MISSION STATEMENT

To improve the quality of life for individuals with disabilities in New York State, and beyond, and to protect their rights by:

- Ensuring and advancing programmatic and fiscal accountability within the state’s mental hygiene system through independent oversight;
- Providing case-specific and systemic investigative and advocacy services, and
- Offering impartial and informed advice and recommendations on disability issues to government officials, program operators, individuals with disabilities and their families and advocates, and the public-at-large.

VALUED AND GUIDING PRINCIPLES

Charged with a variety of investigatory, advocacy and educational activities, our work is guided by the following principles:

- **Committed and Courageous Independence**
  We will carry out the agency’s mission on behalf of individuals with disabilities undeterred by extraneous factors.
  We will gather information and data independently, making findings and recommendations as we see them, consulting with but not controlled by outside parties.
  We will be a voice for the often voiceless, “the everyman” disabled or not, singing praise where praise is due, explaining ways in which services could be improved and expressing righteous outrage when they are not.

- **Compassion**
  We will walk in the shoes of the Commission’s stakeholders, enter their lives by listening and responding with truthfulness and caring.

- **Integrity**
  In our labors, we will exercise diligence in our quest for accuracy, fairness, and the truth through careful research and analysis, attention to detail, application of reasonable standards, and the invitation of peer review and dialogue.

- **Respect**
  In our efforts to uphold their rights and improve the quality of life for people with disabilities, we will always treat each other as we treat the people we serve.
Preface

The New York State Commission on Quality of Care for the Mentally Disabled is responsible for overseeing the operations of the Offices of the New York State Department of Mental Hygiene\(^1\) and for administering certain federal and state funded advocacy programs for individuals with developmental, mental and other disabling conditions. While Article 45 of the Mental Hygiene Law details the powers, duties and functions of the Commission, its mission, put simply, is to improve lives and protect the rights of individuals with disabilities.

This mission, however, is not uniquely the Commission’s. It is a goal shared by consumers, their families and advocates, facility and program operators, regulators and other government officials who establish standards of care and finance service delivery systems, as well as the public at large.

What is unique about the Commission’s role in this shared endeavor is its independence. Unencumbered by the weighty tasks of day-to-day service delivery and long-range policy and financial planning, the Commission is free to step back, objectively assess the quality of care offered by service systems, and impartially speak on behalf of those who depend upon such systems. This gift of independence is one that is not to be taken lightly; it must be used wisely.

To that end, in early 2000 the Commission solicited the input of those who have a stake in the success of the Commission’s mission. Representatives of consumer, family, advocacy and provider groups, Commissioners and senior staff of operating and regulatory agencies within the mental hygiene system, officials from the Governor’s Office and the Division of the Budget, members and staff of the Legislature, as well as the Commission’s own staff and Advisory Council, were invited to suggest ways in which the Commission can best exercise its independent authority to further improve lives and protect the rights of individuals with disabilities.

The ensuing dialogue resulted in a Strategic Plan, published by the Commission in June 2000, to guide Commission oversight and advocacy activities over the next several years as it approaches its 25th year of operation in 2003. Several goals for external Commission activities were articulated in the plan:

- Maintaining and improving the Commission’s traditional oversight activities, and monitoring new and emerging service trends and modalities within the mental hygiene system;

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\(^1\) The Department of Mental Hygiene is comprised of the Office of Mental Health, the Office of Mental Retardation and Developmental Disabilities and the Office of Alcoholism and Substance Abuse Services.
• Endeavoring to ensure that persons with mental disabilities served primarily by non-mental hygiene agencies receive services that effectively meet their needs;

• Advocating for and empowering persons with disabilities in exercising their rights; and

• Promoting excellence and fostering public awareness of the Commission’s mission and services.

This report provides an accounting of the Commission’s major activities and accomplishments for the period January 1, 2000 through December 31, 2001 in pursuit of these goals, undertaken with the strong and continuing support of Governor George E. Pataki and the New York State Legislature.
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Maintaining and Improving Traditional Oversight Activities
and Monitoring New Service Trends and Modalities

The conduct of individual case investigations, as well as broader programmatic and fiscal reviews, has been the backbone of the Commission’s efforts to improve lives and protect the rights of individuals with disabilities since its first year of operation in 1978. That year, the Commission took action on 350 complaints and deaths brought to its attention, conducted programmatic reviews of three psychiatric and developmental centers, and commenced an investigation into the fiscal operations of a 190-bed private school for individuals with developmental disabilities.

Much has changed since then. Smaller, community-based models of care have largely replaced the State institutions of yesteryear. Legislative and regulatory initiatives have strengthened the Commission’s investigative and review functions. And, facilities are required to report a broader array of events to the Commission for its review and, when deemed necessary, intervention.

But one thing has remained constant according to the individuals involved in the Commission’s strategic planning process, and that is the value of the Commission’s “traditional” oversight activities as vehicles for:

✔ Keeping tabs on the pulse of the mental hygiene system;
✔ Offering program operators, regulators and policy makers impartial assessments of the quality of services and suggestions for improvement;
✔ Assuring consumers, their families and advocates that questions and concerns about care will be addressed; and
✔ Deterring abuse, neglect and unscrupulous practices by referring individuals and programs for appropriate administrative, civil or criminal action, and by reporting investigative findings and outcomes.
Individual Case Activities and Investigations

Maintaining a toll-free help line (1-800-624-4143), the Commission aided over 45,000 people in 2000 and 2001 who called in need of assistance in navigating New York’s service systems or with questions or concerns about their care or that of a loved one. When offering advice over the phone, or making contacts with facilities or programs on the callers’ behalf failed to resolve concerns, Commission staff took direct action by conducting care and treatment reviews: examining clinical records, visiting facilities, interviewing program staff and offering recommendations to resolve the matters at hand.

Commission staff, on call 24-7 to receive and immediately commence investigations into allegations of abuse of children residing in mental hygiene facilities, responded to over 400 such reports during the period. Investigations into these reports, transmitted to the Commission from the State Central Register for Child Abuse and Maltreatment, are intended to, first, immediately assure the safety of the involved children and, within sixty days, determine whether child abuse or maltreatment, as defined in Social Services Law, occurred, thus paving the way for appropriate remedial action by facilities and the registration of offenders with the State Central Register.

Commission staff also reviewed over 17,000 reports of patient or client abuse, as defined in the regulations of the respective Offices, and over 5,000 deaths. In addition to investigating untoward events, facilities are required by law to report incidents of abuse and deaths to the Commission for its review and possible action. Upon review of the events reported in 2000 and 2001, the Commission assigned over 1,000 abuse allegations and more than 400 deaths for further inquiry and investigation, usually when the investigation by the facility seemed lacking, or the death appeared to be unusual or due to other-than-natural causes and warranted closer scrutiny. The Mental Hygiene Medical Review Board, a panel of unsalaried medical experts with backgrounds in forensics, pathology, psychiatry, surgery, internal medicine and pharmacology appointed by the Governor, assisted the Commission in these investigations.

Each of the Commission's investigations resulted in a written report to the facility, detailing the findings and offering recommendations, when indicated, to improve the quality of care, further safeguard the well-being of consumers or enhance facility operations, including the conduct of incident investigations.

To improve upon the Commission's management of case activities, a centralized intake unit was created in 2000 and, in 2001, data bases established over the years to track the various types of cases handled - i.e, deaths, child abuse allegations, adult abuse allegations, etc. - were merged, thus facilitating the monitoring of all case activities and creating a mechanism to more readily identify all Commission investigations involving any particular facility over time and their outcomes.
Individual Case Activities and Investigations
January 2000 - December 2001

The Numbers:

Toll Free Calls for Assistance  47,397
Care and Treatment Reviews  494
Child Abuse Investigations  415
Adult Abuse Reports Reviewed  17,521
Adult Abuse Reports Assigned for Further Inquiry  1,024
Death Reports Reviewed  5,167
Death Reports Assigned for Further Inquiry  457

Some Stories Behind the Numbers:

An inpatient on a psychiatric ward of a general hospital called the Commission's Toll-Free Help Line and reported that while he was an amputee with a spinal cord injury who required a wheelchair for mobility, he had no access to a wheelchair since his admission one week prior. Commission staff called the hospital and the patient was promptly provided a wheelchair.

A woman called the Commission to report that her elderly father who lived alone had recently been released from a hospital and was not eating and neglecting his basic care needs. Help Line staff gave her the telephone numbers of the local Mobile Crisis Team and Adult Protective Services. Two hours later, the woman reported she had called the numbers the Commission had provided, that a team responded and her father was being re-hospitalized.

On a site visit to a residential program for children, during the course of a review of another matter, Commission staff found that bedrooms had no curtains, carpets were torn and ragged and bathrooms were filthy and dilapidated with broken fixtures. In response to the Commission's findings, the facility took the necessary steps to provide a safe, clean and appropriate environment, as verified during a follow-up Commission visit.
When a middle-aged resident of a group home for individuals with developmental disabilities died unexpectedly, the local medical examiner classified the death as a suicide due to a prescription drug overdose. This diagnosis raised serious concerns about medication management and supervision within the home. However, the Commission’s investigation, aided with the input of the Commission’s Medical Review Board, found no evidence to support the possibility of suicide; in fact, toxicological studies showed normal drug levels, and other clinical evidence indicated that death was due to a cardiac condition. Also, medication management and supervision practices in the home appeared appropriate. This information was shared with the medical examiner who, upon review, reclassified the death as being due to natural causes.

A Commission investigation at a group home revealed that one client was sustaining bruises from being restrained in a metal chair, which was contraindicated; other clients were enduring restrictive interventions beyond what was called for in their behavior plans; one client, who had no behavior plan in place, required 26 emergency physical restraints in a three month period; and staff, in general, were not following or did not know individuals’ behavior plans. Follow-up visits by Commission staff, after corrective actions were reported by the facility in response to the Commission’s report of findings, indicated that comprehensive and individualized behavior plans were in place for the residents, that staff were knowledgeable of the plans, and that they were being implemented appropriately.

After a woman in a community residence experienced a life-threatening hyperglycemic crisis, the Commission found that her diabetic condition was not well appreciated by her residential staff, who received little information from the medical clinic she attended. Also, staff did not sufficiently monitor her diet and, when she was sick with flu-like symptoms, they advised her to stop taking all medications, including medication for her diabetes, without consulting her physician, thus precipitating the crisis. Subsequent to the Commission’s investigation, the agency provided all staff with training on managing and monitoring diabetes as well as consulting physicians concerning medical decisions; established a new 24 hour-a-day emergency medical contact system; engaged a new medical care provider; and established a protocol for sharing information between medical and residential staff.
Programmatic and Fiscal Reviews

Conditions or situations encountered during the course of individual case investigations and, in one instance, a request from the Assembly Committee on Mental Health, prompted the Commission to undertake broader examinations of certain programs within the mental hygiene system.

Elopement Study

In 2000, the Commission completed work on a study of elopements from child care facilities certified or operated by the Office of Mental Health (OMH) in 1998. The study was prodded, in part, by the Commission's child abuse investigation activities: often times, it is the elopement of a child that triggers a report of abuse or neglect. Seventy facilities, representing 90% of such facilities in the state, responded to a Commission survey and provided data relating to elopements by children in calendar year 1998. The information provided and analyzed by the Commission included the number and circumstances of elopements; admission, discharge and length of stay data; theories on why children elope; and measures facilities have taken to reduce elopements.

The study results were published in the Commission's April 2001 newsletter, *Quality Care*, and are available on the Commission's website. Among the major findings were that in 1998:

✓ Overall, elopements were an infrequent occurrence in the majority of programs.

  Attention to security issues and the development of a therapeutic bond between children and staff were the two factors which most affected running-away behavior.

✓ While overall the rate of elopements was low, there was wide variability of rates among similar types of facilities.

✓ Excessive length of stay was cited as one factor contributing to the high rate of elopements from some Residential Treatment Facilities.

The study, the first of its kind in New York State, has been helpful to facilities in examining where they stand in supporting and protecting children by preventing their elopement.

Improper Billing Practices

An investigation into the suicide of a young patient of Transitional Services Inc. (TSI), which operates residential and outpatient programs in Queens, raised questions about the agency's financial practices, thus prompting a fiscal review.

While the Commission found no deficiencies in the agency's spending practices, major problems were noted in documentation and the nature of the services billed to the Medicaid program by the agency's continuing day treatment and clinic programs. As a result, the Commission recommended, and the Department of Health is seeking, restitution of $1.7 million.
The majority of the recommended disallowance related to the agency’s continuing day treatment programs where Medicaid was billed as if clients had received five hours of service daily when in fact they were served only about one-half of that time. Additionally, inadequate record-keeping systems for attendance offered little proof that clients were actually present for therapy sessions.

There were also concerns about the size and content of group therapy sessions. Documents examined indicated that groups included up to 103 participants. At one continuing day treatment site, the average group size was 30 clients; at the other site, the average size was 19 participants. The size of such groups raised questions about the therapeutic value derived from the sessions by the individuals in attendance. OMH regulations require a continuing day treatment program to provide core services such as medication education, rehabilitation readiness assessment, and symptoms management. Yet at TSI, such services constituted less than 10 percent of the attended groups. It was not unusual to see clients attending other activities, like a movie group, while core service sessions, such as medication education groups or others, were cancelled due to lack of interest.

Similar problems with continuing day treatment programs were found during the Commission’s examination of programs serving adult home residents. In response to concerns about services rendered to adult home residents, the OMH established an adult home surveillance team responsible for reviewing mental health programs serving these individuals.

**Survey of Electro-convulsive Therapy Practices**

In 2001, at the request of the Chair of the Assembly Committee on Mental Health, the Commission undertook a survey of Electro-convulsive Therapy (ECT) practices at state psychiatric centers. The purpose was to obtain information about the frequency of use of this form of treatment, the clinical profiles of the patients who receive it, and facilities’ management of ECT. The survey was not intended to evaluate the efficacy of this form of treatment, which has outspoken proponents and opponents.

The Commission’s findings were published in the August 2001 issue of *Quality Care* and are available on the Commission’s website. It was found that:

- Five New York State facilities - Creedmoor, Manhattan, Pilgrim and Rockland Psychiatric Centers and the New York State Psychiatric Institute - offered ECT to 164 patients during the two year period June 1, 1999 through May 31, 2001. Approximately one-third of these patients were at the New York State Psychiatric Institute and enrolled in research projects.

- Record reviews indicated that these patients carried diagnoses for which ECT, according to scientific literature, has been proven to be an effective form of treatment. Most patients engaged in the treatment on a voluntary, as opposed to court-ordered, basis, and all the patients at the Psychiatric Institute engaged in treatment voluntarily.
While all the facilities had policies in place governing the use of ECT which touched on issues such as indications for ECT, medical clearances, anesthesia, administration of ECT and post-ECT care, these policies, as well as policies regarding informed consent and the credentialing of physicians who administer ECT, varied widely.

The Office of Mental Health concurred with the Commission’s observation of the need to establish ECT protocols that can be applied consistently in state facilities and that promote best practice while ensuring adherence to applicable statutory and regulatory standards safeguarding patient rights. OMH reported that the development of such standards is underway.

Commission Work Revisited

Prior Commission reviews were revisited during 2000 and 2001 in the form of criminal, civil and administrative actions.

In September 2000, the former Executive Director of Special Needs Program, Inc. - a not-for-profit agency operating a ten-bed residence and a transportation service for individuals with developmental disabilities in upstate New York - was sentenced in federal court to six months in-home confinement, five years probation and 500 hours of community service for fraudulently diverting Medicaid funds for personal use. He was also ordered to pay $250,000 in restitution to the Office of Mental Retardation and Developmental Disabilities (OMRDD). This plea-bargain agreement settled a nine-count indictment stemming from the Commission’s 1999 programmatic and fiscal review, *Exploiting Medicaid Through A Shell Not-for-Profit Corporation: The Case of Special Needs, Inc.*, which detailed how the Executive Director created a phantom board of directors, fabricated board minutes and awarded himself and family members inflated salaries and benefits.

That same month, a Certified Public Accountant (CPA) pled “No Contest” to a State Board of Regents’ charge of professional misconduct arising from the Commission’s 1996 report, *Profit Making in Not-for-Profit Care: Part III, The Case of Queens County Neuropsychiatric Institute, Inc.*. New York State relies heavily on CPAs to accurately report on the financial condition of a vast network of not-for-profit agencies providing services to individuals with mental disabilities. In this case, however, the Commission found that the CPA failed to live up to his professional responsibilities, thus allowing the Institute’s founder to divert hundreds of thousands of dollars intended for care. In light of the Commission’s findings, the Institute’s founder made restitution in a deferred prosecution agreement with the United States’ Attorney’s Office, to which the Commission had referred its findings. The Board of Regents’ recent action against the CPA brought closure to the Commission’s investigative recommendations.
In March 2001, a settlement was reached in a lawsuit brought by the State Attorney General seeking $100,000 owed to two elderly tenants of a failed senior citizens apartment project in Amsterdam, New York. The tenants’ situation came to light during the Commission’s 1998 investigation published as *Exploiting Public Funds: The Misguided Mission of the Independent Living Center of Amsterdam, Inc.* In tracing public funds intended for individuals with physical and developmental disabilities served by the Independent Living Center of Amsterdam (ILCA), it was found that the money was being diverted illegally to support ILCA’s poorly conceived and mismanaged retirement project, into which the two elderly tenants had bought. Not only were the elderly tenants not receiving promised services, they had invested and were caught in what the Commission found to be a collapsing housing scheme. In addition to referring the matter of diverted public funds to OMRDD and the Office of Vocational and Educational Services for Individuals with Disabilities (VESID), which acted quickly in 1998 to, among other things, transfer services for ILCA’s disabled clientele to a different agency, the Commission alerted the State Attorney General’s Office to the plight of the two elderly tenants. The 2001 settlement essentially provided them complete restitution and enjoined the defendants from any business activity relating to the offer or sale of real estate securities in the state.

Also in 2001, the license of one physician was revoked and that of a second physician was suspended by the Department of Health for conduct evidencing moral unfitness and gross negligence. The physicians had arranged for and performed unnecessary surgical procedures on approximately 20 mentally ill residents of the former Leben Home for Adults in 1998. The Commission was tipped off to the unnecessary surgery by an anonymous caller. After a preliminary inquiry, during which the names of the patients and dates and nature of the surgeries were determined, the Commission referred the matter to the Department of Health. The Commission’s Medical Review Board assisted the Health Department in reviewing the patients’ need for surgery and issues relating to capacity to consent.

**Monitoring New Service Trends and Modalities**

During the report period, the Commission engaged in several activities to monitor new service trends and modalities. Commission staff sat on several committees and tasks forces relating to the development of new standards and guidelines for the use of restraint and seclusion in mental health facilities, the care and treatment of aging and forensic clients within the mental retardation and developmental disabilities service system, and the oversight of the governor’s 1998 initiative to virtually eliminate the waiting list for residential services for people with developmental disabilities: New York State Creating Alternatives in Residential Environments & Services (NYS-CARES).

Additionally, as an increasing number of programs coming on line are funded by OMH or OMRDD, but not necessarily certified by those agencies, the Commission initiated a dialogue with both agencies to examine how the Commission’s oversight activities can best be employed in monitoring such programs, particularly with regard to serious incidents including deaths and allegations of abuse.
Assisting People with Mental Disabilities
Outside the Traditional Mental Hygiene System

Adult Homes

In 2000, the Commission completed a pilot study which fueled its resolve during the strategic planning process to act directly on behalf of individuals with mental illness residing in adult care facilities, commonly referred to as adult homes.

Approximately 30,000 people live in adult homes, certified by the Department of Health, which provide room, board and some assistance in daily living. Although adult homes were initially intended to serve a frail-elderly clientele, today more than 12,000 people with serious mental illness reside in this modality - more than the number of people residing in any class of facility operated or certified by the Office of Mental Health. Since the early 1990s, the Commission has funded two legal service agencies to provide legal and administrative advocacy for adult home residents.

In the pilot study completed in 2000, Commission staff visited 16 adult homes serving over 2,600 residents, most of whom were mentally ill. During the unannounced two-day visits, staff assessed conditions relating to:

- Housekeeping and Maintenance/Furnishings;
- Fire-Safety and Nutrition/Meals;
- Personal Care and Medication Management; and
- Resident Activities and Resident Rights Protection.

Of the 16 homes, three were graded as “good” on a standardized rating instrument, seven as “in need of improvement,” and six as “poor.” Those rated as poor had pervasive problems which not only compromised the quality of residents’ lives, but adversely impacted on their health and safety. Commission findings in one 365-bed home, in fact, prompted the Health Department, in cooperation with the Office of Mental Health, to immediately relocate 60 residents until life-threatening conditions in their living quarters could be remedied.

Detailed Commission reports were issued to the adult home operators, with requests for plans of corrective action when problems were found, and shared with the Department of Health, which took administrative action against the poorest homes. Subsequently, four of the six poorest homes were closed, one home was transferred to an operator identified in the review as running one of the best homes, and the operators of the sixth home were referred to the Manhattan District Attorney for possible criminal acts.
## Adult Care Facilities
**Reviewed During the Pilot Project and in On-Going Adult Home Activities**
**January 2000 - December 2001**

<table>
<thead>
<tr>
<th>Adult Care Facility</th>
<th>Capacity</th>
<th>County</th>
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</thead>
<tbody>
<tr>
<td>Adventist Home</td>
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<td>Columbia</td>
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<tr>
<td>Anna Erika Assisted Living</td>
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<td>Richmond</td>
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<tr>
<td>Bayview Manor*</td>
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<td>Kings</td>
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<td>Bridgewell*</td>
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<td>Erie</td>
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<td>Hedgewood Home</td>
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<td>United Helpers Adult Home</td>
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</tr>
<tr>
<td>Valentine House</td>
<td>53</td>
<td>Rockland</td>
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</tbody>
</table>

**Total Beds = 6,862**

*Indicates Inclusion in the Pilot Project*
Ongoing Adult Home Reviews and Interagency Activities

The corrective and administrative actions taken in the 13 homes rated as “poor” or “in need of improvement” during the Commission’s pilot study, directly touched and improved the lives of three-quarters of the residents who lived in the 16 homes included in the review. This reality prompted the Commission to make further adult home work a priority in its strategic plan.

With the support of the Governor’s Office and The Division for the Budget, in 2000, the Commission established an adult home team that would provide an on-going capacity to conduct programmatic and fiscal reviews of adult care facilities. During 2000 and 2001, in addition to conducting follow-up visits to monitor the implementation of corrective action plans developed during the pilot study, the Commission conducted comprehensive reviews of 27 additional adult homes serving over 4,000 people. Again, reports of findings, with requests for plans of corrections where deficiencies were found, were issued to the adult home operators and the Department of Health, which in several cases initiated enforcement action to ensure corrective action. The Commission continued to monitor the implementation of promised corrective actions.

Based on concerns identified during these reviews, the Commission joined with the Office of Mental Health and the Department of Health to form an interagency workgroup to address the underlying, systemic issues which negatively impact on residents of adult homes serving significant numbers of persons with mental illness. Among the issues being addressed by the workgroup are: improving the state’s surveillance of homes, including joint-agency inspections; enhancing the quality of mental health services afforded residents by programs certified by the Office of Mental Health to promote residents’ recovery and independence; promoting improved consumer participation in services and protection of their rights; and facilitating the exchange of information among the state agencies which have a stake in the health, safety and quality of life of residents of adult homes. In order to formalize these activities, the Commission, Department of Health and Office of Mental Health signed a Memorandum of Understanding that provides for a continuing commitment by all three agencies to promote improvements in the quality of life for adult home residents.

Dollars and Sense within the Adult Home Industry

Woefully inadequate and dangerous conditions found in one adult home visited in 2000, Ocean House Center, Inc., compelled the Commission to undertake a detailed programmatic and fiscal review of the home and entities serving its 125 residents.

While it is frequently claimed by some that it is difficult to provide adequate services on the $28 a-day, or $10,164 a-year, adult home operators receive from each client’s SSI funds, the Commission’s findings on Ocean House tell a different story. As detailed in the Commission’s December 2001
报告，《侵吞营利性护理：成人之家的真相：Ocean House Center, Inc.的故事》，显示了更多的公共资金，大约每年$37,000的人均，被耗在了家中的居民上。然而：

- Ocean House的运营者将数百万美元的费用转移给个人利益，从一个五年期间；
- 精神健康提供者通过双倍收费和提交服务索赔，这些服务根本不能满足客户的需求，服务如儿童着色书籍中的着色，每人的成本为$141，花15－20分钟；以及
- 在同一期间，家庭医疗机构收到了近50万美元的服务费用，这些服务应该由家中的运营者提供。

这些发现导致了Ocean House的运营者的各种刑事指控被提出，由曼哈顿区检察官；卫生部门要求从几个提供者那里挽回近100万美元的不正当收费；以及由精神健康办公室对意见患者的门诊程序进行增加的监控。

此外，还引发了2001年的委员会调查，该委员会调查了11个最大的州外的成人之家为近3,000名精神疾病患者的住宅、健康和精神健康服务的成本和质量。该委员会的报告，《成人之家，为精神健康居民提供的服务：一种分层服务的研究》，于2002年出版，为讨论提供了基础，以更经济和更临床响应的方法使用公共资金为成人之家的居民提供服务。

**Interfacing with the Criminal Justice System**

在委员会的战略规划过程中，家庭成员、倡导者和项目运营者反复表达对犯罪司法系统安置的精神疾病患者人数以及他们护理质量的担忧。全国估计在监狱和监狱中的人数是精神疾病的患者人数的五倍。在联邦保护和代表项目下，委员会提供资金给法律服务和其他机构来为精神健康的个人提供一系列的倡导服务，包括那些被监禁的人。但是根据州法律，委员会对州和地方的矫正设施没有监督责任——这是由州监狱委员会负责的。

在犯罪司法系统中，使用公共资金为成人之家的居民提供更经济和更临床响应的护理的方法。
Hearing the concerns expressed during the strategic planning process, the Commission took action to explore ways of advancing its moral obligation toward incarcerated individuals with mental disabilities where statutes do not pave a straight path.

In Spring 2001, the Commission convened a one-day meeting of Commissioners and senior staff of all New York State agencies that provide and/or oversee criminal justice or mental hygiene services. During the forum, representatives of the nine agencies present discussed the successes they have achieved, the continuing challenges they face, and ways in which the Commission might be of assistance in service to individuals with mental disabilities who interface with the criminal justice system. The dialogue centered on three themes: diverting incarceration; improving services for those incarcerated; and promoting community reintegration with appropriate services upon release from incarceration.

As a result of the meeting and follow-up discussions, the Commission:

✓ Reaffirmed its relationship with the Commission of Correction to ensure that complaints and concerns about conditions in correctional facilities are referred to COC for investigation;
✓ Partnered with the NYS Division of Probation and Correctional Alternatives to provide staff assistance in the review of alternative-to-incarceration models and to provide training for DPCA staff; and
✓ Designed a study, with field work commencing in 2002, of the experiences and needs of a random sample of state prison inmates who received mental health services, subject to the Commission’s jurisdiction, while incarcerated in 2000.
Advocating For & Empowering People with Disabilities

Complementing the Commission’s individual case investigation and programmatic and fiscal review activities is the work of a statewide network of programs sponsored by the Commission to advocate for and empower people with disabilities in the exercise of their rights. In 2000 and 2001 these programs enjoyed considerable success and growth.

Surrogate Decision Making Committee Program: Statewide Expansion

Accessing appropriate medical care in a timely manner is a basic need of all individuals, but sometimes a difficult task for individuals whose disabling conditions raise concern about their capacity to consent to care. Assisting these individuals is the goal of the Commission’s Surrogate Decision Making Committee (SDMC) program which, with the support of the Governor and the Legislature, became operational statewide in 2001.

“overall, this program is an exceptionally humane way to provide care for individuals who are incapacitated. It expedites treatment…”

*Psychiatric News, January 22, 2002*

Established as a demonstration project in a handful of counties in 1986, the SDMC program was created as an alternative to the court system to provide authorization for non-emergency medical care for individuals who lacked the capacity to consent to treatment and had no legally authorized surrogate decision maker. The pilot SDMC program relied on panels of trained volunteers, consisting of attorneys, medical experts and advocates, to hear cases and render decisions on the individual’s capacity to consent, the availability of authorized decision makers, and the need for medical treatment. Available to residents of OMH and OMRDD facilities in the pilot project counties, the program was deemed a success in an independent evaluation: consents for necessary major medical care were secured through SDMC in an average of 12 - 14 days, or sooner on an expedited basis, whereas courts often took weeks and months. In 1990, the program was made permanent and approved for statewide operation, but funding constraints hampered significant expansion.

In 1998, Governor Pataki approved additional funding that enabled the Commission to incrementally expand SDMC’s operations, with a goal of making the program available statewide in 2001. Over the course of 2000 and in early 2001, volunteers were recruited and they, as well as residential facility operators and major health care providers, were trained for SDMC operation in 23 counties. In June 2001, the program became operational statewide.
The program now consists of over 1,000 panel-member volunteers across New York. In 2000 and 2001 SDMC resolved over 1,600 cases, involving treatments ranging from routine dental care under anesthesia to complex cardiac surgery, bringing the total number of people served since 1986 to over 6,200. Continuing to render decisions within two weeks of petition, or within days in expedited cases, the SDMC Program was featured in the January 18, 2002 issue of *Psychiatric News* for its innovativeness and quality service to individuals with mental disabilities.

**Maintaining and Enhancing a Statewide Network of Advocacy Services**

Facing eviction because a family member is disabled? Denied access to entitlements? Need assistance in appealing a child's educational plan? Refused transportation or accommodation because of a wheelchair?

These are among the thousands of problems successfully resolved in 2000 and 2001 by a state-wide network of regionally based agencies funded by the Commission to provide administrative and/or legal advocacy for individuals with disabilities.

Under federal and state statutes, the Commission is responsible for administering several advocacy programs, including:

- The Protection and Advocacy for Persons with Developmental Disabilities (PADD) program and the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program which respectively serve people with developmental disabilities and mental illness;
- The Client Assistance Program (CAP), which assists individuals with a wide variety of disabilities secure training and services leading to employment and independent living;
- The Protection and Advocacy for Individual Rights (PAIR) program, serving people with disabilities not covered by the federally authorized PADD, PAIMI or CAP Programs;
- The Technology Related Protection and Advocacy program, which aids disabled individuals who require assistive devices (e.g., wheelchairs, special communication equipment, etc.) in their everyday lives; and
- The 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.

Administered by the Commission, these advocacy services are offered by not-for-profit agencies with which the Commission contracts in various regions throughout the state. This contractual and regional model for service delivery allows for timely, efficient and locally-responsive advocacy efforts.
In addition to the thousands of people who received information and referral services — i.e., brief written or oral information about rights, services and resources — from the Commission’s advocacy network, over 10,000 people received direct individual advocacy services through the network in 2000 and 2001. Services included counseling and advice, mediation and negotiation services, assistance in administrative appeals and representation in individual litigation. Over 60,000 additional individuals were the potential beneficiaries of group advocacy efforts by the network during this time frame, through facility inspections, court-ordered monitoring of conditions of facilities and class action litigation. These individuals and groups of clients were assisted in issues relating to education and employment, transportation, securing entitlements and other benefits, health care, and housing, to name but a few. The following cases are illustrative of the work of the Commission’s advocacy network.

Two contract agencies, Disability Advocates, Inc. and MFY Legal Services, Inc., partnered with a private firm in a lawsuit on behalf of the previously mentioned 20+ residents of the former Leben Home for Adults who underwent surgery alleged to have been unnecessary. The suit seeks compensatory and punitive damages as well as declaratory and injunctive relief against the defendants, who include the former operators of the home, a home health aide who provided services in the home and the agency which employed her, Parkway Hospital, where the surgeries were performed, and two physicians at Parkway Hospital.

Legal Services of Central New York assisted a 52-year old female Viet Nam veteran who had been denied Social Security benefits several times despite her psychiatric diagnoses and history. She had become homeless in the absence of income. Legal Services staff represented the woman at a hearing which resulted in a favorable decision. The client received retroactive payment and continuing benefits, and was able to secure permanent housing.

On Long Island, Nassau/Suffolk Legal Services Committee Inc. joined with other advocates in seeking improved compliance with the Americans with Disabilities Act on the part of a public transportation provider. Their advocacy efforts were successful in securing changes to a fixed route system regarding accommodations for visually and mobility impaired passengers.
Neighborhood Legal Services, Inc. (NLS) wrote to an art gallery in western New York on behalf of a wheelchair-dependent client who could not gain access to the gallery. When the gallery did not respond, NLS commenced a law suit against the gallery and the county council for the arts under the Americans with Disabilities Act. Subsequently, NLS successfully negotiated a settlement with the two defendants that provided for full program access by January 1, 2002.

In central New York, a young woman with developmental disabilities was denied access to public housing due to her disability. The local housing authority felt that she would be vulnerable and fall victim to a crime in such housing. When the Commission's PADD agency requested an informal hearing on the woman's behalf, the housing authority reversed its position and the woman secured housing.

In 2001, the Commission expanded its advocacy network by establishing the Protection and Advocacy for Beneficiaries of Social Security (PABSS) program, a new federally funded statewide advocacy service which became operational in the summer of that year. Authorized by the federal Ticket To Work and Work Incentives Improvement Act, this program is designed to provide advocacy services to assist recipients of Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) obtain, maintain or regain employment.

**Knowledge is Power: Empowering Through Training**

In 2000 and 2001, the Commission and its contract advocacy agencies provided training to nearly 28,000 consumers, advocates, family members and interested parties on matters relating to disability services and rights. Among the many topics addressed in statewide and regional forums were:

- Special Education and Educational Advocacy
- Transition from School to Work and Adult Life
- Guardianship and Future Planning
- Self Advocacy
- Mediation
- SSI/SSDI Benefits
- Assisted Outpatient Treatment (Kendra's Law)
- Americans with Disabilities Act
- Ticket to Work and Work Incentives Improvement Act
- Age Discrimination in Employment Act
In each year, the Commission also offered its Disabilities Awareness Program to thousands of school children from around the state. The program is designed to dispel myths about disabilities and people who live with disabilities, through classroom lectures and essay and art contests. In June of 2000 and 2001, award luncheons were held at the Executive Mansion to celebrate each academic year’s contest winners. Their works were also presented in special editions of the Commission's newsletter in the Fall of each year and are available on-line at the Commission’s website.

In 2001, the Commission also completed another installment of its on-going video series, *Disability and the Law*. The award-winning series is co-produced with the NYS Bar Association and broadcast on local cable television stations throughout New York. Videos are also available for purchase and can be ordered through the Commission’s website. The most recent installment focuses on Traumatic Brain Injury.
Promoting Excellence
&
Fostering Awareness of Commission Services

It is rare that someone calls the Commission to register a “compliment.” Most people call with complaints or concerns about care, or to report serious, untoward and frequently tragic events. However, in pursuit of these matters and in the field daily, Commission staff have opportunities to witness many exemplary programs.

Initially hired for their wealth of skills, Commission staff, in their statewide work, continue to be exposed to a breadth of clinical and other practices rarely seen by clinicians and administrators of any one program in New York - practices which should be replicated.

In developing its strategic plan, the Commission decided to capitalize on this reality and to dedicate some of its energies to promoting excellence: to seize opportunities presented by conferences, speaking engagements, written materials and other means to spotlight exemplary programs as well as alternatives to practices which the Commission’s experience has shown to be less than desirable.

As the information shared in this endeavor arises out of the Commission’s everyday work, pursuit of this goal also advances another objective: fostering awareness of the Commission’s services. The following are examples of Commission activities in 2000 and 2001 in these complementary areas.

“Promise of Opportunity”

In March 2000, the Commission joined with the NYS Developmental Disabilities Planning Council (DDPC), the Self-Advocacy Association of New York State (SAANYS) and the Office of Mental Retardation and Developmental Disabilities (OMRDD) to launch the “Promise of Opportunity” initiative. More than 700 direct care staff, agency administrators, consumers, family members and advocates attended an initial two-day conference and met in small teams to examine, discuss and foster best practices in the areas of: person-centered planning; recruiting, supporting and retaining direct support staff; and creating truly individualized service environments. More of a commitment than a simple conference, the attendees were invited to bring the information shared back to their home communities and to participate in local regional forums to spread the lessons learned to an increasing number of people who share in the dream of making NYS-CARES a reality. NYS-CARES - New York State Creating Alternatives in Residential Environments & Services - is Governor Pataki’s initiative to virtually eliminate the waiting list for residential services for people with developmental disabilities.

During the remainder of 2000 and 2001, Commission staff participated in “Promise of Opportunity” regional forums across New York, attended by well over 1,000 additional providers, advocates and consumers and their families who continued to explore ways of replicating model and innovative approaches to service delivery.
NYS Distance Education and Learning Project (NYSDEAL)

As an outgrowth of “Promise of Opportunity”, the Commission, the DDPC, SAANYS, OMRDD and the Office of the Advocate for Persons with Disabilities jointly developed and were awarded a grant from the State Office for Technology to develop an on-line training program for employees within the developmental disabilities service system.

State-operated facilities and over 1500 not-for-profit programs report that issues relating to maintaining a well-trained work force are of paramount concern in providing service to individuals with developmental disabilities and their families. The NYSDEAL project will provide standardized state-wide training in best practices for staff, and do so in a cost-effective manner.

The first training modules under development will focus on: medication administration, incident management and investigation, and case management services.

Speakers Bureau

On an average of twice a month, during 2000 and 2001, Commission staff made presentations on best practices to agencies and hospitals as part of their in-service training or grand rounds programs. The topics ranged from investigation procedures to financial practices. Agencies interested in this free service can schedule a Commission presentation by contacting Bill Combes at (518) 388-2887 or billc@cqc.state.ny.us.

Increased Use of the Internet

Information today is but a mouse-click away and at your desk in a matter of seconds. Receiving nearly two million hits on its website annually, the Commission has endeavored to use this tool wisely. In concert with the State Office for Technology, the Commission has made the site more user friendly and compatible with the Governor’s e-commerce and e-government initiatives: a search engine enables one to research topics appearing on the site, in this report and in past Commission newsletters and reports; and icons bring the visitor to all branches of government service.

Increasingly, the website is used to profile best practices and to share Commission news. Recent additions posted in 2000 and 2001 include:

✓ The Commission’s regular newsletter, Quality Care;
✓ Quarterly reports prepared for the Legislature profiling cases of note and ongoing Commission activities;
✓ Best practices relating to Selecting an Independent CPA and Not-for-Profit Board Governance, the latter piece offering links to web sites researched by the Commission and found to offer sound and critical advice of import to members of Boards of Directors; and
✓ Case studies dealing with diabetes management as well as vacation planning.

Visit the website at cqc.state.ny.us and send your comments to our webmaster: marcusg@cqc.state.ny.us.
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Postscript: 9/11

No accounting of recent events would be fitting without acknowledging and reflecting on the tragedy of 9/11. The year needs no reference; the date alone pinpoints the moment in history that life as we knew it as Americans changed.

In the immediate aftermath of 9/11, the Commission’s Help Line grew eerily quiet. Staff stationed, or in New York City on site visits, volunteered their clinical skills where help was needed. Upstate staff - nurses, Red Cross volunteers or firemen - offered their assistance, and the Commission made its New York City office space available to staff of other agencies displaced by the attacks, and updated its website to provide information on relief services.

In the days that followed, reports of service consumers who died in the Trade Center attacks started to come in. So did word of the tireless and heroic efforts by staff of mental hygiene programs to assist their clients and the community-at-large in a city traumatized by the senseless violence and immobilized by security and search and rescue measures. There were also the reports of service recipients who made room in their residential and day programs for others who had been displaced from their programs.

In a flash, 9/11 reflected our human condition. In that moment, we realized how vulnerable we all are, no matter how seemingly safe, able and healthy. We also realized how resilient we are, and our power, no matter how frail we are by virtue of circumstance or disability, to share in mutual recovery by simply caring, in whatever way, large or small.

These paradoxical lessons of 9/11 are not new. Rather, they are reminders of why all New Yorkers share in the mission of improving lives and protecting rights: it defines us as a civilized people. In concluding this report of activities for the years 2000 and 2001, the Commission recommits itself to fulfilling its unique role in this shared mission.
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Ann Reilly
Elaine Reinke
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Kevin Rex
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Elizabeth Hiddemen Rice
Richard Rice
Glenn Rickles
Elizabeth Riker
Rain Rippel
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Irene Roach
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Donna Robinson
Melvin Robinson
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Neal Rosenberg
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Dante Santora
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Shelley Seidman
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Israel Sherman
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Millicent Silver
Rachel Silverman
Carl Silverstein
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Crystal Simmons
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Jodi Witman
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Judith Young
Daniel Young
Donna Young
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Terence Zaleski
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Beth Zaprowski
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Claire Zerbe
Beth Zerrahn
Karen Ziemianski
Thomas Zimmerman
Molly Zimmerman
Judy Zirin-Hyman
Ronald Zito
Elissa Zucker
Jay Zuckerman
## Advocacy Services Network

<table>
<thead>
<tr>
<th>Region/Agency</th>
<th>Services Offered</th>
</tr>
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<tbody>
<tr>
<td><strong>Statewide</strong></td>
<td></td>
</tr>
<tr>
<td>New York State Commission on Quality of Care</td>
<td>Statewide Coordination of:</td>
</tr>
<tr>
<td>Advocacy Services Bureau</td>
<td>PADD, PAIMI</td>
</tr>
<tr>
<td>401 State Street</td>
<td>PAIR, CAP</td>
</tr>
<tr>
<td>Schenectady, NY 12305-2397</td>
<td>PABSS</td>
</tr>
<tr>
<td>(518) 388-2892 1-800-624-4143</td>
<td></td>
</tr>
<tr>
<td><strong>New York City &amp; Vicinity</strong></td>
<td></td>
</tr>
<tr>
<td>New York Lawyers for the Public Interest</td>
<td>PADD, PAIMI</td>
</tr>
<tr>
<td>151 West 30th Street, 11th Floor</td>
<td>PAIR, CAP</td>
</tr>
<tr>
<td>New York, NY 10001-4007</td>
<td>PABSS</td>
</tr>
<tr>
<td>(212) 244-4664</td>
<td></td>
</tr>
<tr>
<td>Center for Independence of the Disabled in New York, Inc.</td>
<td>CAP</td>
</tr>
<tr>
<td>841 Broadway, Suite 205</td>
<td></td>
</tr>
<tr>
<td>New York, NY 10003</td>
<td></td>
</tr>
<tr>
<td>(212) 674-2300 (Voice or TTY)</td>
<td></td>
</tr>
<tr>
<td>Brooklyn Center for Independence of the Disabled, Inc.</td>
<td>CAP</td>
</tr>
<tr>
<td>2044 Ocean Avenue, Suite B-3</td>
<td></td>
</tr>
<tr>
<td>Brooklyn, NY 11230</td>
<td></td>
</tr>
<tr>
<td>(718) 998-3000 (718) 998-7406 (TTY)</td>
<td></td>
</tr>
<tr>
<td><strong>Long Island Region</strong></td>
<td></td>
</tr>
<tr>
<td>Long Island Advocates, Inc.</td>
<td>PADD</td>
</tr>
<tr>
<td>2868 Merrick Road</td>
<td></td>
</tr>
<tr>
<td>Bellmore, NY 11710</td>
<td></td>
</tr>
<tr>
<td>(516) 783-1450</td>
<td></td>
</tr>
<tr>
<td>Touro College</td>
<td>PAIMI</td>
</tr>
<tr>
<td>Jacob J. Fuchsberg Law Center</td>
<td></td>
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<tr>
<td>300 Nassau Road</td>
<td></td>
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<tr>
<td>Huntington, NY 11743</td>
<td></td>
</tr>
<tr>
<td>(631) 421-2244 Ext. 333</td>
<td></td>
</tr>
<tr>
<td>Long Island Advocacy Center, Inc.</td>
<td>CAP</td>
</tr>
<tr>
<td>Herricks Community Center</td>
<td></td>
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<tr>
<td>999 Herricks Road</td>
<td></td>
</tr>
<tr>
<td>New Hyde Park, NY 11040</td>
<td></td>
</tr>
<tr>
<td>(516) 248-2222 (516) 877-2627 (TTY)</td>
<td></td>
</tr>
</tbody>
</table>
Advocacy Services Network

Nassau/Suffolk Law Services Committee, Inc.  PAIR
1757 Veterans Highway, Suite 50
Islandia, NY 11749
(631) 232-2400

Hudson River Region

Capital District Center for Independence, Inc.  CAP
855 Central Avenue, Suite 110
Albany, NY 12206
(518) 459-6422 (Voice and TTY)

Westchester/ Putnam Legal Services  PADD
4 Cromwell Place  PAIR
White Plains, NY 10601
(914) 949-1305

Disabilities Law Clinic at Albany Law School  PADD
80 New Scotland Avenue
Albany, NY 12208
(518) 445-2328

Disability Advocates, Inc.  PAIMI
5 Clinton Square, 3rd Floor  PAIR
Albany, NY 12207  PABSS
(518) 432-7861

Westchester Independent Living Center, Inc.  CAP
200 Hamilton Avenue, 2nd Floor
White Plains, NY 10601-1812
(914) 682-3926  (914) 682-0926 (TTY)

North Country, Central and Southern Tier Region

North Country Legal Services, Inc.  PADD
100 Court Street  PAIMI
Plattsburgh, NY 12901
(518) 563-4022  1-800-722-7380
and
P.O. Box 648
Canton, NY 13617
(315) 386-4586  1-800-822-8283

Legal Services of Central New York, Inc.  PADD
The Empire Building  PAIMI
472 South Salina Street, Suite 300  PAIR
Syracuse, NY 13202  PABSS
(315) 475-3127
**Advocacy Services Network**

Legal Aid Society of Mid-New York, Inc.  
255 Genesee Street, 2nd Floor  
Utica, NY 13501  
(315) 732-2131 (Voice and TTY)  
CAP

Resource Center for Independent Living, Inc.  
409 Columbia Street  
Utica, NY 13502  
(315) 797-4642 (315) 797-5837 (TTY)  
CAP

Legal Aid for Broome/Chenango Cos., Inc.  
30 Fayette Street  
P.O. Box 2011  
Binghamton, NY 13902  
(607) 723-7966  
PADD

**Western Region**

Western New York Advocacy for the Developmentally Disabled, Inc.  
590 South Avenue  
Rochester, NY 14620  
(585) 546-1700  
PADD

neighborhood Legal Services, Inc.  
295 Main Street  
Ellicott Square Building, Room 495  
Buffalo, NY 14203  
(716) 847-0650  
Statewide Technology Related Protection and Advocacy Program  
PADD, PAIMI

Regional Center for Independent Living, Inc.  
1641 East Avenue  
Rochester, NY 14610-1616  
(585) 442-6470 (Voice and TTY)  
CAP

Western NY Independent Living Project, Inc.  
3108 Main Street  
Buffalo, NY 14214-1384  
(716) 836-0822  
(Voice and TTY)  
CAP
Commission Staff

Executive
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Elizabeth Stack, Commissioner
Louis Billittier, Commissioner
[✝ 8/2/2000]
Angelo Muccigrosso, Commissioner
[since January 2001]
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Sally Rook

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Website: www.cqc.state.ny.us
E-mail: marcusg@cqc.state.ny.us

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1-800-624-4143 (voice and TTY) FAX: (518) 388-2860

Executive Offices: (518) 388-1281 FAX: (518) 388-1276

Press and Freedom of Information Law Officer: (518) 388-1270

Counsel's Office: (518) 388-1270

Death Investigations: (518) 388-2854
FAX: [e.g., Incidents, Deaths] (518) 388-2860

Policy Analysis: (518) 388-2835

Fiscal Unit: (518) 388-2835

Administrative Bureau and Personnel: (518) 388-2804

Advocacy Services: (518) 388-2892 FAX: (518) 388-2890

Surrogate Decision-Making Committee Program: (518) 388-2820
FAX: (518) 388-2828 or (518) 388-2829

Newsletter: (518) 388-1277