medicaid Fraud Control Unit, the U.S. Department of Health and Human Services, Office for Civil Rights, Division of Quality Improvement, NYS OPWDD, and the law firm of Barclay Damon, LLP.

HUMAN RESOURCES CONFERENCE
Nearly 150 human resources professionals from agencies across the state attended the Coalition of Provider Associations (COPA) Human Resources Professionals Conference for the Disability Provider Community in Saratoga Springs April 30-May 1, 2019.

The third annual conference attracted HR professionals from agencies large and small from all areas of New York State.

Presentations included:
• Mary Ellen Donnelly, Partner at Putney Twombley, conducted the opening session on Overview of Trends in HR Law.
• OPWDD Staff discussed Self-Direction and General Recruitment Issues.
• A presentation from Elaine Angelo, Performance Consultant from ProKnowledge, LLC on Resume Review and Bias.
• Linda Clark, partner from Barclay Damon, discussed the impact of the Justice Center on Human Resources and Recruitment & Retention.
• The conference concluded with a panel discussion with Larry Davies (CP Nassau), Doreen Nelipowitz (AccessCNY), Anne Marie Clabough (AccessCNY) and Linda Clark to discuss how agencies are impacted by the Justice Center and discuss possible advocacy strategies.
ADVOCACY INITIATIVES
CP of NYS and our Affiliates continued to participate in the on-going #bFair2DirectCare initiative to convince the Governor and the Legislature to fund pay raises for direct care staff and other low-wage workers at non-profit provider agencies across the state. CP of NYS and Affiliate staff participated in news conferences and other advocacy events around the state in an effort to secure additional funding from New York State. The former #bFair2DirectCare coalition has decided to refocus our efforts and begin a new campaign to secure across the board funding increases for providers in the coming years. More on this subject can be found in the Government Relations section of this report.

CP of NYS TELEMEDICINE GRANT
CP of NYS received a $13M grant award from DOH through the Statewide Healthcare Facility Transformation Program to conduct a telemedicine triage project. The award is for a 5-year period from May 1, 2019 through April 30, 2024. The grant includes 54 agencies (15 CP Affiliates) with over 1,000 sites and 7,000 individuals.

GUARDIANSHIP PROJECT
The Cerebral Palsy Association Guardianship Corporation, which is operating in the Albany area with the Center for Disability Services, is open and available to any CP of NYS Affiliate wishing to participate. The program provides options for decision making for people with disabilities 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) offers a cost-efficient option for people served by CP of NYS Affiliates to place assets/income in their name while ensuring access to government benefits to which they are entitled. Trusts offer both individuals and their families significant opportunities for fiscal peace of mind as government policies on payment for disability services shift.

NYS ELKS ASSOCIATION
The New York State ELKS Major Projects Corporation continues its financial support for the CP of NYS Home Service Program at nearly $500,000 per year. The organization annually provides three $10,000 grants to help Affiliates purchase Home Service vehicles. Once again, smaller cash grants were awarded to help fund local programs and special projects at CP of NYS Affiliates from across the state.

CENTERS OF EXCELLENCE
OPWDD, in collaboration with SED and DOH, is working with CP of NYS to coordinate work activities across three Centers of Excellence (COE) in the care and treatment of children with ASD and other complex disabilities. A key goal of this new network of Children’s Residential Program (CRP) facilities is to improve the quality and efficiency of care as well as the network of support services. In partnership with NYS agencies, the Centers inform State policy development related to transitions, clinical needs and acuity development, best practices in care, value-based payment metrics, among other factors in the services and supports for people with complex needs.

Cheryl Smith, of HCA, receives a grant check from James Peace of the NYS ELKS Major Projects Corp.
Staff from CP of NYS and its Affiliates represent the organization and its constituents on statewide advisory councils, task forces, committees, advisory groups and public hearings, including the following:

**OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES (OPWDD)**
- Commissioner’s Transformation Panel
- Provider Associations
- Employment Training Internship Program Advisory Council
- Workforce Recruitment & Retention Work Group
- Heightened Scrutiny Work Group
- Quality Indicators Subcommittee
- Housing Subcommittee
- Provider Efficiency Work Group
- Regulatory Reform Work Group
- Medicaid Managed Care Advisory Council
- OPWDD Telemedicine Workgroup

**DEPARTMENT OF HEALTH (DOH)**
- DOH/OPWDD APG Workgroup
- Early Intervention Coordinating Council (EICC)
- EICC Executive Committee
- DOH/OPWDD Clinical Services Provider Council
- Consumer Directed Personal Assistance Program Workgroup
- Integrated Primary Care & Behavioral Health Workgroup
- Future of Integrated Care in New York State Stakeholder Group
- Service Authorization & Appeals Stakeholder Workgroup

**STATE EDUCATION DEPARTMENT (SED)**
- SED Work Group on Special Class in an Integrated Setting (SCIS)
- Preschool Special Education Advisory Group
- New York State Board of Regents Early Childhood Blue Ribbon Committee

(Above) Tom Sy, of Aspire of WNY, and Assemblymember Aileen Gunther at Lobby Day in Albany.
#bFair2DirectCare
Increased funding, for all OPWDD non-profits, to move toward a living wage and fiscal stability was the main priority for CP of NYS. CP of NYS had advocated for the #bFair2DirectCare living wage increase to be funded through the 2.9% Human Services COLA. We were disappointed that there was no COLA but appreciate that the Administration provided two more years of a 2% #bFair2DirectCare funding for DSPs and one year of a 2% #bFair2DirectCare funding increase for clinical staff.

The 2019-2020 New York State Budget included the following highlights:

**OPWDD**
- **Deferral of Human Services COLA** – $0 – We are extremely disappointed that the final budget did not include a COLA (2.9% this year) and defers it to 3-31-21.
- **#bFair2DirectCare** – The final budget included funding for a 2% increase, including salary and salary-related fringe benefits, effective 1-1-20, for 100 and 200 CFR codes and another 2% increase, effective 4-1-20, for 100, 200 and 300 codes. $8.4 million state share. Increases provided from 4-1-19 can be counted towards the 1-1-20 2% increase for 100 and 200 code employees.
- **Development** – ACCEPTS the Governor’s proposal for an additional $30 million state share this year for a fully annualized all shares $120 million (State and federal funding for a full year) in additional funding available for “Program Priorities,” including; certified housing supports in the community; independent living; day program and employment options and respite.
- **Housing** – ACCEPTS the Governor’s proposal for an additional $15 million in capital funds to develop affordable housing.
- **Managed Care Readiness** – ACCEPTS the Governor’s proposal for $5 million for the NY Alliance for Inclusion and Innovation “to improve provider readiness for managed care through the development of best practices, performance measurement and outcome monitoring tools.”
- **“More efficient use of state resources”** – ACCEPTS the Governor’s proposal for OPWDD to continue to work with DOH and CMS on efficiencies including to “reconcile” room and board financial support against actual room and board costs and a proposal to modify rate methodology to reduce administrative reimbursement to 15% in accordance with the cap in Executive Order 38, presumably on a program by program basis.
- **Integrated Outpatient Services** – ACCEPTS the Governor’s proposal to add Article 16s to the list of clinics that do not need an additional license to provide multiple services. Last year, Article 28, 31 and 32 clinics were granted joint licensure to provide any of those clinic services under their current license. Article 16 clinics are now included.
- **Minimum Wage Funding** – ACCEPTS the Governor’s proposal for $47.4 million state funding (for a total of approximately $94.8 million with the federal funds included).

**DOH**
- **Early Intervention** – ACCEPTS the Governor’s proposal to provide a 5% rate increase for Early Intervention PTs, OTs and SLPs. The Legislature did not expand the 5% increase to all EI providers as COPA had advocated, and the 5% increase is not extended to services provided by PT and OT Assistants. Additionally, the “covered lives pool” language did not make it into the final budget.
- **Consumer Directed Personal Assistance Program (CDPAP) Program/Fiscal Intermediary (FI) Changes** – MODIFIES the Governor’s language to require FIs to submit a contract application to DOH within 90 days of it’s posting on the DOH website. Eligible applicants include, but are not limited to, FIs established prior to 2012 and continually providing services, and independent living centers. Additionally, the DOH Commissioner shall establish a stakeholder workgroup, no later than May 15, 2019, to address fiscal intermediary services, the needs of consumers including transition plans and criteria for selecting FIs. FI reimbursement will move to a per member/per month methodology with three corridors. Unfortunately, the CDPAP Workgroup was not allowed to discuss reimbursement and DOH set PM/PM rates that will force most every
FIs to close. A number of associations and FIs have sued New York State and await the court’s decision on whether DOH can move forward.

- **Health Facility Transformation Fund Phase IV** – ACCEPTS the Governor’s proposal to use $300 million, of the $525 million in new Phase III funding, that was included in the 2018-2019 budget, to fund Phase II applicants that did not receive a grant. These Phase II applicants will be rescored and those who will be awarded a grant, from the $300 million, will be notified by May 1, 2019 – this was amended to September 1, 2019 at the end of session. There will be a new RFP for the remaining $225 million from Phase III with no new funding in the 2019-2020 budget proposal for Phase IV.

- **Applied Behavioral Analysis (ABA)** – ACCEPTS the Governor’s proposal for Medicaid coverage of ABA for over 4,000 children with Autism Spectrum Disorders, including those who have aged out of the Early Intervention program. $6.4 million for 2019-20.

**OMH**

- **Human Services COLA** – $0 and defers the COLA (2.9% this year) to 3-31-21.

- **#bFair2DirectCare** – The final budget included funding for a 2% increase, effective 1-1-20, for 100 and 200 CFR codes and another 2% increase, effective 4-1-20, for 100, 200 and 300 codes. $1.2 million state share.

- **Mental Health Education in Schools** – ACCEPTS $1.5 million in the SED budget to prevent bullying, trauma, suicide, etc.

- **Supportive Housing and SROs Rate Increase** – ACCEPTS the Governor’s $10 million increase.

- **Supports for High-Need Individuals** – ACCEPTS the Governor’s $10 million for those residing in adult homes with specialized supports such as peer support and in-reach.

- **Community Reinvestment** – ACCEPTS funding for community services expansion derived from the closure of additional state hospital beds of $5.5 million/$11 million fully annualized.

- **Funds for Community Based Nonprofit Housing Providers** – ACCEPTS $60 million addition

- **Behavioral Health Parity** – Budget includes several million dollars to enhance staff at the Department of Financial Services and the Department of Health to help assure health plans have adequate provider networks and are in compliance with parity requirements dedicated to network adequacy and reviewing existing health plans to help ensure compliance with parity. Some of the specifics are: assures 28 days of SUD services and 14 days of inpatient psychiatric services for youth without the barriers associated with prior or concurrent insurer and health plan approval; assures access to prescribed medications for treatment of substance use related conditions without prior insurer and health plan approval; assures that the clinical review criteria used by utilization review agents must be approved by OMH and OASAS; requires insurers and health plans to post additional information regarding their in-network providers of MH/SU services

**OTHER**

- **STATE AND MUNICIPAL FACILITIES PROGRAM (SAM)** – The final Capital budget was not negotiated by the April 1st deadline and did not include new SAM funds which will be distributed by Senators, Assemblymembers and the Governor. However, the end of session bills included a Capital budget with $385 million in new/additional SAM funding but the appropriation language does not include “non-profits” this year. It does continue to include our 853 schools. We have received clarification from the Division of Budget that non-profits can apply for the $385 million in SAM grant funding in 2019-2020 budget that included nonprofits. CP of NYS urges all Affiliates to request SAM funding from your Senator and/or Assemblymember.

- **4410 & 853 SPECIAL EDUCATION** – CP of NYS and our COPA partners continued to work with the Legislature, the State Education Department (SED), the Division of Budget (DOB), the Governor’s office and the Legislature to highlight the 4410 and 853 staffing crisis with our 4410 and 853 advocacy campaign called “Our Kids Are Your Kids” to enhance reimbursement, recruitment and retention funding for teachers, clinicians, paraprofessionals and other school staff.
The Division of Budget has approved the 2019-2020 tuition methodology for 4410, 853 and Special Act Schools. The methodology includes:

- 3.6% growth for school-age programs
- 2% growth for 4410 preschool programs
- No new funding for Excessive Teacher Turnover Prevention (funding remains at $8 million). We were particularly disappointed that the Administration did not add any new funding to begin to address the staffing crisis.

**SIGNIFICANT LEGISLATION**

With the November 2018 defeat of the Senate Republicans and the emergence of a strong and unified Senate Democratic Majority to partner with the Assembly Democratic Majority, 2019 was lauded as one of the most progressive sessions in New York history. A number of high profile items were passed by both Houses in the first year of one-party rule in New York including: fundamental changes to the Election Law and the Campaign Finance Law; decriminalization (not legalization) of marijuana and vacating some prior marijuana-related convictions; the “Green Light” bill to allow undocumented immigrants to get driver’s licenses; allowing undocumented New Yorkers to receive TAP college benefits (The Dream Act); strengthening of state sexual harassment laws, extension and expansion of rent regulations; an increase in labor rights for farm workers; a sweeping measure to combat climate change; eliminating the religious exemption from the requirement that school children be vaccinated; strengthening the State’s gun control laws and an extension of the minority-and-women-owned business enterprises law to 2024, among others.

With the focus on the “progressive agenda,” there were not as many bills that passed this year that impact individuals with disabilities, families and staff. On the positive side, not one of the bills that was opposed by CP of NYS and our COPA colleagues passed this session.

The following are the bills of interest to CP of NYS which passed both Houses:

**SUPPORT**

- **OLAS 4410** – CP of NYS requested this legislation, at the suggestion of an Affiliate, which authorizes boards of cooperative educational services (BOCES) to enter into contracts with 4410 preschool special education providers to use their online recruitment tool.
- **ABLE Act Expansion** — This Office of the State Comptroller bill increases the maximum account balance for the New York ABLE program in accordance with the NY state college choice tuition savings program.
- **Repeal of Vaccine Exemption for Religious Beliefs** – Repeals subdivision 9 of section 2164 of the public health law relating to exemption from the vaccination of school children due to religious beliefs. Signed by the Governor on 6-3-19. Chapter 35 of the Laws of 2019.
- **Small Business Tax Credit** – S.5545 (Addabbo)/A.7475 (Cusick) – Establishes a small business tax credit for hiring individuals with disabilities.
- **Complex Rehabilitation Technology (CRT)** – Codifies the existing process to qualify for CRT, ensures that appropriately diagnosed patients have access to CRT and that suppliers meet stringent requirements to protect quality and access to services and repairs. Requires Medicaid billing codes be updated to conform with Medicare.
- **Changes OMRDD to OPWDD** – Amends numerous sections of law to change OMRDD to OPWDD.
- **Non-MedicalSwitching Bill** – Prohibits health plans from making prescription drug formulary changes during a contract year except to add generics and a few other exceptions.
- **Rare Disease Advisory Council** – Establishes a Rare Disease Advisory Council consisting of 21 appointed members. The role of the Council would be to advise and consult on policy matters related to rare diseases. The Council would meet at least three times annually.
- **Printed Material for College Students with Disabilities** – Extends the program that provides instructional materials for college students with disabilities for three more years.
- **OPWDD Front Door Process Awareness** – Requires the Commissioner of OPWDD to publish, on their website, information regarding the process for obtaining eligibility for services and access to services, including but not limited to, residential, respite, employment, habilitation, and self-directed services.
The Coalition of Provider Associations (COPA) continued to grow in influence in its third year. COPA has become visible and recognizable by State legislators and Agency personnel, as well as the Governor’s staff as a respected and united voice for people with disabilities and the organizations that provide critical supports and services.

COPA representatives meet frequently with policy makers at all levels of state government and have also provided testimony at legislative hearings.

COPA members were very visible and key to several important campaigns including:

- Participating in the ongoing statewide #bFair2DirectCare campaign to provide a living wage for direct support professionals.
- Initiated the “Our Kids Are Your Kids” campaign to provide sufficient funding for 853 and 4410 schools.
- Participated in several advocacy campaigns to protect Medicaid funding.
- Provided weekly conference calls to update members on both New York State and Federal activities and advocacy regarding issues of importance to people with disabilities and the COPA members.

**COPA Legislative Briefing Calls**

In order to keep all CP of NYS Affiliates, staff and COPA members up to date, the COPA Legislative Team provide Legislative Briefing Calls. These COPA Legislative Briefing Calls are every Monday at 11 a.m. during session and monthly for non-session months (July through December). We encourage everyone to join us on these calls for an update on state and federal issues of interest to people with disabilities, families and staff.

Barbara Crosier, Vice President, Government Relations for CP of NYS, was the recipient of the fifteenth annual Legislative Disabilities Awareness Day “Dr. Henry Viscardi, Jr.” Advocacy Award. The award honor’s Dr. Viscardi’s “lifelong commitment to advocacy on behalf of people with disabilities.” Ms. Crosier was selected to receive the award because of the tremendous work she has done to further Dr. Viscardi’s work on behalf of New Yorkers with disabilities.
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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