IMPROVING LIVES, PROTECTING RIGHTS

ADVOCACY FOR ALL NEW YORKERS WITH DISABILITIES

NEW YORK STATE COMMISSION ON QUALITY OF CARE AND ADVOCACY FOR PERSONS WITH DISABILITIES

2004 – 2005 ACTIVITIES

FOREWORD

Article 45 of the New York State Mental Hygiene Law describes in great detail the duties of the Commission. Put simply, our mission is to improve lives, protect rights and advocate for needed change on behalf of New Yorkers with disabilities.

We are guided in that mission by the mandates of the Mental Hygiene Law as well as a strategic plan developed with the input of individuals who have a stake in the Commission's mission – our staff and Advisory Council, individuals with disabilities, their families, service providers and government officials.

More fundamentally, though, we are assisted in fulfilling our mission by a host of individuals, far outnumbering our 100 staff and numerous volunteers, who share in the Commission's mission – facility directors and their staffs who cooperate with our investigations and act on our suggestions and advice; individuals with disabilities and their families who routinely bring issues of concern to our attention; sister State agencies and other public bodies who invite the Commission's consultation in the development of disability-related policies; initiatives and programs; and the Governor and Legislature who support the Commission with funding and something even more important – the mandate to be an independent voice for New Yorkers with disabilities.

During this report period that mandate was strengthened.

Initially created in the 1970s to oversee New York's mental hygiene system, in 2005 the Commission on Quality of Care for the Mentally Disabled was merged with the State Office of Advocate for Persons with Disabilities, which typically assisted individuals with physical and sensory disabilities. The resulting single agency, the Commission on Quality of Care and Advocacy for Persons with Disabilities, drawing on the strengths of both former agencies, became a one-stop shop for individuals with any type of disability seeking assistance. While still carrying out oversight activities relating to the Office of Mental Health, the Office of Mental Retardation and Developmental Disabilities, and the Office of Alcoholism and Substance Abuse Services, the new Commission was able to capitalize on the strengths of the staffs of the two former agencies and, through administrative cost savings, enhance outreach and advocacy efforts for persons with all types of disabilities.

This report presents an accounting of the Commission's activities in 2004 and 2005 under the four major goals of its strategic plan:

- Maintaining Traditional Oversight Activities;
- Assisting Persons with Mental Disabilities Served Outside the Traditional Mental Hygiene System;
- Advocating for and Empowering Persons with Disabilities; and
- Promoting Excellence and Awareness of Commission Services.

It is dedicated, in gratitude, to our staff and volunteers, and to all those individuals too numerous to mention who assisted the Commission in advancing its mission.

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MAINTAINING TRADITIONAL OVERSIGHT ACTIVITIES

CASE ACTIVITIES

At the cornerstone of the mental hygiene system should be the individuals it was designed and built to serve. It is only natural that responding to individuals' complaints and concerns, investigating allegations and untoward events, and conducting program reviews form the heart of the Commission's oversight functions. Such activities:

- present opportunities to provide program operators, regulators and policy makers with unbiased assessments of the quality of services and suggestions for improvement, assessments and suggestions rooted in the experiences of service consumers;
- assure consumers, families, advocates and providers that concerns about care will receive a fair and objective review;
- deter further abuse, neglect and unscrupulous practices through the reporting of findings and the referral of individuals and programs for appropriate administrative or legal sanctions; and
- enable the Commission to keep tabs on the pulse of the system.

To achieve these ends, the Commission staffs a toll-free telephone line for people who have concerns about their care, or that of a loved one, or who are in need of assistance in navigating the system; reviews all allegations of abuse and deaths occurring within the system, conducting direct investigations into those where facility investigations seem lacking or the nature of the event warrants independent scrutiny; maintains investigative staff on-call 24 hours-a-day, seven days-a-week; and conducts hundreds of announced and unannounced site visits and program reviews each year.

In 2004 and 2005, the Commission responded to over 64,000 requests for assistance, reviewed over 25,000 deaths and allegations of abuse reported by mental hygiene facilities, and conducted nearly 2,500 program reviews and investigations into reported deaths and allegations of abuse. The Commission is assisted in its clinical investigations by the Mental Hygiene Medical Review Board, a panel of volunteer medical professionals appointed by the Governor.

Individual Case Activities
2004 – 2005

Toll-Free Calls for Assistance	64,795
Care and Treatment/Program Reviews	468
Child Abuse Investigations	560
Adult Abuse Reports Reviewed	19,025
Adult Abuse Reports Assigned for Further Action	814
Death Reports Reviewed	6,327
Death Reports Assigned for Further Action	626

EXAMPLES OF INDIVIDUAL CASE ACTIVITIES: 2004 – 2005

A Commission investigation sustained a complaint that a hospital did not secure treatment information from collateral sources (outpatient providers and family members) which would have had an impact on decisions regarding a patient's treatment and discharge even though consent to obtain such information was secured. It was also alleged that the patient was over-medicated. The allegation of over-medication was not sustained, but there were no written rationales for the medications or changes ordered. As a result, the hospital revised its procedures for securing collateral information in the treatment and discharge planning processes, and commenced an internal audit to ensure 100 percent compliance with its expectation that physicians' orders for medications are accompanied by written rationales.

A family's complaint prompted the Commission's review of the residential care and treatment of a young man who had a propensity for ingesting inedible objects. Over the last several years, he had engaged in this behavior more than a dozen times, with some of the incidents necessitating medical hospitalization. The review revealed that there were lapses in the individual's supervision, and that not all staff supervising him were aware of the requirements of his behavior management plan that were designed to prevent the dangerous behavior. Following the Commission's review, the agency adjusted the individual's supervision level and re-trained all assigned staff in his behavior management plan.

A Commission investigation into the death of a person with developmental disabilities indicated that he had received inappropriate care in a hospital emergency room prior to his transfer to the ICU, where he died despite having received appropriate care. The Commission requested that the hospital conduct an internal review. Upon review, the hospital concurred with the Commission's findings and provided additional training to the individuals involved. However, the hospital reported that the review brought to light a different problem as well. Initially, when the individual died, the hospital conducted a peer review; but that review focused only on the ICU where the patient died. As a result of the Commission's findings concerning the care in the ER, the facility indicated that it would modify its peer review process to ensure that the care of all services that worked with a patient is included in peer reviews.

In reviewing a family care home sponsored by a private agency, the Commission found that the family care provider did not ensure that the consumer she was responsible for made it to all medical appointments; nor did she inform the sponsoring agency of changes in the consumer's medical condition. The sponsoring agency terminated the provider's certification and revamped its protocols for monitoring family care homes and providers' compliance with consumers' medical and other service appointments.

WATCHING OVER THE CHILDREN

Watching over children receiving residential care in New York's mental hygiene system is an everyday activity for Commission staff. Under Social Services Law, allegations reported to the State Central Register's hotline for child abuse and maltreatment (1-800-342-3720) involving children in OMH or OMRDD residential facilities are routed to the Commission for investigation. On call 24 hours-a-day, seven days-a-week, Commission investigators respond to these reports within 24 hours to assure the safety of the children involved and to make a recommendation to the New York State Office of Children and Family Services (OCFS) as to whether the report is "indicated" – i.e., there is some credible evidence that abuse or maltreatment, as defined in Social Services Law, occurred – or "unfounded."

DEFINITIONS OF CHILD ABUSE AND MALTREATMENT

Social Services Law, Article 6, Title 6, defines an abused child in residential care as one whose custodian:

- inflicts or, with knowledge or deliberate indifference, allows to be inflicted any injury which causes death, serious or protracted disfigurement or protracted impairment of physical health, protracted impairment or loss of the function of any organ, or a serious emotional injury;
- creates a substantial risk of such injury; or
- commits, promotes, or knowingly permits the commission of a sex offense against such child.

A maltreated, or neglected, child in residential care is defined as one whose custodian:

- inflicts by act or omission, physical injury, excluding minor injury, by other than accidental means;
- creates a substantial risk of physical injury, excluding minor injury, by other than accidental means;
- intentionally administers any prescription drug other than in substantial compliance with the physician's prescription; or
- fails to comply with state regulations involving the care and treatment of children, resulting in foreseeable and serious emotional injury, or in physical injury, excluding minor injury.

In 2004 and 2005, the Commission conducted over 550 child abuse and maltreatment investigations. Most of the investigations (60 percent) pertained to allegations of physical abuse by staff, including the inappropriate use of, or excessive force during, restraint (13 percent). Allegations of lax supervision and staff negligence were the focus of 21 percent of the cases. Inappropriate sexual contact between staff and children or between children was alleged in 14 percent of the cases, with psychological

abuse or other forms of mistreatment constituting the remaining 5 percent of allegations investigated.

In 10 percent of the cases investigated, the care provided or the conduct of staff was found to be substandard, warranting recommendations and remedial action. In those cases where the level of harm, or risk of harm, to children met the Social Services Law definitions of abuse or maltreatment, the case was recommended for "indication," which has serious implications for the custodian's future work with children.

During the same period, pursuant to its authority under Mental Hygiene Law, the Commission conducted over 90 clinical or programmatic reviews in facilities serving children. These were often commenced in response to cases of alleged abuse which did not meet the strict definitions of child abuse under Social Services Law, but warranted closer scrutiny of supervision, behavior management or staffing issues. Recommendations to improve care were offered in two-thirds of the cases.

Children's Activities
2004-2005
Child Abuse Investigations: N=560 Cases

	Total Cases	Indicated Cases	Cases Resulting in Recommendations
OMH Operated Facilities	83	5	10
OMH Licensed Facilities	143	8	25
OMRDD Operated Facilities	70	5	3
OMRDD Licensed Facilities	264	7	17

Clinical/Programmatic Reviews: N=91 Cases

	Total Cases	Cases Resulting in Recommendations
OMH Operated Facilities	7	2
OMH Licensed Facilities	46	30
OMRDD Operated Facilities	10	8
OMRDD Licensed Facilities	30	21

EXAMPLES OF CHILDREN'S ACTIVITIES: 2004 – 2005

Commission investigations at two private psychiatric facilities where children engaged in sexual activities led to changes in the facilities' policies on assessing children's histories of sexual acting-out and routine and special observation procedures.

In response to a Commission investigation into a report that two children were lost while on outings (and subsequently found safe and sound), the agency revised it's policies on lines of supervision and accountability during off-campus trips.

When the Commission investigated why it took so long for a security guard to respond to an alarm for assistance at a children's treatment facility, it was learned that sometimes guards were assigned to the facility from an affiliated adult care facility nearby. The guards from the adult facility, however, did not receive training in the alarm systems of the children's facility. Consequently, the guard in this case could not tell the nature or location of the crisis when the alarm sounded; thus his response was delayed as he tried to make these determinations. All guards assigned to provide coverage in the children's facility have subsequently been trained.

A mother contacted the Commission on behalf of her 14-year-old son who is autistic and, because of behavioral difficulties, was brought by police to a hospital. The hospital had no psychiatric unit and he spent over 60 hours in the emergency room. The Commission's preliminary review indicated that the boy spent almost all that time in restraints, and the manner in which he was restrained and monitored suggested violations of Federal and the Joint Commission on Accreditation of Healthcare Organization's standards on restraint and seclusion in hospitals. The Commission referred the matter to the Department of Health which cited the hospital for numerous violations in the areas of restraint, medications, securing appropriate consultations, protecting patient rights and assuring their comfort.

RESIDENTIAL TREATMENT FACILITIES FOR CHILDREN

In addition to conducting individual investigations, during the report period the Commission commenced a broader review of children's issues by examining Residential Treatment Facilities (RTF), a care modality licensed by OMH to serve children and youth requiring out-of-home placement. The study will examine the needs of children being served, admission and discharge practices and the actual experiences of a sample of children, and their families, who were served by RTFs in 2004 and 2005.

ADDICTION TREATMENT CENTER REVIEW

In 2004, the Commission undertook a review of the 13 Addiction Treatment Centers (ATCs) operated by the State Office of Alcoholism and Substance Abuse Services (OASAS). The review was invited by the new OASAS Commissioner who was interested in an objective assessment of the consistency in services and conditions among the centers. The Commission's report, which detailed the findings of its unannounced visits, interviews with patients and staff, and reviews of selected policies, was offered as guidance to OASAS in its endeavors to promote best practices and consistency in its services. It is available on line at http://www.cqcapd.state.ny.us/OnlineReports/ATCReport.htm.

Among the major findings were:

- Overall, the ATCs offered clean, well-maintained, and comfortable treatment environments. During unannounced site visits, Commission staff found programming occurring as scheduled.

- Patients interviewed spoke highly of their care at the ATCs. When asked what they found most helpful in their treatment, the top three responses were: the staff, programming, and peer support.
- In reviewing events that could adversely impact on patient health and safety, the Commission found that most were duly reported and managed as incidents consistent with OASAS policies.
- The policies of individual facilities on topics including admission and discharge practices, incident management, psychiatric and medical emergencies, and patient rights were generally consistent. The Commission was very impressed with the patient handbooks given to patients at each ATC at the time of their admission, orienting them to the facility, the treatment process, their rights and responsibilities, and the grievance processes, should they have any concerns.
- There were areas in which OASAS could devote additional attention to ensure best practices and consistency in service across the ATC system:

  - Some ATCs were not accessible to individuals with physical disabilities. However, in every case, agreements existed to admit individuals with mobility impairments to another ATC that is fully accessible.
  - While programming was occurring as scheduled at all the ATCs, program offerings and intensity varied.
  - Although the vast majority of ATC staff felt safe, a small number of staff indicated that they did not feel safe within the ATCs, some citing the increasing number of patients with mental illness and/or behavioral difficulties.
  - There also appeared to be variations among the facilities on how they manage discharges against clinical advice (ACA), with some treating the event as an incident and examining the reasons why patients left, while others did not conduct such a review.
  - Finally, in each of the policy areas examined, better or best practices emerged at different ATCs which may be worthy of replication statewide. These items ranged from who should accompany patients to hospitals in psychiatric/medical emergencies to documentation practices surrounding discharge planning and follow up.

CONTINUING DAY TREATMENT PROGRAM REVIEW

In 2004, the Commission conducted a programmatic and fiscal review of OMH licensed Continuing Day Treatment (CDT) programs which are designed to provide a comprehensive array of services on a long term basis for persons with mental illness. In 2003, CDTs served over 20,000 individuals at a total annual cost of approximately $175 million.

As detailed in its report on line at http://www.cqcapd.state.ny.us/OnlineReports/CDTReport.htm, the Commission made the following findings:

- The quality of services provided varied widely, not only throughout the State but also within individual programs. Services ranged from those which were creative, individualized and beneficial to recipients to those which engaged recipients in meaningless activities providing little therapeutic value. Some programs even allowed recipients to wander halls or sleep throughout the day.
- The quality of treatment planning was poor in many of the programs visited. Quarterly revisions of treatment plans often demonstrated no meaningful consideration of treatment needs, but rather were rewordings of previous plans. Commonly, treatment plans failed to address significant life events that consumers were wrestling with, such as the death of a loved one, divorce, or the loss or regaining custody of a child.
- Fiscal accountability was lacking throughout the programs reviewed. The Commission examined 1,100 claims billed to Medicaid and found that a significant number of the claims reviewed did not have the proper documentation to support the billing to Medicaid.

In its response to the report, also available on line, OMH describes in detail its initiatives to address the programmatic issues described by the Commission. The Commission is continuing to work with OMH on addressing the fiscal accountability issues.

ECT REVIEW

In 2004, at the request of the Legislature, the Commission conducted a review of the status of implementation of the January 2003 OMH guidelines regarding the provision of electro-convulsive therapy (ECT) at State-operated facilities. The Commission conducted site and record reviews at the five State psychiatric centers which offer ECT. The Commission's overall finding was that the five centers were following the new OMH guidelines.

ASSISTING PERSONS WITH MENTAL DISABILITIES SERVED OUTSIDE THE TRADITIONAL MENTAL HYGIENE SYSTEM

During its strategic planning process, the Commission was urged to devote attention to two groups of individuals with mental disabilities being served outside the "traditional" mental hygiene system: those in adult homes certified by the Department of Health (DOH); and those within the criminal justice system.

MONITORING CONDITIONS IN ADULT HOMES

During the report period, the Commission conducted 33 comprehensive reviews of 28 adult homes serving over 2,200 people, most of whom have mental disabilities. Each review was conducted by a two- or three-person team, which made an unannounced visit. During the two-day reviews, through observations, record reviews, and staff and resident interviews, teams assessed:

- basic living conditions, including housekeeping, furnishings and maintenance;
- fire/safety and food service/nutritional issues;
- personal care and medication management;
- resident activities; and
- protection of resident rights.

Reports of findings, with recommendations or requests for plans of corrective action, were issued to the adult homes visited. Copies of the reports were also provided to DOH, which ensured that facilities responded to the Commission's findings.

An additional 94 visits were made to 22 homes serving over 1,500 individuals to follow up on complaints or problematic conditions found earlier, and, in the case of ten homes that were in the process of closing, to monitor conditions and ensure residents' rights were protected in the closure process.

ASSISTED LIVING PROGRAM REVIEW

In 2004, the Commission commenced a review of Assisted Living Programs in 13 adult homes which serve a significant number of individuals with mental disabilities. (The Commission's jurisdiction in adult homes is limited to those that are deemed "impacted" – i.e. ones in which at least 25 percent of the residents, or 25 residents, whichever is less, have a mental disability.)

The Assisted Living Program (ALP) was established in 1991 to provide a cost-effective alternative to individuals eligible for nursing home placement. It is essentially an "add-on" of services to supplement the residential care provided by an adult home or

enriched housing program. The additional services of an ALP include nursing, therapy and supplementary personal care. Such extra services are covered by a Medicaid rate that is set in law at 50 percent of the nursing home rate.

As detailed in its report, available on line at http://www.cqcapd.state.ny.us/OnlineReports/ALPReport.htm, the Commission made following findings:

- Medicaid payments for ALPs averaged $60 per day per resident, while the ALP program spending was about one-half that amount. The disparity between the funding and program cost was greatest at homes in New York City, where providers received higher rates, despite spending less than the rest of the State.
- In some instances, Medicaid payment levels appeared inflated due to unsupported level of need assessments that indicated residents needed substantial assistance with toileting.
- There were substantive disparities between level of need ratings and plans of care, and between plans of care and actual services provided.
- The annual financial reports filed with DOH by the homes did not contain adequate disclosures on related-party transactions, thus diminishing the usefulness of the report.

During the course of this study, the Commission worked with DOH to improve the financial reporting requirements.

In response to Commission findings, which focused only on impacted homes, which operate about 20 percent of the ALP beds statewide, DOH indicated that a broader study would be necessary in order to draw any conclusions concerning costs/ profitability. The Commission is cooperating with DOH in this review. The Department also described the steps it was taking to implement more accurate assessment instruments and to strengthen surveillance activities to assure the provision of appropriate services.

HEALTH CARE IN ADULT HOMES

A Commission study of health care in adult homes, commenced in 2004, focused on the health care needs and services provided to a sample of 69 residents living in 13 homes serving primarily individuals with mental disabilities. A report of the study, published on line at http://www.cqcapd.state.ny.us/HealthCare.htm describes the multiple and complex needs of these residents and the health services they received. The Commission made the following findings:

- In several major disease categories, the incidence rate of illness among the sample population exceeded that of the general population.
- Individuals in the sample were not as likely as the general population to receive common health care screenings – such as dental, vision, gynecological, etc.

- Hospital emergency room usage for the sample individuals was nearly three time the rate of that of the general population.
- The coordination of care (or documentation of such), among the various residential and health care providers involved in the lives of sample individuals seemed problematic.

In its response to the Commission's review (also posted on line), DOH described the steps it was taking or would take to strengthen the coordination and oversight of medical care for adult home residents.

ADULT HOME CLOSURE STUDY

Between 2002 and 2004, 17 adult homes, serving significant numbers of persons with mental disabilities, closed. In an effort to better understand what policies and practices relating to the closure process best promoted residents' interests and choices, particularly regarding alternative housing and support services, and whether the relocated individuals' current placements and services met their needs, the Commission commenced a closure study in 2005. Focusing, through record reviews and interviews, on the individual experiences and needs of residents displaced through the homes' closures, the study is intended to offer the Department of Health, which licenses adult homes, and the Office of Mental Health, which licenses clinical programs serving many adult home residents, feedback on what works well when individuals have to relocate and what can be improved in easing individuals' transition when an adult home closes.

PRIOR ADULT HOME WORK REVISITED

Prior Commission work in adult homes was revisited in 2004 and 2005 in the form of criminal, civil and administrative actions by various agencies.

- Seventeen residents of the former Leben Home for Adults were awarded over $7 million in settlement of a Federal lawsuit against the home's operator, two physicians and a local hospital. The residents were coerced into unnecessary surgery, an allegation investigated by the Commission which was tipped off by an anonymous caller. The plaintiffs were represented by law firms with which the Commission contracts and their *pro bono* partners. Trust funds have been established for the men, who were unable to consent to the procedures, to ensure proper accounting of the settlement funds on their behalf.

- Based, in large part, on Commission findings detailed in a 2001 report, ***Exploiting Not-For-Profit Care in an Adult Home: The Story Behind Ocean House Center, Inc.***, the facility operators pleaded guilty to criminal and civil charges in Federal and State courts relating to their theft of funds from the facility. One was sentenced to prison for one-to-three years; the second to three years probation. Additionally, they must pay over $3 million in restitution. The Commission assisted Federal and State prosecutors in the investigations which followed the 2001 report.

- Also related to its Ocean House investigation, First to Care, a home health care agency, admitted to State prosecutors that it had received approximately $400,000 in Medicaid overpayments between 1997 and 2004 as a result of irregular billing practices and questionable services. The agency agreed to make restitution and implement a corporate compliance program, a code of employee conduct and other measures. The Commission offered technical assistance to the State Attorney General's Office in its prosecution of the case.

- Difficulty in discerning the true costs of operating adult homes was illustrated in the Commission's 2002 report: **Adult Homes Serving Residents with Mental Illness: A Study on Layering of Services**. The Department of Health's cost reporting requirements did not capture true costs and profits of adult homes, often hidden in related party transaction – non-arms-length payments to, or purchases from, organizations related to the adult home by common ownership or control. Subsequent to its report, the Commission assisted DOH in developing a new cost reporting system which went into effect beginning with reports for 2004.

CRIMINAL JUSTICE MATTERS

While having no direct jurisdiction over the State's criminal justice system, during the report period the Commission sought other ways to promote appropriate services for individuals with mental disabilities who encounter that system.

The Commission provided funding, through the Division of Probation and Correctional Alternatives (DPCA), for a study to identify factors that either facilitate or inhibit the appropriate diversion of criminal justice detainees from incarceration to mental health services. The study, ***Clarifying the Parameters: A Survey of Programs in New York State for Mentally Ill Defenders and Offenders***, focused on seven programs developed across the State with grants provided by the DPCA and identified several critical elements of a model program for delivering community forensic mental health services. Information on the project is available on the DPCA website, http://www.DPCA.state.ny.us, under the topic "Shared Services for the Mentally Ill."

The Commission also provided a grant to the NYS Unified Court System, Office of Court Administration, to carry out training programs to increase the understanding of mental health issues on the part of judges who administer drug treatment courts. The two-phase project provided support for the Drug Court Association Annual Meeting which focused on mental health issues within the context of the drug courts, and for follow-up regional roundtables for judges on mental health issues pertinent to drug courts. Primary topics addressed included:

- understanding mental illness within the confines of the drug treatment courts;

- best practices for the integration of substance abuse treatment and mental health services, with an emphasis on coordination and collaboration among local agencies and the courts; and
- mental health issues among youth and young adults.

Finally, in cooperation with the NYS Bar Association, the Commission produced the nineteenth installment of the "Disability and the Law" videotape series. The 30 minute show – "A Third Way to Justice" – focuses on the Brooklyn Mental Health Court. More information about the series and the latest installment is available at: www.cqcapd.state.ny.us/advocacy/pavideo.htm.

ADVOCATING FOR AND EMPOWERING PEOPLE WITH DISABILITIES

The merger of the former Commission on Quality of Care for the Mentally Disabled and the State Office of Advocate for Persons with Disabilities enabled the new Commission to carry on, and bolster, the advocacy related activities of both organizations on behalf of all New Yorkers with disabilities.

SURROGATE DECISION-MAKING COMMITTEE PROGRAM

Accessing appropriate medical care in a timely fashion is a fundamental need of all people. But for some it is difficult, particularly when their capacity to consent is compromised and they have no legally authorized surrogate willing or able to consent on their behalf. Assisting these individuals is the goal of the Surrogate Decision-Making Committee (SDMC) program.

Historically, authorization for non-emergency medical care for people who lacked the capacity to consent for such, and had no legal guardian or surrogate decision-maker to do so, had to be secured from the courts. This involved a sometimes protracted process which could delay needed medical attention for weeks, if not months in some cases. The SDMC program was created as an alternative to the courts. Individuals residing in facilities certified or licensed by OMH or OMRDD who require medical care, but lack the capacity to consent to or refuse treatment, and have no legally authorized surrogate to act on their behalf, can have their cases determined by an SDMC panel.

The four-member volunteer panels – consisting of an attorney, medical professional, family member and advocate – review documentary evidence, interview the individual, receive testimony from care providers and make three determinations.

- Does the individual have the capacity to make this decision for himself/herself?
- If not, is there a legally authorized surrogate to make the decision on the person's behalf?
- If not, is the proposed medical intervention in the person's best interest?

Panel members are appointed and trained by the Commission. On average, the panels' determinations are issued within two weeks from the date of application for SDMC assistance. If requested, cases can be resolved on an expedited basis within a couple of days.

In 2004 and 2005, the SDMC Program assisted 3,614 individuals in need of medical procedures.

SDMC IN ACTION

On August 10, 2005, the Surrogate Decision-Making Committee program received a request for an expedited review of a case involving a man with mild mental retardation who was also blind and deaf. He had been diagnosed with a kidney tumor that was suspected to be cancerous and it was recommended that he undergo a laparoscopic examination with possible removal of the kidney to prevent spread of the disease and death. Within the next 24 hours, SDMC staff obtained additional information from the man's caretakers, a panel was convened and a hearing was held. Consent for the procedure was granted on August 11 and surgery was successfully performed.

MAINTAINING A STATEWIDE NETWORK OF ADVOCACY SERVICES

In New York City, a physician refused to treat a 22-year-old man with mental retardation. In the Hudson Valley Region, a school district failed to include needed services into a medically frail child's Individualized Education Plan. In Central New York, a man with degenerative bone disease was offered no reasonable accommodation and was terminated from employment, in violation of the Americans with Disabilities Act. In Western New York, a county refused to provide funding for adaptive equipment a physically disabled youngster required.

Miles apart and facing different challenges, these individuals had one thing in common in 2004 and 2005: the assistance of a statewide network of agencies administered and funded by the Commission. These agencies provide administrative and legal advocacy for individuals with disabilities.

Under Federal and State statutes, the Commission administers the following advocacy programs:

- Protection and Advocacy for Persons with Developmental Disabilities (PADD) program and the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program which, as their names imply, respectively serve people with developmental disabilities and mental illness;
- Client Assistance Program (CAP), which assists individuals with a wide variety of disabilities secure training and services leading to employment and independent living;
- Protection and Advocacy for Individual Rights (PAIR) program, which serves people with disabilities not covered by the Federally authorized PADD, PAIMI or CAP programs;
- Protection and Advocacy for Assistive Technology (PAAT) program, which aids individuals with disabilities who require assistive devices (e.g., wheelchairs, special communication equipment, etc.) in their every day lives;
- Protection and Advocacy for Beneficiaries of Social Security (PABSS) program, which provides advocacy services to assist recipients of Social

Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) obtain, maintain or regain employment;
- Protection and Advocacy for Persons with Traumatic Brain Injury (PATBI) program which provides legal and non-legal advocacy services for individuals with traumatic brain injury;
- Protection and Advocacy for Voting Access (PAVA) program, which seeks to ensure the full participation of individuals with disabilities in the electoral process; and
- Adult Home Advocacy program, established by New York State law in 1995, to provide advocacy services on behalf of people with mental disabilities residing in adult homes.

The Commission contracts with over 30 not-for-profit agencies in various regions of the State to carry out advocacy activities consistent with the Federal and State mandates. This contractual/regional model allows for timely, efficient and locally-responsive advocacy services.

Each year, the Commission's network of advocacy agencies serves nearly 100,000 individuals, providing information and referral services, training, direct representation in legal and administrative matters, and systemic advocacy through class action law suits and other means.

KNOWLEDGE IS POWER: ADVOCACY AND OUTREACH

Empowering people to protect and exercise their rights by providing them with needed information through technical assistance, education and training is an everyday activity for the Commission and its advocacy network which, in 2004 and 2005, provided such services to over 30,000 people with disabilities, advocates, family members and other interested parties.

The merger of the former Commission and Office of State Advocate offered the new Commission opportunities to maintain and strengthen efforts in this regard. The Commission's toll-free helpline provides technical assistance to callers with questions about disability related issues. On average, over 3,900 individuals avail themselves of this service each month.

The merger also allowed the Commission, using resources of the two former agencies, to establish a Division of Advocacy and Outreach. The primary responsibility of the Division is to provide outreach, training, and technical assistance to people with all types of disabilities, with a special emphasis on individuals with physical or sensory disabilities, helping to ensure that they are afforded the opportunity to exercise all of the rights and responsibilities accorded to all citizens of the State.

Within the first nine months of its creation in April 2005, the Division, among other things, offered 91 training sessions around the State attended by over 2,500 people. Topics included – Educational Advocacy, the Americans with Disabilities Act

(ADA), Disability Awareness, the Help America Vote Act (HAVA), Assistive Technology, Reasonable Accommodations and the State Building Code.

EMPOWERMENT THROUGH TECHNOLOGY

With the merger, the new Commission assumed responsibility for administering the Federally funded Technology-Related Assistance for Individuals with Disabilities (TRAID) program. The program's goal is to empower individuals with disabilities – in their educational, employment, community living and communications endeavors – by increasing their access to and acquisition of assistive technology.

The Commission, as had the former Advocate's Office, approaches this goal in a "top-down, bottom-up" fashion. On a State level, the Commission works in collaboration with sister agencies on assistive technology policy issues which have statewide impact.

On a local level, to enhance individuals' access to assistive technology, the Commission contracts with 12 Regional TRAID Centers (RTC) housed in Independent Living Centers, academic institutions or community based service organizations. Each year, the RTCs assist nearly 30,000 individuals by providing:

- assistive technology-related information and referral services;
- awareness training;
- devise demonstrations; and
- equipment loans.

Additionally, the Commission sponsors the TRAID-IN equipment exchange program, an electronic service designed for individuals seeking to sell, donate or obtain used assistive devices for persons with disabilities, and in collaboration with the Interagency Partnership for Assistive Technology, sponsors a Governor's Expo on Assistive Technology every two years. An Expo was held in May 2004.

PROMOTING EXCELLENCE AND FOSTERING AWARENESS OF COMMISSION SERVICES

The Commission has been blessed with a highly skilled workforce, most of whose members have spent many years working in related fields before joining the Commission. In the course of their statewide work with the Commission, these men and women encounter and examine situations and practices, gaining a wealth of information that few administrators, managers, clinicians or staff of any one agency have the opportunity to glean.

Often, given the nature of the Commission's work, these situations and practices are problematic – few people call the Commission to register a compliment about a program. But in the resolution of problems, better or best practices are found from which others can learn. And, sometimes in their journeys, Commission staff find excellent programs worthy of replication elsewhere.

As such, in its strategic planning process, the Commission made sharing information, from which others could learn in their quest for quality and excellence, a priority. As the information shared arises from its everyday work, the process of sharing fosters awareness of the Commission's services so that others may avail themselves of such when needed.

CASE STUDIES

During the report period, the Commission published five case studies. The studies, intended for use as quality assurance and training tools, are part of an ongoing series of case studies, drawn from Commission investigations, entitled ***Could This Happen in Your Program?***

The studies published in 2004 and 2005 addressed issues relating to: securing timely medical care; preventing accidents in adult homes; Do Not Resuscitate (DNR) orders; promoting transportation safety; and, looking beyond staff actions in search of systemic problems. These, and all the studies in the series, are available on the Commission's website.

NEWSLETTER

Like most agencies, the Commission publishes a newsletter. Three issues of ***Quality of Care*** were published in 2004 and 2005. In addition to providing updates on Commission activities and news germane to the field, the newsletters featured articles aimed at promoting quality and excellence in serving people with disabilities. Among the articles were the following:

- ***The Importance of Being Earnest: Nonprofit Board of Directors Accountability After Sarbanes-Oxley,*** which described the corporate

climate which led to the 2002 Congressional Sarbanes-Oxley Act and lessons not-for-profit corporations can learn.

- ***Promoting the Wise and Caring Guardian,*** discussed the standards for guardianship.
- ***How to Assure No One Gets Left on the Bus,*** which explained an alarm mechanism a number of agencies have installed on buses to ensure that drivers conduct visual inspections of their vehicles at the end of runs to ensure that no one was unintentionally left on board.
- ***IRS Targets Excessive Compensation,*** which described the Internal Revenue Service's efforts to end abuses by tax-exempt organizations and offered suggestions on how agencies can set reasonable compensation levels for executives.
- ***Promoting Autonomy and Protecting Best Interests,*** which explained the various standards guiding medical decision making.

Recent issues of the Commission's newsletters are available on the Commission's website.

SPEAKERS BUREAU

The Speakers Bureau was created as a vehicle for interested parties to gain a better understanding of the Commission's activities and perspective on certain issues. Topics include – An Overview of the Commission, Conducting Investigations, Sexuality and Consent, Board of Directors' Training, Personal Allowance Fund Issues, Future Planning: Wills, Trusts, Estates, and End of Life Decision-Making, to name but a few. A complete list of topics is available on the Commission's website. As part of this program, in 2004 and 2005, Commission staff made over 62 presentations to 1,504 from agencies across the State. Agencies interested in this free service can schedule a Commission presentation by calling (518) 388-2887 or by e-mail at webmaster@cqcapd.state.ny.us.

Appendix A

ADVOCACY AGENCIES WITH WHICH THE COMMISSION CONTRACTS

FEDERAL/STATE FUNDING GRANT RECIPIENTS

MFY Legal Services, Inc.
Nassau/Suffolk Law Services Committee, Inc.
Long Island Advocacy Center, Inc.
Parent Network of Western New York
Resources for Children with Special Needs, Inc.
Common Ground Dispute Resolution, Inc.
The Peacemaker Program
Volunteer Counseling Service of Rockland County, Inc.
Education & Assistance Corporation
Center for Dispute Settlement
Child and Family Services of Erie County
Southern Tier Independence Center
Upstate Cerebral Palsy
Resource Center for Independent Living
Enable
Glens Falls Independent Living Center
Westchester Institute for Human Development
AIM Independent Living Center
SUNY–Buffalo
SUNY–Plattsburgh
United Cerebral Palsy Association of Nassau County, Inc.
United Cerebral Palsy of New York City, Inc.
United Cerebral Palsy of Ulster County, Inc.
Catskill Center for Independence
Center for Independence of the Disabled in New York
New York Lawyers for the Public Interest, Inc.
Legal Services of Central New York, Inc.
Neighborhood Legal Services, Inc.
Legal Aid Society of Northeastern New York, Inc.
Touro College
Disability Advocates, Inc.
Albany Law School
Legal Services of the Hudson Valley
Western New York Advocacy for the Developmentally Disabled, Inc.
Westchester Independent Living Center, Inc.
Capital District Center for Independence, Inc.
Western New York Independent Living Project, Inc.
Regional Center for Independent Living

REGIONAL TRAID CENTERS

Nassau/Suffolk TRAID Centers
UCP of Nassau and Suffolk
380 Washington Avenue
Roosevelt, NY 11575-1899
(516) 378-5089 (voice/TTY)
Counties served: Nassau, Suffolk

Central New York TRAID Center
ENABLE 1603 Court Street
Syracuse, NY 13208
(315) 410-3336 (voice)
(315) 455-1794 (TTY)
Counties served: Oswego, Onondaga, Cayuga, Madison, Cortland, Tompkins

Adirondack Regional Technology Center
SUNY Plattsburgh
Alzheimer's Disease Assistance Center
101 Broad Street, Sibley 227
Plattsburgh, NY 12901
(800) 388-0199 (voice/TTY)
(518) 564-3368 (voice)
Counties served: St. Lawrence, Franklin, Clinton, Essex

Lower Hudson Valley Technology Center
Westchester Institute for Human Development
Cedarwood Hall
Valhalla, NY 10595-1689
(914) 493-1317 (voice)
(914) 493-1204 (TTY)
Counties served: Rockland, Westchester, Putnam

Genesee-Finger Lakes TRAID Center
Regional Center for Independent Living
497 State Street
Rochester, NY 14608
(585) 442-6470 (voice/TTY)
Counties served: Monroe, Wayne, Livingston, Ontario, Yates, Seneca

AIM ILC
271 East First Street
Corning, NY 14830
(607) 962-8225 x23 (voice/TTY)
Counties Served: Steuben, Schuyler, Chemung, Cattaraugus, Allegany, Chautauqua

Center for Assistive Technology
University of Buffalo
322 Kimball Tower, 3435 Main Street
Buffalo, NY 14214
(716) 829-3141 x108 (voice/TTY)
(800) 628-2281 (voice/TTY)
Counties Served: Niagara, Erie, Orleans, Genesee, Wyoming

Capital Region TRAID Center
Southern Adirondack ILC (SAIL)
71 Glenwood Avenue
Queensbury, NY 12804
(518) 792-3537 (voice)
(518) 792-0505 (TTY)
Counties Served: Warren, Washington, Saratoga, Albany, Greene, Schenectady, Rensselaer, Schoharie, Columbia

Southern Tier Independence Center
24 Prospect Avenue
Binghamton, NY 13901
(607) 724-2111 (voice/TTY)
Counties Served: Tioga, Broome, Chenango, Otsego, Delaware

Hudson Valley Regional TRAID Center
UCP of Ulster County
250 Tuytenbridge Road, PO BOX 1488
Kingston, NY 12402
(845) 336-7235 x 129 (voice)
(845) 336-4055 (TTY)
Counties served: Ulster, Sullivan, Orange, Dutchess

Technology Resources Center
United Cerebral Palsy of New York City
120 East 23rd Street, 5th Floor
New York, NY 10010-4519
(212) 979-9700 x 279 (voice)
(212) 475-0842 (TTY)
Counties served: Kings, Richmond, Queens, Manhattan, Bronx

TRAID Center at Upstate Cerebral Palsy in Utica
3390 Brooks Lane.
Chadwick, NY 13319
(315)737-0912 (voice/TTY)
Counties served: Jefferson, Lewis, Oneida, Hamilton, Herkimer, Fulton, Montgomery