

Cerebral Palsy Associations
of New York State



**2004-2005
Annual Report**

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.

Cover Art Courtesy Of

Robert Markowitz, Lloyd Rainford, Jeffrey Johnson, Hillel Will, Carmen Ramos,
Reginald Caldwell, Darlene Graves, Debra Freese & Linda Speed
CP of NYS – Metro Services

BOARD OF DIRECTORS

2004-2006

President	James E. Johansen
Executive Vice President	Idajeane Windell, Ed.D.
Vice President for Finance	Robert C. Miller, Esq.
Vice President for Legislation	Jack M. Weinstein, Esq.
Vice President for Program Services	Ann B. LeMark
Vice President for Volunteer Services	Barbara N. Scherr
Secretary	Cora Baliff
Directors at Large	Ellis I. Barowsky, Ph.D. Thomas J. Caserta, Jr., Esq. Nancy Corelli John Ferrari Megan Henry John R. Horvath Marvin S. Reed Ernest Southworth Beatrice S. Wellens
Active Past Presidents	Robert M. DiFrancesco Anthony J. Koenig Natalie K. Rogers

Executive Staff

Executive Director	Susan Constantino
Associate Executive Director	Duane Schielke
Associate Executive Director	Michael Alvaro
Vice President of Finance	Thomas Mandelkow
General Counsel	Steven Mosenson, Esq.
Assistant to the Executive Director	Heidi McManus

Cerebral Palsy Associations of New York State and its 22 Affiliates provide services to over 65,000 individuals with disabilities and their families. CP of NYS advocates on behalf of the Affiliates and the people we serve to ensure that high quality, cost efficient services are available in the most appropriate setting.

The past year marks our first with a new Executive Director and CP of NYS has made this transition in leadership with the Board of Directors' full support. Under this new leadership, the organization's three-year Operational Plan has continued successfully with Year II goals completed and reported to the Board.

CP of NYS's strong advocacy efforts have helped to ensure that services for people with disabilities are available when needed. New York State's Options for People Through Services (OPTS) program, funded through the NYS Office of Mental Retardation and Developmental Disabilities, has continued to develop over the past year. With assistance from our Affiliate Services staff, many Affiliates have submitted creative proposals to better target the individual needs and desires of the people they serve.

In addition, our advocacy efforts included the development of a proposal to streamline the cumbersome State Education Department tuition reimbursement system that will assist our Affiliates' school programs. CP of NYS has been the leader in voicing concern for the contradictory rules and regulations in the Article 28 clinic system through which medical and therapeutic services are provided to people with disabilities. This concern brought about the creation of the OMRDD/DOH Provider Council, which will work on all of the critical issues around the clinics.

New York State's budget difficulties continue to pose a threat to the services we provide, particularly as Medicaid spending is scrutinized. This year we were successful in our campaign to put a face on Medicaid, to tell the stories of the individuals who rely on Medicaid for their long term care or for needed equipment. Disability Service Providers of America (DSPA) represents our concerns in Washington, DC, ensuring that the needs of people with disabilities are considered when new federal cut-backs or mandates are under discussion. Federal Medicaid is again under attack and DSPA provides us with the leadership needed to target our efforts.



All our advocacy efforts have been made to ensure that our Affiliates might continue their work as leaders in the provision of programs, services and assistance to people with disabilities. The Affiliates throughout New York State work day in and day out to fulfill our collective mission of promoting lifelong opportunities and choices for independence, inclusion and enhanced quality of life for people with disabilities. They do it with an enthusiasm and ingenuity that is truly remarkable. We are honored that together, we are all a part of the CP family.

We look forward to the challenges of the year ahead, to working with our Affiliates on new innovative services for people with disabilities and their families and to building a stronger and even more effective organization.

James E. Johansen
President

Susan Constantino
Executive Director

LEGISLATIVE

The 2005 New York State Legislative Session produced the first on-time state budget in twenty years with its adoption on March 31, 2005. All the CP of NYS budget priorities were included in the Legislature's budget and signed into law by the Governor on April 12, 2005. These priorities included:



- **Article 28 Capital Rate Appeal Language** – Advocated for by CP of NYS.
- **Medicaid Restorations** – The Medicaid cuts, including podiatry, were restored.
- **Durable Medical Equipment** – The language restoring the Medicare/Medicaid crossover payment for two months was included.
- **Special Education Teacher Shortage** – The Governor's proposal for \$2 million for teacher recruitment and retention was approved. Additionally, the Governor's proposal to use \$13 million in uncommitted IDEA funds for teacher certification initiatives was approved.
- **OMRDD Budget** – The Governor's OMRDD (Office of Mental Retardation and Developmental Disabilities) budget proposal, including the trends and health insurance adjustment, was approved.
- **Health Care Decisions Act for Article 17-A Guardians of Individuals with Developmental Disabilities** – This authorizes Article 17-A guardians of individuals with developmental disabilities to make health care decisions for whom they are a guardian.
- **Legislation to Conform to Federal IDEA** – This amends the state education law to comply with amended provisions of IDEA.
- **Distribution of Federal 611/619 Funding** – This mitigates the unequal distribution of 611/619 funds for preschool children with disabilities.
- **IEP Extender** – Extends the authority of Article 28 clinics, which are also a 4410 provider, to bill Medicaid for the Individual Educa-

With the budget passed on time, the Legislature also passed all the CP of NYS legislative priorities which the Governor signed into law. These priorities included:

A C T I V I T I E S

tion Plan (IEP) services of the preschool children they serve.

- **PTA Extender** – Extends the authority of a physical therapist assistant (PTA) to provide therapy services for primary, secondary and preschool children with disabilities.
- **Oversight Committee for Children Placed in Out-of-State Programs and Facilities** – Establishes an out-of-state placement committee to provide oversight, control and accountability concerning the financing and quality of care that children placed out-of-state receive. This committee will also promote in-state placements of these children.
- **Surrogate Decision Making Program** – Extends the authority of the surrogate decision making committee to make decisions for an individual when they are moved to a nursing home.

CP of NYS once again held an Albany Lobby Day on March 1, 2005. The CP of NYS 2005 Legislative and Budget Priorities were discussed with legislators and there was a particular emphasis on the problems of access-

ing Durable Medical Equipment (DME). Each packet given to legislators and staff included the CP of NYS priorities and vignettes from individuals around the state who rely on DME and how important it is for them. CP of NYS strongly advocated for the establishment of a DME Workgroup within the Health Department and for legislative hearings to address the problems of accessing DME equipment. As the result of this advocacy, the Health Department established the workgroup in June 2005 and the Assembly held hearings over the summer.

Additionally, the March 1, 2005 edition of the “Legislative Gazette” weekly newspaper included the CP of NYS insert. This year’s insert theme was “**Medicaid Works.**” The insert had stories and vignettes from various Affiliates highlighting how “Medicaid Works,” including vignettes on the importance of DME for individuals with disabilities.



GOVERNMENT NETWORKING

Cerebral Palsy Associations of New York State continues to increase staff participation on state-wide Advisory Councils and Task Forces in an effort to ensure that the needs and desires of people with disabilities and their families are represented before changes in policy and service designs are made. Staff members from CP of NYS and Affiliates across the state represent the organization and its constituents on an increased number of committees and advisory groups including:

OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES (OMRDD)

- ◆ Medicaid Service Coordination Task Force
- ◆ Commissioner's Advisory Council
- ◆ New York State CARES Advisory Council
- ◆ Home & Community Based Services (HCBS) Waiver Units of Service Task Force
- ◆ Provider Council
- ◆ Provider Council Clinical Services Subcommittee
- ◆ Voluntary Agency HIPAA Work Group
- ◆ OPTS Steering Committee on Work Groups

STATE EDUCATION DEPARTMENT (SED)

- ◆ Preschool Special Education Longitudinal Study Advisory Group
- ◆ Vocational and Educational Services for Individuals with Disabilities (VESID) Supported Employment Stakeholders Group
- ◆ NYS Rehabilitation Council

NYS COMMISSION ON QUALITY OF CARE AND ADVOCACY FOR PERSONS WITH DISABILITIES

- ◆ TRAIID Interagency Partnership for Assistive Technology Advisory Board

DEPARTMENT OF HEALTH (DOH)

- ◆ Early Intervention Coordinating Council (EICC)
- ◆ EICC Task Force on Evaluation and Eligibility Determinations
- ◆ Early Intervention Outcomes Advisory Group
- ◆ Durable Medical Equipment Work Group

OTHER STATEWIDE ACTIVITIES

- ◆ CP of NYS submitted a proposal to DOH and was awarded funding to develop new statewide training curricula for the Early Intervention Program. This project will begin in late 2005.

STATEWIDE COMMITTEES

CP OF NYS STATEWIDE COMMITTEES

- Assistive Technology
- Health & Clinical Services
- Development/Public Relations
- Education
- Employment/Vocational
- Finance
- Medical Directors Council
- Residential and Day Services
- Traumatic Brain Injury
- Guardianship
- Managing Multiple Sites
- Quality Assurance



WORKGROUPS

- HIPAA
- Medicare Part D
- Rate Setting

A F F I L I A T E

The State Association works collaboratively with Affiliates in many ways to create, or enhance, opportunities for people with disabilities to reach their full potential and to deliver services more efficiently to consumers and their families.



ANNUAL CONFERENCE

Consumers and their families, volunteers and staff from 22 Affiliates across the state attended the 44th Cerebral Palsy Associations of New York State Annual Conference in Albany October 25-27, 2004.

Workshops and meetings dealing with issues critical to people with disabilities presented information on recreation, assistive technology, advocacy and grassroots lobbying and much more. The sessions and workshops were conducted by health care professionals, doctors, attorneys, consumers and other highly respected and nationally known speakers.

The Conference began with a Keynote Address by Geri Jewell, an actress and comedienne who used humorous anecdotes and personal experiences to present some alternative views on the

daily challenges faced by people with disabilities. She had the audience laughing and thinking about ways to create opportunities when faced with challenges.

TUITION RATES

Collaborated with Affiliate representatives and other advocacy groups on a proposal that would improve the methodology for setting education program tuition rates.

HIPAA

Four committees were organized in 2002 to deal with the effect of the HIPAA regulations (Steering Committee; Privacy Committee; Transaction, Code Sets and Identifiers Committee; and Security Committee). Having completed the tasks assigned for the Privacy and the Transaction, Code Sets and Identifiers Committee, these committees are currently inactive. The Security Committee is still active and met in 2005 to discuss the development of policies and to discuss the best way to help Affiliates reach compliance.

A C T I V I T I E S

TECHNICAL ASSISTANCE

- ◆ Served as liaison with SED for approval of new or modified school programs.
- ◆ Provided technical assistance to Affiliates regarding Early Intervention, Preschool & School-Age Special Education, Supported Employment, Assistive Technology and Traumatic Brain Injury issues.
- ◆ Provided technical assistance to Affiliates regarding OMRDD program development and reimbursement issues.
- ◆ Provided technical assistance and advice to Affiliates regarding DOH Fiscal and Regulatory issues.
- ◆ Assisted Affiliates with matters related to tuition rates and fees for education programs.
- ◆ Five Affiliates conducted a cooperative hole-in-one golf event that attracted almost 400 participants.
- ◆ Affiliate Services staff was instrumental in assisting Affiliates with several million dollars in appeals, waiver and other funds from SED, DOH and OMRDD.

NYS ELKS ASSOCIATION AND THE HOME SERVICE PROGRAM

The CP of NYS Home Service Program is a collaborative effort of the New York State Elks Association and Cerebral Palsy Associations of New York State. CP of NYS Affiliates provide direct services to adults and children with disabilities and their families in their home communities through a network of 27 Home Service Directors, serving all 62 counties in the state. Through its Major Projects Campaign, the Elks Association raised more than \$500,000 last year to support the Home Service Program across the state. In the past 40 years, this extraordinary organization has raised nearly \$20 million to support the Home Service Program. The Elks Association also helped fund new Home Service vehicles for four Affiliates this past year.



METROPOLITAN

Metropolitan Services of CP of NYS is one of the largest organizations of its kind in New York City. In addition to comprehensive health care services, CP of NYS offers a wide range of programs and services designed to support individuals with disabilities in leading more independent and productive lives. These include community living services, adult day programs, vocational services, traumatic brain injury services, summer camp and vacations, service coordination and family support services.

COMMUNITY LIVING SERVICES

- Three hundred and eighteen individuals live in seventy-two residences certified as Individual Residential Alternatives (IRAs) and one hundred and twenty-four individuals live in twelve residences certified as Intermediate Care Facilities (ICFs). Included in these are four ICFs and one IRA, serving sixty-four consumers that provide around the clock, on-site nursing service.

DAY AND VOCATIONAL SERVICES

- Metro Services' Day Programs provide services to 345 consumers. The programs feature inclusionary programs which are integrally involved in their immediate communities, such as volunteering at various community programs and participating in community restoration and gardening projects.
- Vocational services were provided exclusively in community-based settings. A total of 56 individuals were enrolled in VESID-sponsored services (35 Intensive Services and 21 Extended Services); twenty-six individuals in OMRDD Extended Services; 10 individuals in OMRDD Day Habilitation; and 2 individuals were served with OMRDD HCBS Residential Habilitation. Seven individuals were successfully "rehabilitated" and 9 individuals were employed under the VESID contract which also provides opportunities for individuals with TBI. Forty individuals were gainfully employed by year-end.

HEALTH CARE CENTERS (Diagnostic & Treatment Centers)

- Metropolitan Services of CP of NYS specializes in a wide range of primary and specialty health, medical, and rehabilitative services for people with disabilities. Our physicians specialize in meeting the health care needs of people with developmental disabilities in a comfortable and caring atmosphere. The Health Care Centers' services continue to steadily increase. This year, 52,556 visits were provided, an increase of 9.3% compared to last year.

JENED RECREATION VILLAGE

- Camp Jened served 994 guests in ten residential camping sessions during the summer of 2004.
- Eighty-five guests enjoyed Travel Camp vacations in Washington, DC; Atlantic City, NJ; Cape Cod; The Catskills; Claws & Paws Wild Animal Park, PA; Six Flags, NJ; Mystic, CT; Hershey Park, PA; Saratoga Springs, NY; New York City, NY (Opera Night); Allegany State Park, NY; and Las Vegas, NV.

SERVICE COORDINATION

- Metro Services provided Medicaid Service Coordination (MSC) to 328 individuals over the past year. Two hundred seventy individuals live in IRAs operated by CP of NYS and 58 individuals live with their families or on their own or with other agencies.

S E R V I C E S

TRAUMATIC BRAIN INJURY SERVICES

- Forty-four individuals with Traumatic Brain Injuries receive service coordination; 15 individuals are currently enrolled in the Structured Day Program that will be expanded to 5 days per week in October 2005; and Independent Living Skills Trainers are currently providing one-to-one assistance and training to 34 repatriated individuals living in "Supported Community Living" arrangements. Services are provided through the DOH Medicaid Waiver Program.

STAFF DEVELOPMENT AND RECRUITMENT

- In 2005, CUNY's School of Professional Studies, in collaboration with the John F. Kennedy, Jr. Institute for Worker Education, introduced a new graduate certificate program in Disability Studies. Professionals from Metro Services are enrolled in the program, which is designed specifically for staff currently working with people with developmental disabilities.
- International recruiting has been necessary to allow CP of NYS to maintain adequate staff. These efforts have faced increasingly restrictive visa application processing.

COMMUNITY AFFAIRS

- The Volunteer Services Program has recruited and trained 150 volunteers for day programs, residences, health care centers and Metro Services offices. Affiliations have been established with schools and job training programs including Goodwill/Pride 2000, Abilities, Inc., Girl Scouts of Greater New York, Youth Action Programs and Homes, New York School of Urban Ministry, NYC Technical College, Roberts Business School and the SUNY/BEOC, ASA Institute.



NEW PROGRAM DEVELOPMENT

- Sites are being identified in the Bronx to relocate the Jerome Belson Center, which houses Day Programs, Health Care Centers and the Bronx Community Living Program offices. The new location will provide state of the art, accessible facilities, convenient to public transportation.
- Two apartments in a large building complex in Manhattan were opened in November 2004, allowing the relocation of consumers previously living elsewhere. These residences serve "aged out" young adult males referred to the NYC Agency for Children's Services. The multi-floor structure of the "brownstone" building created a physical layout impractical for effective supervision, so downsizing the facility into two apartments provided a more manageable and home-like environment for the consumers.
- A new residence was developed in Brooklyn to house five individuals with multiple disabilities. The new facility is barrier free and located on the first floor to provide easy access. The new home was opened in June 2004 and all of the consumers were moved in by July 2005.
- The relocation of the Queens Health Care Center occurred in January 2005, to 59th Street, a facility co-located with Cerebral Palsy Transport, approximately 8.5 miles from the current location at the Queens Centers for Progress facility on 164th Street. The site offers barrier free easy access and a private parking lot.

PROFILE

CP of f NYS' Metro Services staff provides a wide range of direct services designed to address the individual needs of consumers. We operate many residences and conduct programs for consumers throughout New York City. In June of 2005, three new consumers, Joe, Jonathan and Benjamin, came to CP of NYS with the opening of a new five bedroom, wheel chair accessible residence in Brooklyn. Two other residents, Reggie and Tony, came from another CP of NYS residence and joined the three newcomers in the new residence.

Joe has used a wheel chair to get around since an accident 10 years ago. He came to the new residence from a second-floor apartment which limited his ability to get out and be active in the community. Since moving into his new home, he has lost weight, can move short distances without his wheel chair and loves to get out in the community and talk with his neighbors.

Jonathan came to the Brooklyn residence from his foster home. He also uses a wheel chair to get out into the community and has made several friends in the neighborhood. He enjoys having his own room, doing his daily chores, playing computer games and cooking in his wheel chair accessible kitchen.

Benjamin relocated to the Brooklyn residence from his home, where he had lived with his brother and sister-in-law. Ben also uses a wheel chair to move about the community. He loves his new home, but also likes to get out into the neighborhood, meet people and shop. He especially loves to shop for movies, music and video games. He also enjoys his role as "big brother" to his four housemates.

Reggie and Tony have fit right in with their new housemates and are very happy with their new home with individual bedrooms, cable television and a beautiful community to explore and enjoy.

The new Brooklyn residence is just one example of how Metro Services helps to create opportunities for people with disabilities to participate more fully in their communities.

FINANCIAL REPORT

CEREBRAL PALSY ASSOCIATIONS OF NEW YORK STATE STATEMENTS OF SUPPORT, REVENUE AND EXPENSES FOR THE YEARS ENDED JUNE 30, 2005 AND 2004

	<u>6/30/05</u>	<u>6/30/04</u>
SUPPORT AND REVENUE		
Support from public:		
Contributions		
NYS Elks Association Major Projects, Inc.	\$ 424	\$ 424
Total Support	<u>\$ 424</u>	<u>\$ 424</u>
Government Fees/Grants for Program Services:		
Medicaid Fees	\$ 85,829	\$ 81,857
Grants/Fees: Education, Training and Direct Consumer Services	<u>670</u>	<u>\$ 989</u>
Total Grants and Fees	<u>\$ 86,499</u>	<u>\$ 82,846</u>
Other:		
Camp Fees	\$ 1,257	\$ 1,204
Affiliate Support	490	457
Other Revenues	<u>396</u>	<u>401</u>
Total Other	<u>\$ 2,143</u>	<u>\$ 2,062</u>
TOTAL SUPPORT AND REVENUE	<u>\$ 89,066</u>	<u>\$ 85,332</u>
EXPENSES		
Program Services		
Day Services	\$ 9,973	\$ 9,319
Residential Services	64,351	61,597
Clinic	5,098	5,030
NYS Elks Association Major Projects, Inc.	424	424
Affiliate Clinics	694	1,009
Affiliate Services and Conference	923	882
Transportation	<u>\$ 178</u>	<u>\$ 290</u>
Total Program Services	<u>\$ 81,641</u>	<u>\$ 78,551</u>
Administrative/Supporting Services	<u>\$ 6,791</u>	<u>\$ 5,451</u>
TOTAL EXPENSES	<u>\$ 88,432</u>	<u>\$ 84,002</u>
EXCESS (DEFICIENCY) OF SUPPORT AND REVENUE OVER EXPENSES	<u>\$ 634</u>	<u>\$ 1,330</u>

* Copies of complete financial statements and auditor's report are available upon request from Cerebral Palsy Associations of New York State, 330 West 34th Street, New York, NY 10001.

CEREBRAL PALSY ASSOCIATIONS OF NYS

330 West 34th Street, New York, NY 10001

(212) 947-5770 ■ Fax (212) 594-4538

90 State Street, Suite 929, Albany, NY 12207

(518) 436-0178 ■ Fax (518) 436-8619

www.cpodnys.org