



# Improving Lives, Protecting Rights

## Commission Activities 2000 - 2001



NEW YORK STATE COMMISSION ON QUALITY OF CARE  
FOR THE MENTALLY DISABLED



George E. Pataki  
*Governor*

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## 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<sup>1</sup> 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 25<sup>th</sup> 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.

# Contents

<b>Maintaining and Improving Traditional Oversight Activities and Monitoring New Service Trends and Modalities .....</b>	<b>1</b>
Individual Case Activities and Investigations .....	2
Programmatic and Fiscal Reviews .....	5
Elopement Study .....	5
Improper Billing Practices .....	5
Survey of Electro-convulsive Therapy Practices .....	6
Commission Work Revisited .....	7
Monitoring New Service Trends and Modalities .....	8
<b>Assisting People with Mental Disabilities Outside the Traditional Mental Hygiene System .....</b>	<b>9</b>
Adult Homes .....	9
Ongoing Adult Home Reviews and Interagency Activities .....	11
Dollars and Sense within the Adult Home Industry. ....	11
Interfacing with the Criminal Justice System .....	12
<b>Advocating For and Empowering People with Disabilities .....</b>	<b>14</b>
Surrogate Decision Making Committee Program: Statewide Expansion .....	14
Maintaining and Enhancing a Statewide Network of Advocacy Services .....	15
Knowledge is Power: Empowering Through Training .....	17
<b>Promoting Excellence and Fostering Awareness of Commission Services .....</b>	<b>19</b>
“Promise of Opportunity” .....	19
NYS Distance Education and Learning Project .....	20
Speakers Bureau .....	20
Increased Use of the Internet .....	20
<b>Postscript: 9/11 .....</b>	<b>22</b>
<b>Appendices:</b>	
Appendix A: Listing of Advisory Council and Medical Review Board Members	
Appendix B: Listing of Surrogate Decision Making Committee Panel Members	
Appendix C: Listing of Regional Advocacy Offices	
Appendix D: Listing of Commission Staff	



## **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 task 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**

Adult Care Facility	Capacity	County	
Adventist Home	49	Columbia	
Anna Erika Assisted Living	427	Richmond	
Bayview Manor*	229	Kings	
Bridgewell*	166	Erie	Now a Supported Housing Program
Brooklyn Manor	216	Kings	
DiAntoni's Home for Adults*	24	Rockland	Closed
Elm York Home*	286	Queens	
Garden of Eden Home	202	Kings	
Green Hills Estate	164	Rockland	
Hedgewood Home	200	Dutchess	
Hylan Manor Center*	62	Richmond	
Johnson's Adult Home	24	Chautauqua	
King Solomon Manor	240	Queens	
Lakeside Manor Home for Adults	200	Richmond	
Leben Home for Adults*	361	Queens	Now Known as Queens Adult Care Center
Loeb House for Adults	87	Rockland	
Long Beach Atlantic	200	Nassau	
Martin Residence	45	Columbia	Closed
Monticello Manor*	100	Sullivan	
New Brighton Manor*	130	Nassau	
New Monsey Park Home	263	Rockland	
New Haven Manor	123	Queens	
New Brookhaven Town House*	182	Suffolk	
New Rochelle Home for Adults	250	Westchester	
Ocean House Center*	125	Queens	
Seabay Manor	176	Kings	Now Known as Oceanview Manor
Pacific House Residence*	80	Kings	Closed
Park Inn Home*	181	Queens	
Queens Manor*	266	Queens	Closed
Rena's Residence for Adults	99	New York	
Renaissance Plaza	316	Broome	
Ridge Rest Home*	58	Suffolk	
Roscoe Manor	35	Sullivan	
Rosewood Terrace Home	40	Otsego	
Sanford Home*	200	Queens	
Seaport Manor*	346	Kings	Closing
South Country Adult Home	172	Suffolk	
Surf Manor Home for Adults	200	Kings	
Surfside Manor	124	Queens	
The Abbey	88	Albany	
Troy Adult Home	33	Rensselaer	
United Helpers Adult Home	40	St. Lawrence	
Valentine House	53	Rockland	

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

report, *Exploiting Not-for-Profit Care in an Adult Home: The Story Behind Ocean House Center, Inc.*, considerably more public funds, approximately \$37,000 a year per-capita, were expended on the home's residents. However:

- ✓ Ocean House operators diverted millions of dollars that could have been spent on client services for their personal gain over a five year period;
- ✓ Mental health providers improperly obtained hundreds of thousands of dollars in slightly over one year through double billing and by submitting claims for services which hardly met clients' needs, services such as coloring pictures in children's coloring books at a cost of \$141 per person for a 15 – 20 minute session; and
- ✓ During the same period, a home health care agency received nearly a half-million dollars for services that should have been provided by the home's operators.

These findings resulted in the indictments of Ocean House's operators on various criminal charges brought by the Manhattan District Attorney; proceedings by the Health Department to recoup nearly a million dollars in improper billings to the Medicaid program by several providers; and increased monitoring by Office of Mental Health of outpatient programs serving adult home residents.

Moreover, they prompted a broader 2001 Commission inquiry which examined the costs and quality of services, including residential, health and mental health services, for residents of 11 of the largest down-state adult homes serving nearly 3,000 residents with mental illness. The Commission's study, *Adult Homes Serving Residents with Mental Illness: A Study on Layering of Services*, published in 2002, established a foundation for discussion among advocates, operators and policy makers on more fiscally sound and clinically responsive means of using public funds to serve adult home residents with mental illness.

## **Interfacing with the Criminal Justice System**

During the Commission's strategic planning process, family members, advocates and program operators repeatedly voiced concern over the numbers of individuals with serious mental illness consigned to the criminal justice system and the quality of their care. Nationally, it is estimated that the number of people with mental illness in jails and prisons is five times the number of patients in state hospitals.

Under the federal protection and advocacy program, the Commission provides funding to legal service and other corporations to offer an array of advocacy services for individuals with disabilities, including those who are incarcerated. But under state law, the Commission has no oversight responsibility for state or local correctional facilities - such is the responsibility of the NYS Commission of Correction.

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.

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

*Psychiatric News*, January 22, 2002

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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 every-day 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](mailto: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](http://cqc.state.ny.us) and send your comments to our webmaster:

[marcusg@cqc.state.ny.us](mailto:marcusg@cqc.state.ny.us).

<b>Speaker's Bureau Topics</b>			
<b>Legal</b>	<b>Investigations</b>	<b>Fiscal</b>	<b>Life Planning</b>
Rights of Minors in Decision-Making	Child Abuse in Facilities	Board of Directors Training	Advance Directives
Ethical Issues in Representing People with Disabilities	Adult Abuse & Death Investigations	Current Legislation on Intermediate Sanctions	End of Life Decisions
General Rights of People with Disabilities	Sexuality & Consent	Diversion of Funds	Guardianship: Why & How To
Legislative Process	Record Reviews	Personal Allowance Fund Issues	Future Planning: Wills, Trusts, Estates
Americans with Disabilities Act & Section 504 of the Rehabilitation Act	Restraint & Seclusion	Not-For-Profit Pitfalls: Could This Happen to You?	The Protection and Advocacy for Beneficiaries of Social Security Program
Human Rights Law & Public Policy	Could This Happen in Your Facility?		
Legal Ramifications of Child Abuse Reporting	Less Adversarial Advocacy		
Commission on Quality of Care Overview	Abuse/Neglect: What Is It and How to Stop It		

## **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.

# Appendices



# Mental Hygiene Medical Review Board

Michael Baden, M.D.  
Harvey Bluestone, M.D.  
Jerry Broman, M.D.  
Peter Fisher, M.D.  
Irwin Hassenfeld, M.D.  
Arnold Merriam, M.D.  
Saul Moroff, M.D.  
Moritza Molina, M.D.  
Sophia Socaris, M.D.  
H. David Stein, M.D.  
Dan Thompson, M.D.  
Edward Timm, Pharm.D.  
Heidi Van Bellingham, M.D.

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Anna Marie Lusins  
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E. Regis Obijiski  
Dimitra Risueno  
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Elizabeth Wickerham



## Surrogate Decision-Making Panel Members

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David Adelson	Kermit Augustine	Marc Berk	Colleen Brown	Robert Cincotta
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Sandra Affolder	Matthew Babcock	Irving Berkowitz	Ethlyn Gean Brown	Leslie Clark
Diana Aguglia	Mary Elizabeth Babcock	Elizabeth Berman	Mary Browne	Mary Ann Clark
Patricia Al-Ali	Amindra Babilonia	Erica Berman	Patricia Brunetti	Dennis Clary
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Betty Allen	Kathy Fiato Baker	William Biggee	Francis Burke	Robin Collins
Patty Allen	Vicki Baldwin	Yvonne Bisel	Douglas Burleigh	Deborah Combs
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Lisa Antrim	Janet Bedney	Joseph Brady	Rokki Knee Carr	Amanda Beth Crowley
Robert Apple	Lea Bedore	Anne Brady	William Carroll	Danny Cuciti
Stanley Applebaum	Maria DeMarco Begley	Marie Brane'	Marie Carrubba	Leslie Cumming
Mark Applewhite	Glen Begrow	Joseph Braziller	Maryjoan Case	Kevin Currier

## Surrogate Decision-Making Panel Members

Linda Curtis	Cassandra Duff	Louis Gallagher	John Hamm	Lydia Hucker
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Robert Davey	Patrick Dwyer	Pamela Gardner	Janet Hansen-Moyes	Connie Hynes
Mark Davidson	Anthony Earley	Theresa Gardner	Anne Hanson	Salvatore Iacullo
Jordan Davis	Lori Edwards	Charlotte Gardner	Patricia Harding	Beth Imperial-Rogers
L. Richard Davis	Gregory Edwards	Margaret Gardner	William Harker	Paige Ann Ingalls
Hilary Davis	Maria Eisenhauer	Pamela Doyle Gee	John Harkulich	Anne Jackson
Raymond de Silva	Patricia Ellison	Ira Gelinson	Claire Harnick	Stephen Jacobs
Joan Dean	Charlene Endal	Geneva Genovese	Joanne Harpel	Seymour Jacobson
James DeBerry	Debra English	Gail Ghigliotti	Tami Harpster	Paul Jaffe
Michel DeBottis	Tina Eskreis-Nelson	Dana Gibbs	Lynne Harrison	Janis Jastrebski
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Jean Ann Decker-Zambrano	Richard Everitt	David Gilbert	Susan Harvey	JoAnn Johnson
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Michael Dempsey	Helen Farrell	Charles Githler	Michael Heaney	Mary Jones
Dorothy Dempsey	Elizabeth Argar Fass	Roni Glaser	Susan Heath	Tracy Jong
Sandra DeMyer-Gapin	Tina Fassnacht	Leo Glass	Mary Heavey	Kimberly Kadziolka
Victoria DeNinno	Salvatore Fauci	Martin Gleeson	Betty Helmsworth	Judith Kahn
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Gladys Jean Diji	Margaret Flint	Isabelle Grenon	Arthur Holmberg	Zarina Khan
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Gail Donus	Elizabeth Frederick	Mark Gustin	David Hornick	Earl Klein
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Lori Doughty	David Freshi	Susan Haggett	Marie Horton	Joan Klink
Colleen Downes	Lisa Friedman	Irene Hakanson	Sheryle Hosking	Kathleen Knaak-Cole
Lori Ann Drake	Patricia Frungillo	Sinai Halberstam	Jack Houk	Patricia Knamm
Doris Drucker-Katz	Julianne Furlong	Rosa Hall	Mari Howard	Marie Knapp
Jean DuCoffe	Mary Gage	Patricia Hall	Sharon Huck	Patricia Knuth

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Margaret Kolodzey	Lynette Loadholt	Thomas McCluskey	Therese Mudd	Joseph Paris
Deborah Kolomick	Carl Lobdell	Michele McConville	Robert Muhlnickel	Margaret Parise
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Maneck Kotwal	Geoffrey Long	Brigid McGinley	Lisa Murphy	Mary Parker
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Mary Krebs	Constance Lopez	Janet McGlone	John Murphy	Michael Pasternack
Carol Kriesberg	John Lounsbury	Jane McGrady	Janet Murphy	Joan Pastore
Jocelyne Kristal	Linore Lounsbury	Regina McGraw	Mary Ellen Murphy	Denise Paszkiewicz
Bina Kumar	Guido Loyola	Peter McHugh	Debbie Murray	Jill Patel
Cathy LaBarge	Rhys Ann Lukens	Kathy McKeever	Catherine Myers	Nora Pavlak
Laure Lafontant	Robert Lukow	Colin McMahan	Ellen Naidus	Renee Peay
Joanne LaForge	Dana Lundberg	Nora McQueeney	Virginia Nailor	Andreas Pederson
Lawrence Lagarenne'	Anastasia Lupe	Janet Meaney	Elaine Nakovics	Jane Ann Peer
Eunice LaLonde	Mitchell Lurye	Lisa Meissner	Donald Napolean	Darlene Peets
Pamela LaLonde	Arthur Lussi	Angel Mejias	Hinda Naschke	Paul Peets
Deanna Lamb	M. Kathleen Lynn	Marcia Menasse	Ann Nehrbaauer	Phylliss Pellet
Joseph Lamendola	Gary Maas	Ann Marie Menendez	Joan Nelson	Marjorie Perfetti
Barbara Lamoreaux	Audrey MacDougall	Alan Merkin	Danielle Newman	Everett Person
Diane Lang	Ellie Mack	Henrietta Messier	W. Bruce Newman	Barbara Petak
Kathleen Lang	Michael MacWilliams	Mildred Messmer	Mary Nicholls	Jean Petela
Delores Langford	Carl Madonna	Mark Metzger	Frederick Niebuhr	Linda Peters
Susan LaPlante	Gary Maffei	Edward Mevec	William Night	Karen Petrie
Helen LaRue	Eileen Mahar-Mallon	David Meyers	Joan Niles	Margaret Petrosino
Sylvia Lask	James Maher	Harold Meyers	Peter Nilsson	Tanya Pfaff
Bonnie Laugen	Josephine Maimone	Angela Mezzomo	Toni Nixon	Flo Pflaster
Bertha Laury	Linda Mainetti	Linda Miele-Cavallaro	Kristen Northrup	Jacqueline Phillips
Ann Marie Lavallo	Laura Malachowski	Tracy Miller	Margaret Worden Norton	Collette Phillips
Dawn LaVigne	Carolyn Malenda	Anita Miller	Toni Norton	Siebert Phillips
Francis LaVigne	Joanne Mallon	Selma Miller	Pamela Nowinski	Gary Piccione
Kevin Lawkowski	Catherine Maloy	Margaret O'Grady Miller	Robert Nugent	Daphne Pickert
James Lawler	Roger Manning	Rosa Miller-Martin	Lawrence Nusbaum	Barbara Pioli
Fran Lawless	Robert Manor	Judith Mills	Kevin O'Brien	Alva Pisapia
Christine Lawrence	Polly Maouris	Joann Mills	Timothy O'Connor	George Plevretes
John Lawrence	Mary Marcantonio	Joseph Mineo	Karen Odock	Thomas Plimpton
Lorriane Lawson	Richard Marchese	Nelli Mitchell	Pat O'Hara	Beatrice Plympton
Robert Lazow	Mary Jo Marchisello	Stuart Mitchell	Nancy O'Hara-Kraft	Darlene Podolak
Philip Learned	Sara Marcille	Lynda Molesworth	Patricia Okoniewski	Carol Poisman
Chung Lee	Maureen Marcus	Robin Moller	Elizabeth Oliver	Elizabeth Polisoto
Donald Lefari	Barbara Margolis	Michael Monahan	Barry Organ	Erno Poll
Sharon Lehmann	Ari Markenson	Richard Monck	Judy O'Rourke	Aileen Pollack
Ronald Lehrer	Jeffrey Marks	George Monk	Sara Ort	Davis Pollack
Risa Leonard	Stella Marrs	Wendy Monroe	Phyllis Osborne	AnnMarie Pollard
Juliette Levin	Andrew Marshall	Patricia Monteverde	Marion Ostrander	Aaron Pomerantz
Debra Lewis	Rita Martin	Susan McDonald Montrose	Philip O'Sullivan	Paul Pontiff
Randall Lewis	Shirley Martin	Michelle Montroy	Melissa Ottenstein	Patricia Potocar
Kimberly Lewis	Jean Martin-Cinelli	Joanne McElroy Moore	Sheila Otto	Diane Price
Ted Lewis	Victor Martini	Rosalyn Moore	Ellen Owens	Marian Prince
Frederick Lewis	Joan Masaitis	Sallie Moore	Samuel Pagano	Valorie Joy Promisel
Marcia Lieb	Barbara Masi	Andrea Moran	Margaret Paine	Onofrio Puleo
Mai Lutterus Liinve	Kathaleen Mason	Sherman Moreland	Carolyn Pal	Carol Puschaver
Beth Linderman	JoAnn Matthewson	Stephanie Moriarity	Margaret Palmer	David Putney
Dora Lipman	Emily Maute	Jean Morris	Judith Palumbo	John Quain
Bonnie Lisbona	Terri Maxymillian	Patricia Morrison	Barbara Pancari	Jack Rabin
Alison Lisefski	Michele Mayer	Maira Morrissey	Laura Panek	Edythe Raiten
Ronald Litchman	Robert Mayo	Steven Mosenson	Donald Pangburn	Stephen Ramos
Harold Litter	Kevin McCardle	Norma Moss	Michelle Paniccia	Mary Randall
Thomas Lloyd	June McCarrell	Kim Mosteller	Polly Panzella	Joseph Ranni

## Surrogate Decision-Making Panel Members

Mary Rappole	Donna Saskowski	Paulette Sladkus	Barbara teRiele	Michelle Whitcomb
Margaret Raustiala	Tracy Sawyer	Erica Slezak	John H. Thomas	Daniel White
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Richard Reich	Scott Sayward	Mary Ellen Smith	Anne Thompson	Barbara Widrig
Fiona Reid	Carol Scal	Brenda Smith	Caryl Tierney	Edward Wilcenski
Ann Reilly	Randy Schaal	Carolyn Smith	Richard Timo	Shirley Wilcox
Elaine Reinke	Juli Schaefer	Kellie Smutz	Susan Todd	Ken Wiley
Paul Reiter	John Scheffel	Kevin Snider	Stacey Torchio	Richard Willert
Stephanie Repak	Janet Scheiber	Elizabeth Snyder	Monica Toye-Smith	Kimball Williams
Kevin Rex	Suzanne Schein-McLemore	John Sparrer	Joseph Trachtenberg	Karl Williams
Louise Rheem	Ann Scherff	Malcolm Spector	Gerry Trautz	Peter Williams
Judy Rhodes	Mark Schneider	Jerome Sperber	Kendra Travis	Maria Willis
Elizabeth Hiddemen Rice	Shirley Schoener	Marlene Sprague	Thomas Trevett	Lesmore Willis
Richard Rice	Ellen Schoonover	Traci Stahl	Maryellen Tria	Scott Wing
Glenn Rickles	Peter Schreier	Carolyn Stalker	Gloria Trombly	Amy Winn-Claus
Elizabeth Riker	Irene Schukin	Carol Staves	Helen Trowbridge Hanes	Jodi Witman
Rain Rippel	Isabel Schwartz	Rosemarie Stazzone	Kimberly Tubo	Alden Wolfe
Leslie Rivkin	David Sears	Jeanne Stearns	Nora Tulchin	Kathryn Wood
Irene Roach	Linda Sears	Lori Stefferson	James C. Tunny	Alice Woodford
Peter Robbins	Cara Seekings	Evelyn Stefos	Josena Turner	Joanne Woodside
Joan Lensky Robert	Colleen Seeley	Ronnie Steinwolf	Toni Turner	Ronald Wozniak
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Melvin Robinson	Shelley Seidenberg	Thomas Stephens	Eleanor Tyler	Diane Yaddow
Matthew Rock	Steven Seidman	Philip Sterdt	Sharon Tyo	Amy Yero
George Rockman	Linda Selby	Sandra Stevens	Jan Ulman	James Yonai
Robert Roe	Jack Sender	Maureen Stewart	Lyn Nicole Uterano	Patricia Young
Maureen Romer	Richard Sepe	Charles Stewart	Judith Valenti	Judith Young
Bernice Romig	John T. Servodidio	Robert John Stewart	Linda Van Buskirk	Daniel Young
Irene Ropelewski	Theresa Sgrulletta	Brenna Stewart	Craig Van Vessem	Donna Young
Lisa Rosen	Kristen Shaheen	Timothy Stickelman	David Vandenburgh	Patricia Zaccari
Philip Rosenberg	Rita Shantzis	Wendy Stickley-Ocker	Barbara Venete	Jennifer Zagami
Neal Rosenberg	Mildred Shapiro	Christina Stile	Viena Victoria	Terence Zaleski
Michael Rosenberg	John Sharon	Claire Stratford	Ralph Vinchiarello	Mel Zalkin
Linda Ross	Barbara Sherman	Oscar Straus	Linda Virelli-Gucker	Beth Zaprowski
Wendy Rothstein	Debra Sherman	Susan Streeter	John Von Ahn	Merryl Snow Zegar
Patrick Rourk	Israel Sherman	Howard Strongin	Cheryl Wahl	Martha Zell
Richard Rowe	Alla Shkolnik	Risa Sugarman	Barbara Wale	Charles Zelows
Debra Royce	Barbara Short	Catherine Sullivan	Elliot Wales	Claire Zerbe
Judith Rubin	Helene Shulkin	Mary Sullivan	Susan Wallach	Beth Zerrahn
Isaac Rubin	Eric Shults	James Sullivan	Timothy C Walsh	Karen Ziemianski
Cheryl Rundle	Joanne Siegal	Merle Sullivan	Stephen Walsh	Thomas Zimmerman
Karen Russell	Carolyn Siegel	Kathy Summa	Maureen Walsh	Molly Zimmerman
Claudia Russell	Albert Siewers	Nadean Summers	Amy Walsleben	Judy Zirin-Hyman
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Kathleen Ryan	Carl Silverstein	Patricia Swolak	Diane Webster-Brady	
Linda Sager	Cheryl Simeone	John Szolnoki	Eileen Wegman	
Jane Salchli	Marjory Scarlet Simmons	Jan Tacoronti	Barry Weiner	
Rebecca Salerius	William Simmons	Karen Taddeo	Rosalie Weiner	
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Margaret Sandercock	Randy Siper	Darleen Taylor	Mark Flack Wells	
M. Madeline Sansever	John Peter Sipp	Joan Taylor	Lauren Welsh	
Carman Santor	Lorraine Siskavich	Claudia Taylor	Frances Wenderlich	
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Michael Sarner	Nancy Skiff	Paul Tendler	Frederick Wetzel	

# Advocacy Services Network

## Region/Agency

## Services Offered

### Statewide

New York State Commission on Quality of Care  
Advocacy Services Bureau  
401 State Street  
Schenectady, NY 12305-2397  
(518) 388-2892      1-800-624-4143

Statewide Coordination of:  
PADD, PAIMI  
PAIR, CAP  
PABSS

### New York City & Vicinity

New York Lawyers for the Public Interest  
151 West 30<sup>th</sup> Street, 11<sup>th</sup> Floor  
New York, NY 10001-4007  
(212) 244-4664

PADD, PAIMI  
PAIR, CAP  
PABSS

Center for Independence of the Disabled in New York, Inc.  
841 Broadway, Suite 205  
New York, NY 10003  
(212) 674-2300 (Voice or TTY)

CAP

Brooklyn Center for Independence of the Disabled, Inc.  
2044 Ocean Avenue, Suite B-3  
Brooklyn, NY 11230  
(718) 998-3000      (718) 998-7406 (TTY)

CAP

### Long Island Region

Long Island Advocates, Inc.  
2868 Merrick Road  
Bellmore, NY 11710  
(516) 783-1450

PADD

Touro College  
Jacob J. Fuchsberg Law Center  
300 Nassau Road  
Huntington, NY 11743  
(631) 421-2244 Ext. 333

PAIMI

Long Island Advocacy Center, Inc.  
Herricks Community Center  
999 Herricks Road  
New Hyde Park, NY 11040  
(516) 248-2222      (516) 877-2627 (TTY)

CAP

## 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. CAP  
255 Genesee Street, 2nd Floor  
Utica, NY 13501  
(315) 732-2131 (Voice and TTY)

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

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

## Western Region

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

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

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

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



## Commission Staff

### Executive

(518) 388-1281

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Elizabeth Stack, Commissioner  
Louis Billittier, Commissioner  
[† 8/2/2000]  
Angelo Muccigrosso, Commissioner  
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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





**George E. Pataki**  
*Governor*

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**New York State Commission on Quality of Care  
for the Mentally Disabled**  
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