Cerebral Palsy Associations of New York State

2005 - 2006 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.

Many of the pictures in this publication were taken by CP of NYS Metro Services consumers, using a digital camera. Currently, they are using two cameras, a standard Canon digital camera and for those who require it, a paddle switch adaptive camera. This adaptive camera was purchased from Ablenet and is connected to an articulated metal arm which mounts to the person’s lapboard.

Instruction is provided to Photo Club members on how to use the camera, letting them know that they must ask permission before taking someone’s picture, and how to be observant for interesting things to photograph.

Some of our adaptive photographers need assistance in positioning their wheelchair and focusing on what they want to shoot. Ultimately, during the picture taking process, it is the Photo Club member who presses the shutter to make the picture.

Photo Club Members took the following photos: Cover – P. Emproto; Back Cover – E. Perez; “Bridge” Photo – E. Monsanto

Elva Monsanto uses a camera attached to an articulated arm and red adaptive switch enabling her to activate the camera's shutter.
2004 - 2006

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At the height of the woman’s movement, there was a popular advertising slogan that claimed “You’ve come a long way, baby!”

As part of a civil rights movement that grew out of family members coming together to find services for their loved ones with cerebral palsy and other significant disabilities, Cerebral Palsy Associations of New York State has matured, as has our entire society, over the past sixty years. This year marks the sixtieth anniversary of the founding of CP of NYS and we’re proud of all that the entire CP family, including its Affiliates, volunteers, staff and program participants, have accomplished in assisting and enabling people with disabilities to thrive in a fulfilling life.

When our founding families first got together, there were few government or private supports, such as day or clinical services, education or Early Intervention, small community residences or any of the programs that now form the backbone of our complex system of services. The founders of CP of NYS were a group of pioneers who joined a nationwide movement, seizing an opportunity to establish services to meet the needs of their family members with disabilities. CP of NYS and the Affiliates rose to accept the challenges presented by this movement, to develop and offer services that would allow people with disabilities to remain vibrant participants in all aspects of our society. While the early years presented many obstacles for the CP of NYS family to overcome, together we have successfully met those challenges and creatively forged a path that has led us to where we are today. At the back of this annual report is a short history of that struggle and those accomplishments of which we are so proud.

As we look to the future, CP of NYS and the 24 Affiliates are assured of a strong foundation reflected in our statement of common values and principles that we have all endorsed and which have led us to where we are today, including respect for individual dignity, the importance of community inclusion and family support, and commitment to proactive advocacy, continuous improvement and responsible citizenship. However, even with that sound footing for all the CP of NYS family, a reflection on the most recent year of our activities and the environment in which we work gives us both reason for hope and cause for concern.

Much of that hope lies in our efforts to build upon our strength and our success. We have accomplished the goals outlined in our operational plan, and have identified new goals and objectives for CP of NYS and our Affiliates. Our advocacy efforts in Albany and Washington have been particularly effective in protecting existing programs and obtaining needed changes to ensure that people with disabilities continue to receive the services and programs they need. Further, our technical support and direct assistance to our Affiliates has become increasingly important to their successful operation as they wind their way through a myriad of regulations, inter-agency confusion, and an ever complex world.

Cerebral Palsy Associations of New York State
Typical of the activities that have built our reputation for effective advocacy for both providers of services and people with disabilities is our leadership in Albany in the fight for people seeking to obtain needed durable medical equipment (DME), initiating a series of legislative hearings on the topic and prompting legislators to call for drastic improvements in the DME approval process. Similarly, we continued to advocate strongly for fair and appropriate funding for school, health, and residential programs that benefit people with disabilities statewide. In Washington, we work with Disability Service Providers of America (DSPA) to advocate on Medicaid reforms at the highest levels of government, thereby ensuring a voice for providers of services for people with disabilities as cuts to the funding system are debated.

The uncertainty surrounding the change in State government administration this year is both a source of hope as well as a cause for apprehension, as we are increasingly concerned that misinformation and misunderstanding about our programs could erode community and governmental support. Proposed Medicaid cuts remain a key area for us to monitor, as do the threats to funding for the school, residential, clinic and other programs run by our Affiliates. The challenge for us in the coming years is to continue our work to ensure adequate governmental and public support for our essential programs and services, to enable community inclusion and acceptance of people with disabilities as valued members of our society. Together, we must work to ensure that our governmental representatives and community members reaffirm their commitment to inclusion and participation by all. Inspired by our founders and the obstacles they overcame, we are resolved to meet these challenges.

Looking back on our beginnings, we most certainly have made huge strides toward a world where society embraces people with disabilities, both as valued and ultimately, simply as community members. However, it is our hope for the future – and the difference that we can make in peoples’ lives – that truly drives us forward. It is our commitment to embrace that challenge, to not lose sight of the movement that has gotten us to this point, to rekindle the fires that moved so many people to want to make a difference. It is only by rejuvenating that passion and renewing our commitment to overcoming those challenges, that will enable all of us to say in another sixty years – “we have come a long way, baby!”
The 2006 New York State Legislative Session produced the second “on-time” state budget in twenty years with both Houses of the Legislature passing their budgets on March 31, 2006. Although the Governor vetoed parts of the budget, these items were negotiated and included in budget “clean-up” bills that were signed by the Governor in June. Most of CP of NYS’ budget priorities were included in the Legislature’s budget and signed into law by the Governor on April 12, 2006. These priorities included:

- **OMRDD Budget** – The Governor’s Office of Mental Retardation and Developmental Disabilities (OMRDD) budget proposal, including the trends, a COLA for non-trended programs and health insurance adjustment, was approved.

- **Medicaid Restorations** – The Medicaid cuts were restored including an extension of the Medicaid “wrap-around” for Medicare Part D to January 1, 2007.

- **Special Education** – Private Excess Cost Aid was restored and the Legislature rejected the proposal to shift the cost of preschool education evaluations to school districts.

- **Special Education Teacher Shortage** – The Governor’s proposals for $2 million for teacher recruitment and retention and $13 million in uncommitted IDEA funds for teacher certification initiatives were approved.

- **Camp Jened** – The Governor approved a Legislative grant for health and safety improvements at Camp Jened.
With the budget passed on time, the Legislature also passed many bills of interest to CP of NYS. Governor Pataki signed several of these bills into law but vetoed the majority of bills. The following are some of the bills of interest.

**BILLS SIGNED BY THE GOVERNOR**

- **Medicaid Inspector General** – This new law establishes the office of the Medicaid Inspector General. The new law includes the CP of NYS revised advisory opinion language, which only authorizes prospective recoupment and requires that any changes be based on regulation or statute.

- **FBI Criminal History Check** – This law requires OMRDD to do a national/FBI criminal history check in addition to the state Division of Criminal Justice Services (DCJS) criminal history check for all prospective not-for-profit OMRDD agency workers.

- **Legislation to Conform to Federal Individuals with Disabilities Education Act (IDEA)** – This law extends the New York State statute which is required to be in compliance with the federal IDEA.

- **Crisis Intervention Standards** – This new law establishes a restraint and crisis intervention technique committee and coordinated inter-agency standards for all agencies on the use of crisis interventions (including a definition of aversives) for children.

**BILLS VETOED BY THE GOVERNOR**

- **Burden of Proof** – This proposal would have maintained the burden of proof with the school district in all impartial due process special education hearings.

- **SED Methodology** – This bill would have required the implementation of a three-year rate setting methodology and authorized private 853 and 4410 schools for children with disabilities, and special act school districts to maintain a 2% fund balance.
**Legislative Activities**

- **Cash and Counseling** – This legislation would have created the self-directed personal assistance services program. It authorized the Health Commissioner to establish a Cash and Counseling program, allowing them to modify the Medicaid State Plan pursuant to the federal Deficit Reduction Act of 2005.

- **Medicaid Exempt Trusts for People with Disabilities** – This bill would have clarified the exempt status of people with disabilities’ income that is deposited to certain Medicaid-acceptable trusts.

CP of NYS once again held an Albany Lobby Day on March 7, 2006. The CP of NYS 2006 Legislative and Budget Priorities were discussed with legislators and there was a particular emphasis on the importance and successes of Medicaid. Additionally, the March 6, 2006 edition of the “Legislative Gazette” weekly newspaper included the CP of NYS insert. This year’s insert theme was how important Medicaid is in providing people with disabilities opportunities that others take for granted. The insert had stories and vignettes from various Affiliates highlighting these opportunities.
In order to ensure that the needs and desires of people with disabilities and the interests of our 24 Affiliates are represented before policies and regulations are changed or enacted, CP or NYS participates on statewide Advisory Councils and Task Forces. Staff members from CP of NYS and its Affiliates represent the organization and its constituents on various committees and advisory groups, as well as at public hearings, including the following:

**OFFICE OF MENTAL RETARATION 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
- OPTS Steering Committee and Work Groups

**STATE EDUCATION DEPARTMENT (SED)**
- Preschool Special Education Longitudinal Study Advisory Group
- NYS Rehabilitation Council
- CRP Planning Group
- VESID Supported Employment

**NYS COMMISSION OF QUALITY OF CARE AND ADVOCACY FOR PERSONS WITH DISABILITIES**
- TRAID Interagency Partnership for Assistive Technology Advisory Board

**DEPARTMENT OF HEALTH (DOH)**
- Early Intervention Coordinating Council (EICC)
- EICC Task Force on Provider Approval (Chairperson)
- Durable Medical Equipment (DME) Work Group
- Provided Testimony at the Legislative Hearings on Access to Medicaid Funded DME
- DOH/OMRDD Clinical Services Provider Council

**DEVELOPMENTAL DISABILITIES PLANNING COUNCIL (DDPC)**
- DDPC Assistive Technology Work Group

**OTHER STATEWIDE ACTIVITIES**
Development of new statewide training curricula for the NYS Early Intervention Program via competitive grant funds from the NYS Department of Health. The five-year project began in January 2006.
The State Association works collaboratively with Affiliates to promote lifelong opportunities for people with disabilities and to deliver programs and services more efficiently to consumers and their families.

**ANNUAL CONFERENCE**

The 45th CP of NYS Annual Conference brought nearly 900 people from across the state to Albany on October 24-26, to exchange ideas and view new technologies affecting the lives of people with disabilities. The 2005 conference, entitled “Teamwork – The Key to Success,” included nearly 50 sessions and meetings dealing with a wide range of issues. Representatives from state agencies also addressed conference attendees on new initiatives. John J. Pelizza, Ph.D., an authority on wellness, change process, productivity, team building and personal growth, delivered a high-energy keynote address that set the tone for the entire conference.

Artwork submitted by consumers from across the State for the second annual *Visions of New York* Consumer Art Contest was also on display during the event.

Eleven individuals and organizations were honored for their accomplishments or for service to people with disabilities at the CP of NYS Annual Awards Banquet on Monday, October 24. A special video produced by CP of NYS commemorating our unique 40-year relationship with the New York State Elks Association was also shown at the dinner. The next night nearly 60 employees were honored for outstanding service at the *Celebrate Staff* awards dinner.

**CP OF NYS AND AFFILIATES ASSIST HURRICANE VICTIMS**

CP of NYS and its Affiliates across the State collected supplies and money to assist people with disabilities in areas affected by Hurricanes Katrina and Rita. Enough Durable Medical Equipment (DME) to fill a 50-foot truck was sent to United Cerebral Palsy of Middle Tennessee in Nashville to be distributed to people along the Gulf Coast. A truck donated by the Teamsters Union Local 294 in Albany was loaded at the CP of NYS Koicheff Health Care Center in Staten Island. Our Affiliates in Rochester, Niagara Falls, Syracuse, Chemung, Albany, Nassau and Ulster also collected equipment and supplies needed by people with disabilities in the affected region. The truck, which was arranged through the efforts of the Center for Disability Services in Albany, also made pickups in Albany and Syracuse before going on to Nashville. Drive Medical Design and Manufacturing donated more than 100 wheelchairs to the effort.

New York University, Columbia University, Dominican College, the New York City Board of Education, as well as equipment vendors and other private donors, also donated DME for the relief effort. Continental Airlines donated free air freight to fly some of the equipment to Baton Rouge for distribution by agencies in the region.

CP of NYS, its Affiliates, their staff and volunteers also donated thousands of dollars to help both workers and people with disabilities served by UCP agencies in the Gulf Coast. The Board of Directors of CP of NYS authorized a gift to create the cash fund to benefit people who lost their jobs and their homes in the hurricanes.
TECHNICAL ASSISTANCE

- Provided information, technical support and/or direct assistance to Affiliates regarding Early Intervention, Preschool & School Age Special Education, Assistive Technology and Traumatic Brain Injury issues.

- Provided assistance with SED regarding approval of new special education program models.

- 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.

NYS ELKS ASSOCIATION AND THE HOME SERVICE PROGRAM

More than 40 years ago, CP of NYS asked the New York State Elks Association (NYSEA) to help fund a desperately needed program to provide services to individuals with disabilities in their homes, and the Home Service Program was adopted as an Elks Major Project.

Since that time, the program has grown and expanded into every county of New York State with 27 Home Service Directors serving thousands of individuals with disabilities and their families. The Elks continue to be active partners in the funding of the Home Service Program, raising more than $20 million in contributions to the program. The NYSEA continues to contribute nearly $500,000 each year to support the Home Service Program.

The relationship between CP of NYS and the NYS Elks Association goes beyond the Elks’ financial support. Local Elks Lodges and individual members work with Home Service Directors, and other staff and volunteers from CP of NYS and its Affiliates, to increase opportunities for people with disabilities to become more active members of their communities. People with disabilities participate in many Elks events each year and Elks members serve as volunteers with local Affiliates and as members of the Boards of Directors of CP of NYS and its Affiliates.

In addition, the NYS Elks Association provides grants to four Affiliates each year to assist with the purchase of Home Service vehicles for those organizations.
**CP of NYS Statewide Committees**

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

**Workgroups**

- Corporate Compliance
- HIPAA
- Managing Multiple Sites
- Medicare Part D
Janina Jansen has been dubbed a “distinguished artist” by her friends and colleagues. She has lived in a CP of NYS Metro Services apartment on Rockaway Parkway in the Carnarsie section of Brooklyn since 1979. Ms. Jansen’s speciality is India ink paint. She spends hours during the evening painting pictures using magazines as a model.

She also will paint both objects and people within her environment and loves when she can find a willing “live model!” She has a keen eye for capturing detail and her paintings currently adorn the walls of many apartments, houses and offices throughout the borough of Brooklyn. She also works in photography and is a member of several photography groups.

Throughout the years, Ms. Jansen has participated in various art groups which is where she perfected her craft. In the future, she hopes to pursue individual art lessons with a local artist or art student to continue to develop her artistic talent.
Metropolitan Services of 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 comprehensive health care services, 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 twenty one individuals live in 72 residences certified as Individual Residential Alternatives (IRAs) and 124 individuals live in 12 residences certified as Intermediate Care Facilities (ICFs). Included in these are four ICFs and one IRA, serving 64 consumers that provide around the clock, on-site nursing service.

DAY AND VOCATIONAL SERVICES

- Metro Services’ Day Programs provide services to 353 consumers. The programs feature inclusionary programs which are integrally involved in their immediate communities, providing volunteer opportunities at various community programs and participation in community restoration and gardening projects.

- Vocational services were provided exclusively in community-based settings. A total of 57 individuals were enrolled in VESID-sponsored services (33 Intensive Services and 24 Extended Services); 26 individuals in OMRDD Extended Services; 19 individuals in OMRDD Day Habilitation; and two individuals were served with OMRDD HCBS Residential Habilitation. Eleven individuals met the VESID mandated criteria for having been successfully “rehabilitated” and 13 individuals were employed under the VESID contract which also provides opportunities for individuals with TBI. Forty-two 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 continue to seek increased opportunities to provide services. This year, 52,363 visits were provided.
CAMP JENED

- Camp Jened served 1,080 guests in ten residential camping sessions during the summer of 2005.


SERVICE COORDINATION

- Metro Services provided Medicaid Service Coordination (MSC) to 328 individuals over the past year. A total of 270 individuals live in IRAs operated by CP of NYS and 58 individuals live with their families or on their own or with other agencies.

TRAUMATIC BRAIN INJURY SERVICES

- Forty-eight individuals with Traumatic Brain Injuries receive service coordination; 13 individuals are currently enrolled in the Structured Day Program that was expanded to five days per week in October 2005; and Independent Living Skills Trainers are currently providing one-to-one assistance and training to 91 repatriated individuals living in “Supported Community Living” arrangements. Services are provided through the DOH Medicaid Waiver Program.

STAFF DEVELOPMENT AND RECRUITMENT

- CUNY’s School of Professional Studies, in collaboration with the John F. Kennedy, Jr. Institute for Worker Education, continues to offer a Graduate Certificate in Disability Studies designed for direct support professionals who already have a bachelor’s degree. Professionals from Metro Services are presently enrolled in the program. The JFK, Jr. Institute is applying for additional funds including tuition assistance from the NYS DOH to expand the program. Metro Services, as a collaborative partner, submitted a letter of support to assist in obtaining additional funding.
COMMUNITY AFFAIRS

■ Again this year, volunteers and interns have been an integral part of the clinics and the Community Living Services (CLS) programs. In all of the clinics, some volunteers provide clerical support. Others, who come from Medical Assistant training programs, assist more directly with patient care. In the CLS programs, interns are assisting the consumers in meeting their community inclusion goals. Volunteers and interns also play an essential role in preparation for the annual art show.

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.
CEREBRAL PALSY ASSOCIATIONS OF NEW YORK STATE

STATEMENTS OF SUPPORT, REVENUE AND EXPENSES

FOR THE YEARS ENDED JUNE 30, 2006 AND 2005

(In Thousands)

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<td>SUPPORT AND REVENUE</td>
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<td>NYS Elks Association Major Projects, Inc.</td>
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<td>Total Support</td>
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<td><strong>TOTAL SUPPORT AND REVENUE</strong></td>
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EXPENSES

| Program Services   |         |         |
| Day Services       | $10,497 | $9,973  |
| Residential Services | 67,470  | 64,351  |
| Clinic             | 5,266   | 5,098   |
| NYS Elks Association Major Projects, Inc. | 424 | 424 |
| Affiliate Clinics  | 715     | 694     |
| Affiliate Services and Conference | 926 | 923 |
| Transportation     | $315    | $178    |
| **Total Program Services** | **$85,613** | **$81,641** |
| Administrative/Supporting Services | $6,662 | $6,791 |
| **TOTAL EXPENSES** | **$92,275** | **$88,432** |
| **EXCESS (DEFICIENCY) OF SUPPORT AND REVENUE OVER EXPENSES** | **$3,429** | **$634** |

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

Annual Report
Cerebral Palsy Associations of New York State (CP of NYS) was founded in 1946 by parents of children with cerebral palsy, who sought critically needed services from government, and envisioned the organization to be their voice and their advocate. From these early beginnings to the present day, CP of NYS has served this role. Under the leadership of family members and together with its Affiliates, CP of NYS constitutes a network of service providers and advocates for individuals with disabilities across New York State, focusing on both the state and national levels.

Many of the CP of NYS Affiliates also began as advocacy groups for families seeking services. Over time, groups from several regions of New York State banded together for the common purpose of collective advocacy. In the mid-1970s, with the closing of developmental centers such as Willowbrook and deinstitutionalization of individuals with developmental disabilities, voluntary agencies such as CP of NYS and the Affiliates also began providing direct services to these individuals. CP of NYS itself has become a significant provider of such services in New York City, and its Metropolitan Services is considered an Affiliate of the state organization.

Today, the service delivery system in New York has matured into a complex array of service providers and services supported by government programs such as Medicaid. The twenty-four CP of NYS Affiliates provide a wide range of those services, including residential, clinic, day services, employment, transportation, early intervention, mental health and educational services to thousands of New Yorkers with disabilities. Each Affiliate operates in its own territory, ensuring a collaborative, non-competitive relationship with the other Affiliates. The Affiliates are significant economic forces in their communities, and many are among the largest employers in their regions.

In addition to their role as service providers, the Affiliates also maintain their historical commitment to advocate for expansion and preservation of the rights of people with disabilities and their families, and they work in partnership with their respective constituencies, including service recipients, families, employees and others in their communities toward achieving these goals. Affiliates and the people they represent have collectively recognized the ethical
principles upon which they operate, including respect for individual dignity, the importance of community inclusion and family support, and commitment to proactive advocacy, continuous improvement and responsible citizenship.

Despite their growth, all 24 Affiliates have maintained their core identities, focusing on the individual needs of the persons and families they serve. All are separately incorporated not-for-profit, tax-exempt corporations, with family members continuing to provide the core leadership on their governing boards, and professional, highly trained and highly qualified staff providing services. Each has voluntarily affiliated with CP of NYS for mutual support, advocacy and advancement of services to individuals with disabilities. The Affiliates as organizations fulfill their collective purposes through a commitment to each other that is rooted in a mutual respect and appreciation for the diversity and uniqueness of each Affiliate. The Affiliates commit to each other in honoring their shared goals, values, and leadership, and recognize their interdependence and the synergy created by their affiliation. These principles serve the Affiliates as the foundation for their working relationship and as a guide to shared decision making.

The Affiliates, as voluntary members of CP of NYS, provide direction to the state organization through election of their own board members to serve on the CP of NYS statewide board, which, by its own bylaws, must be controlled by representatives of Affiliate boards. Additionally, regular meetings are convened with executive and senior management so that common issues are identified and resolved. CP of NYS provides a wide range of technical support and direct assistance to Affiliates in their role as members of the service delivery system, enhancing their ability to provide programs and services to the people they serve. In this role, CP of NYS not only advocates for its Affiliates, but for all people with disabilities, including those not served by Affiliates. CP of NYS has itself become a recognized expert in service delivery systems for people with disabilities, and is regularly called upon by government for advice and comment on proposals to improve those systems and to enhance the rights and services for individuals with disabilities.