NEW YORK STATE COMMISSION ON

QUALITY OF CARE for the Mentally Disabled

AC 92 Rev. (4/82)

STATE OF NEW YORK

STANDARD VOUCHER

Voucher No.

1 PAY TO:

Payee Name (Limit to 31 spaces) Commission on Quality of Care for the Mentally Disabled

Address (Limit to 29 spaces) 99 Washington Avenue

City & State (Limit to 24 spaces) Albany, New York

Zip Code 12210

ANNUAL REPORT 1995-96

QUANTITY	DESCRIPTION OF SERVICES--July 1, 1995 to June 30, 1996	Amount
39,324	Persons Served Through PADD, CAP,& PAIMI Networks	
23,883	Complaints Acted Upon	
5,962	Reports of Suspected Adult Abuse Reviewed	
2,188	Recommendations Made	
603	Site Visits	
252	Deaths Investigated	
319	Surrogate Decision-Making Cases Reviewed	
147	Reports of Suspected Child Abuse Responded To	
6	Published Reports	
	TOTAL EXPENDITURES FOR SERVICES	
	State Operations	
	General Fund	$3,097,205
	Special Revenue Fund - Federal	3,312,056
	Special Revenue Fund - Other	1,442,407
	Aid to Localities	
	General Fund	$ 112,104

PAYEE CERTIFICATION:
I certify that the above bill is just, true and correct that no part thereof has been paid except as stated and that the balance is actually due and owing, and that taxes from which the State is exempt are excluded.

Laurence J. Brandon

PAYEE'S SIGNATURE IN INK

1995-96

Date

Chairman

Title

Commission on Quality of Care for the Mentally Disabled

Name of Company

TOTAL	$7,963,772
Discount %	
NET	$7,963,772

In an effort to reduce the costs of printing, please notify the editor of this annual report if you wish your name to be deleted from our mailing list, or if your address has changed. Contact:

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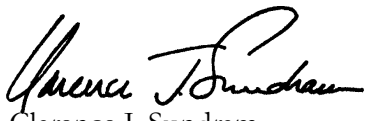
Foreword

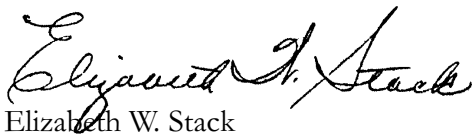
The exercise of compiling an annual report is more than simply an attempt to meet the requirements of a law that commands state agencies to produce such a report. That legal mandate could be satisfied in a number of ways, most of which would require less effort than it takes to produce this report each year.

We could count the countable or resort to grand generalizations about the value of the work we do. But the heart of our mission lies in the lives of the people we touch in day-to-day interactions – in answering their questions about care and treatment or their rights and options; in linking them to an agency or person who can help them; in investigating a complaint or concern; in advocating on their behalf; and sometimes in simply comforting them in a moment of grief and anguish. We are called by consumers, their families and friends, and their advocates; by administrators and concerned program staff, case managers and staff in regulatory agencies; by state legislators and local government officials. These contacts enable us to see the performance of the service system from many different vantage points, and to continually renew and inform our own oversight and advocacy perspectives.

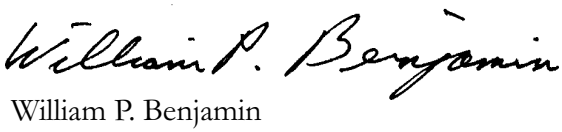
In each annual report, the Commission recognizes the importance of the individuals we serve and their concerns by recounting their experiences, and the effect that they had in remedying specific problems and in improving the quality of care for others. We have learned over the years that readers of the annual report value these personal stories and the lessons they teach. They thus have a continuing and contagious effect upon the process of quality improvement which is, after all, the Commission's central mission.



Clarence J. Sundram
CHAIRMAN



Elizabeth W. Stack
COMMISSIONER



William P. Benjamin
COMMISSIONER

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Assuring Quality in the Mental Hygiene System

The Commission, by its nature, statute, background and mission focuses on quality of care for individuals with disabilities. The Commission's roles as monitor and advocate have been essential for an historically vulnerable class of people. Through responses to individual complaints and calls for assistance, investigations of improper care, alleged abuse, deaths, and systemic practices such as incident review and programming, the Commission operates first and foremost to assure quality and accountability in the services provided to New York state citizens with disabilities.

During the reporting period, a review commenced following individuals discharged from developmental centers into a new community modality: Individual Residential Alternatives (IRAs). Another review reported on incident review practices in five New York City psychiatric centers, in the wake of prior investigation of violent incidents at Kingsboro Psychiatric Center. Active programming in psychiatric centers was revisited a decade after the Commission conducted extensive living conditions reviews and found a major factor which eroded the quality of life for patients: idleness. Meanwhile, we continue to receive 1500 calls per month for assistance on our 800 number, about 500 reports per month of alleged abuse or neglect, and another 150 or so cases per month of deaths to investigate.

Ultimately, the Commission has the responsibility of monitoring the system of mental hygiene services and reporting to the Governor, the Legislature, and the public on the manner in which laws and policies to protect the rights and promote quality of life for mentally disabled citizens are being implemented.

From Developmental Centers to the Community: Reviewing IRAs

In 1978, the year the Commission began operations, over 16,000 individuals resided in 20 state developmental centers, and only about 3,200 people lived in community residential facilities (i.e., community residences and intermediate care facilities).

By the end of the Commission's 18th annual report year, fewer than 3,100 individuals lived in the state's nine remaining developmental centers and their specialty units.

The downsizing and closure of state developmental centers was made possible by the steady development of community residential facilities and, by June of 1996, nearly 23,000 individuals with developmental disabilities resided in such facilities, which can be found in nearly every village, town, and city across the state.

Over the past 18 years, the Commission has monitored the growth and quality of community residential programs through its individual case investigation activities and more formal policy and fiscal studies (e.g., *Crossing the Line from Empowerment to Neglect: The Case of Project L.I.F.E.,* July 1994; *Missing Accountability: The Case of Community Living Alternative, Inc.,* June 1994; *Pitfalls in the Community-Based Care System: A Review of the Niagara County Chapter New York State Association for Retarded Children, Inc., and Agencies Responsible for Its Oversight,* September 1984; *Right at Home: A Review of Upstate Community Residences of the Mentally Disabled,* November 1983; *Willowbrook: From Institution to the Community, A Fiscal and Programmatic Review of Selected Community Residences in New York City,* August 1982; *Converting Community Residences into Intermediate Care Facilities for the Mentally Retarded: Some Cautionary Notes,* October 1980).

A late 1995 complaint sparked a Commission review of a relatively new modality in the state's continuum of community residential care: the Individualized Residential Alternative (IRA).

With less regulatory requirements than New York State's traditional community residences, or the highly federally regulated ICF/DD program, by design IRAs are to be, as the name implies, residences designed to meet the needs of the individual rather than a set of one-size-fits-all governmental standards. Whereas a person living in a traditional community residence or an ICF could expect to receive all the services spelled out in voluminous regulation (which all his or her peers in the residence would also receive), a person entering an IRA would be assured a safe and healthy living environment (in accord with applicable regulations and codes) and additional services, the nature and frequency of which would be prescribed by his or her unique needs and desires, not regulation. This individualized bundle of residential and other services would be financed through SSI and Medicaid under the Home and Community-based Waiver Service Program initiative.

The IRA care modality was piloted in the early 1990's and expanded dramatically in 1994-95 when a large number of traditional community residences and ICF/DDs converted to IRAs. By December 1995, there were almost as many people living in IRAs (7,261) as in traditional community residences (7,487), and as in ICF/DDs (8,552).

In late 1995, the Commission received an anonymous complaint that individuals being placed in the state-operated IRAs from Letchworth Village Developmental Center, which was in the process of closing (and has since closed), were not receiving appropriate services.

In response, Commission staff conducted unannounced visits to six Letchworth Village IRAs in which half of the individuals discharged from the developmental center in the last quarter of 1995 had been placed.

Overall, with minor exceptions, it was found that the individuals were receiving appropriate, but only basic, custodial care. That is, they were well-dressed and groomed, their homes were in good repair and nicely decorated, and rudimentary life-safety and nutritional needs were met.

In four of the six homes, however, Commission staff found that individuals' developmental needs were not being appropriately addressed: severe maladaptive behaviors, including PICA, self-abuse, excessive masturbation, etc., were not adequately responded to; individuals in need of psychiatric care, occupational therapy, physical therapy, adaptive equipment, or even the most basic care of being repositioned in bed to prevent skin breakdown, were not receiving such; opportunities for integrating individuals into the community, now that they were "living in the community," were lost: the individuals spent most of their time in their homes due to, as staff reported, maladaptive behaviors, staff shortages, and adaptive equipment problems.

The average annual cost of care for the individuals living in the IRAs visited by the Commission was $145,000/per person.

The Commission's reports of findings to the OMRDD Commisisoner and Director of the Letchworth Village Developmental Disabilities Services Office resulted in an OMRDD Task Force review of IRAs in the Letchworth Village Developmental Disabilities Services Office and a plan of action to address underlying problems identified by the Commission including:

- inadequate service planning and coordination for IRA clients;
- poor staff training and oversight by clinicians; and
- inadequate staffing patterns and equipment.

Follow-up visits by Commission staff in 1996 indicated that the corrective action plan is being implemented. Most illustrative: in one home where five severely physically disabled residents spent most of their days at home in bed, without being properly repositioned, for want of adequate transportation, a day program, and guidance for staff, the house now has an extra van, the residents are attending out-of-home programming five days a week and seem, as house staff report, "brighter" and "happier," and evidence less maladaptive behaviors.

The Letchworth Village Developmental Disabilities Services Office review raised questions: was this an isolated problem, unique to the management of a particular developmental center in the final throes of closure? Or does it suggest more systemic problems in the design of the IRA modality? And, what of the costs? For $145,000/year per IRA individual in this DDSO, shouldn't one expect more than what was found during the Commission's initial unannounced visits?

At the request of the legislature, the Commission is currently seeking answers to these questions through a statewide fiscal and program review of IRAs operated by DDSOs and not-for-profit agencies.

Monitoring Incident Review at NYC Psychiatric Centers

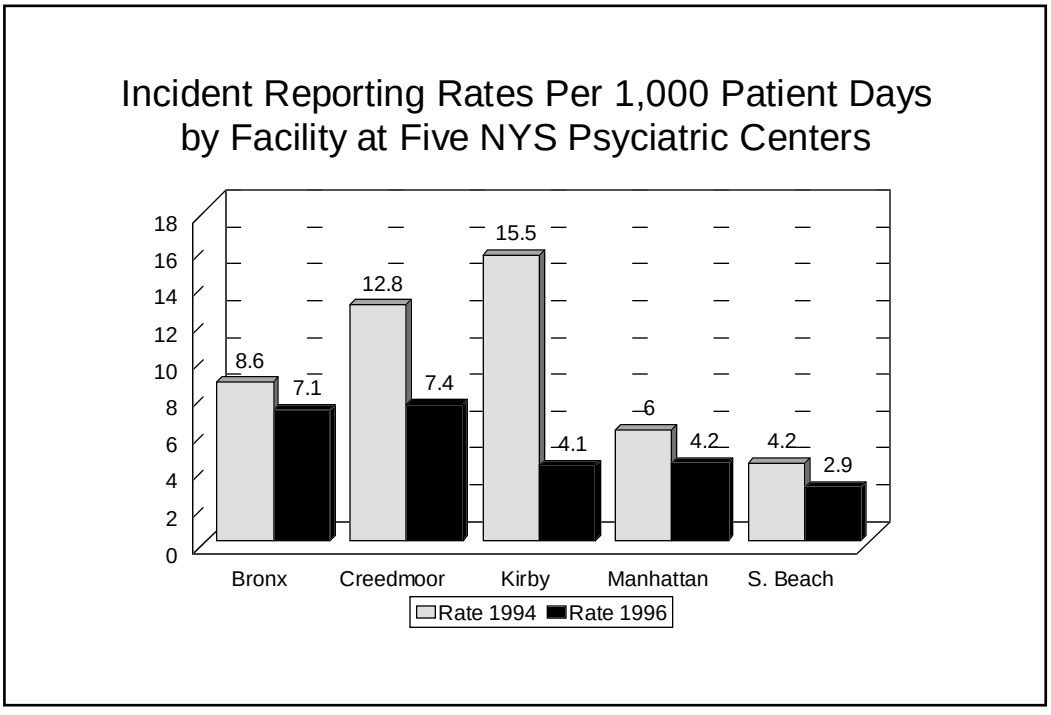
Protecting and promoting the well-being of the individuals they serve is a fundamental obligation of facilities operated or licensed by New York State to care for people with mental disabilities. The maintenance of an effective incident management system — one in which potentially harmful situations are identified, investigated and remedied — is a critical component of facilities' operations and vital to their fulfilling this basic mission.

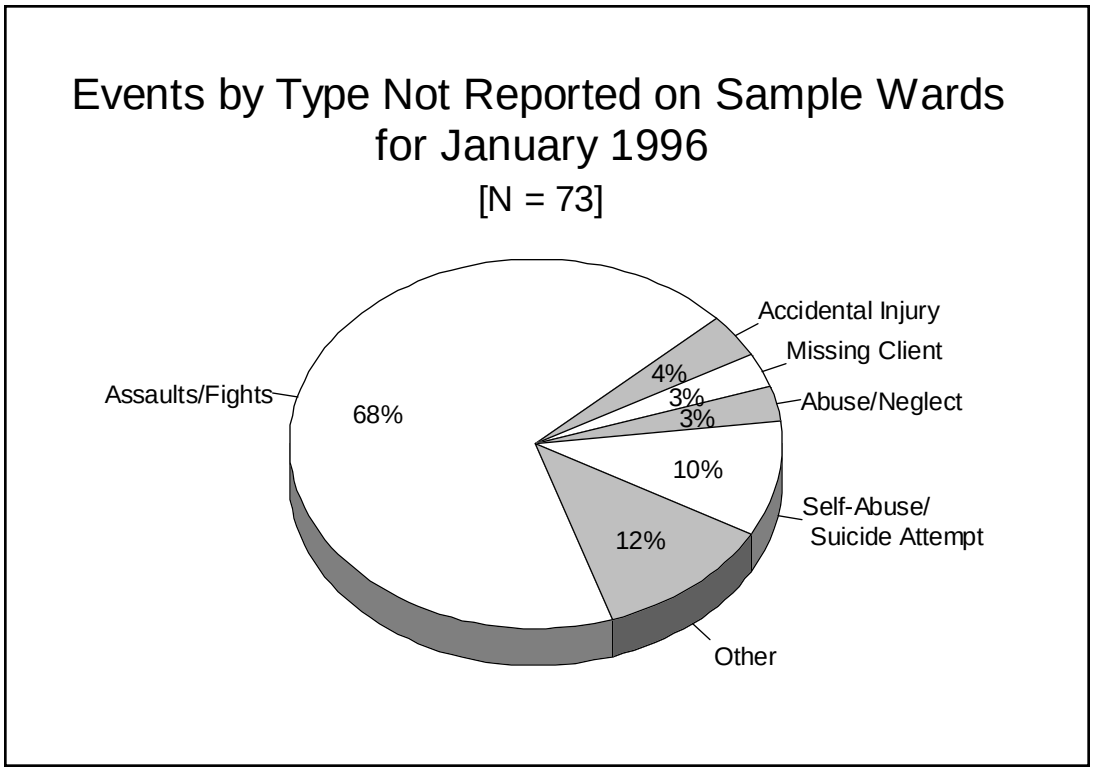
The 1994 homicide of one Kingsboro Psychiatric Center patient allegedly by a fellow patient, and the resulting Commission investigation of incident management practices at that facility [*Patient Safety and Services at Kingsboro Psychiatric Center,* July 1995], led to a broader Commission inquiry into incident management practices at five other adult psychiatric hospitals in New York City operated by the Office of Mental Health: Bronx, Creedmoor, Kirby Forensic, Manhattan, and South Beach Psychiatric Centers. The Commission report, *Incident Reporting and Management Practices at Five NYS Psychiatric Centers,* issued findings and made recommendations to the Office of Mental Health to address incident reporting and management deficiencies.

Findings

The Commission's review surfaced several positive findings:

- when incidents jeopardizing patient safety were identified and reported, patients were provided prompt protective measures and/or treatment services;





- episodes of patient elopements were reduced by more than 80% from 1994 to 1996 [reflecting the fruits of OMH's efforts to improve security at centers and accountability for patients' whereabouts];

- internal Incident Review Committees [IRCs] play an important role in monitoring facilities' responses to the most serious incidents. IRCs proposed recommendations for clinical intervention or enhanced safety above and beyond facility investigation recommendations in one-third of the cases reviewed by the Commission.

The Commission's review, however, also found a number of areas in need of improvement:

- the most serious deficiency was the underreporting of incidents, particularly patient-to-patient altercations, and the inconsistent interpretations of OMH regulations among various facilities;

- OMH's new computerized Incident Management and Reporting System [IMRS] rejected as "non-incidents" certain events historically managed as incidents, such as patient fights;

- The role and composition of the Incident Review Committees need re-examination—implementation of the IMRS system resulted in IRC review of fewer than half the incidents rated as more serious;

- both Bronx and Manhattan Psychiatric Centers experienced difficulties ensuring timely and thorough investigations.

Recommendations

The Commission report, while recommending the Office of Mental Health specifically address problem practices at Bronx and Manhattan Psychiatric Centers in conducting timely and thorough investigations, also called for OMH to take systemic steps to ensure an effective incident management system by:

- clarifying what constitutes a reportable incident and restating facilities' obligation to report, investigate, and remedy situations, regardless of possible erroneous prompts from the new IMRS system;
- convening a work group to critique the utility of the mandated IMRS system, including its value in identifying and classifying incidents;
- establishing criteria for which incidents require review by IRCs, to ensure review of all serious incidents and a sample of less serious ones, and including direct care therapy aides in their deliberations; and
- requiring facilities' Quality Assurance Programs to detect and remedy lax incident reporting practices on wards.

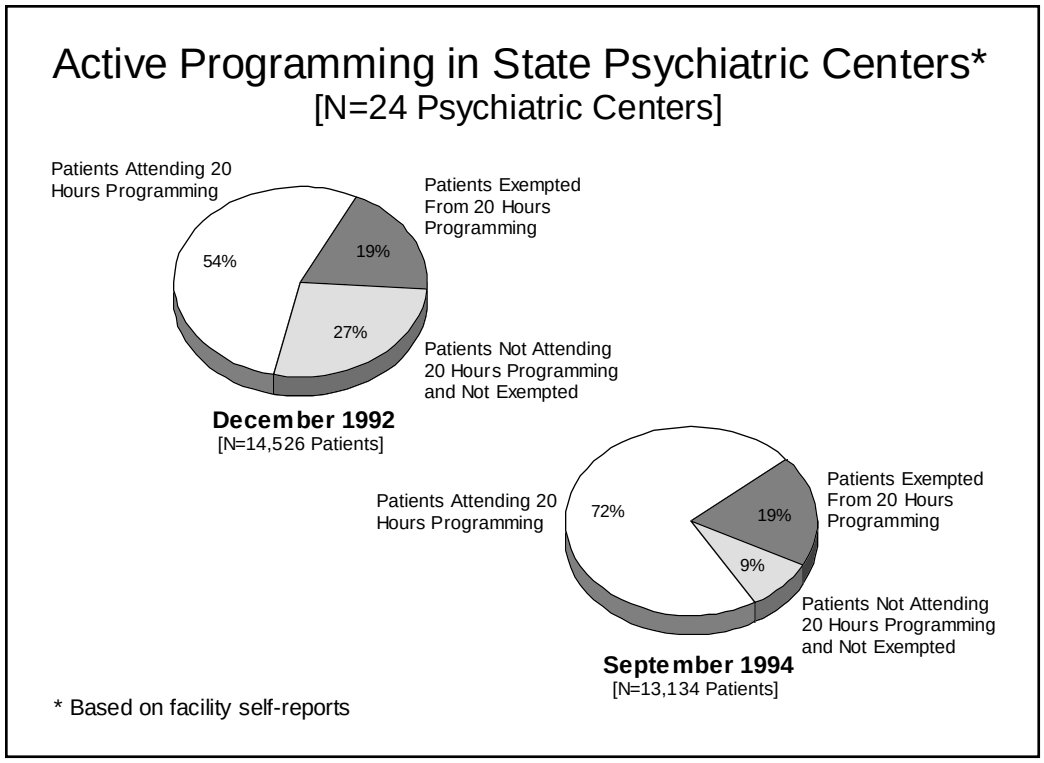
In response to a draft of the Commission's report, the Office of Mental Health generally concurred with the findings and recommendations.

Following Active Programming in State Psychiatric Centers

In the mid-1980's, the Commission conducted extensive reviews and issued reports on living conditions at all New York State's psychiatric centers. A common finding and central issue determined from these reviews to erode the quality of life of the individuals residing there was the prevalence of patient idleness and lack of active programming. Without meaningful activities, most patients spent the majority of their days just sitting in overcrowded dayrooms, wandering, sleeping, or staring at television, with few opportunities to acquire or maintain skills necessary to develop a sense of worth and good mental health.

Partly in response to the Commission's recommendations, Chapter 57 of the Laws of 1988 was enacted, which required the Commissioner of the Office of Mental Health to establish standards for active programming for patients in state psychiatric centers, including a standard for a minimal number of hours of activities to be provided each patient weekly unless he or she is exempted for clinical reasons.

The Commission publication, *A Brief Report on Active Programming in State Psychiatric Centers: Has Anything Changed?* indicates that, in the decade since the Commission last reviewed living conditions at the centers, meaningful activities for patients have both increased and improved.



In the very early years of implementation of the new statute, OMH could not verify the amount of programming or exemptions. By 1992 an automated system was in place and tracking on a quarterly basis was possible. By September 1994, 72 percent of patients served during that quarter were engaged in 20 or more hours of programming and only 9 percent were exempted.

The Commission's review also indicated that the data reported by OMH in its quarterly reports to the Legislature may be flawed as a result of differing opinions at various state psychiatric centers of what constitutes active programming, variable means of accounting for patient participation in activities and different standards for exempting patients. Commission recommendations in the report address the need to:

- establish consensus on what constitutes active programming;
- standardize the means for ascertaining the level of patient participation;
- clarify standards concerning patient exemptions; and
- provide technical assistance to those centers with low levels of activity, and replicate at other facilities the approaches to programming employed by facilities truly providing high levels of activity.

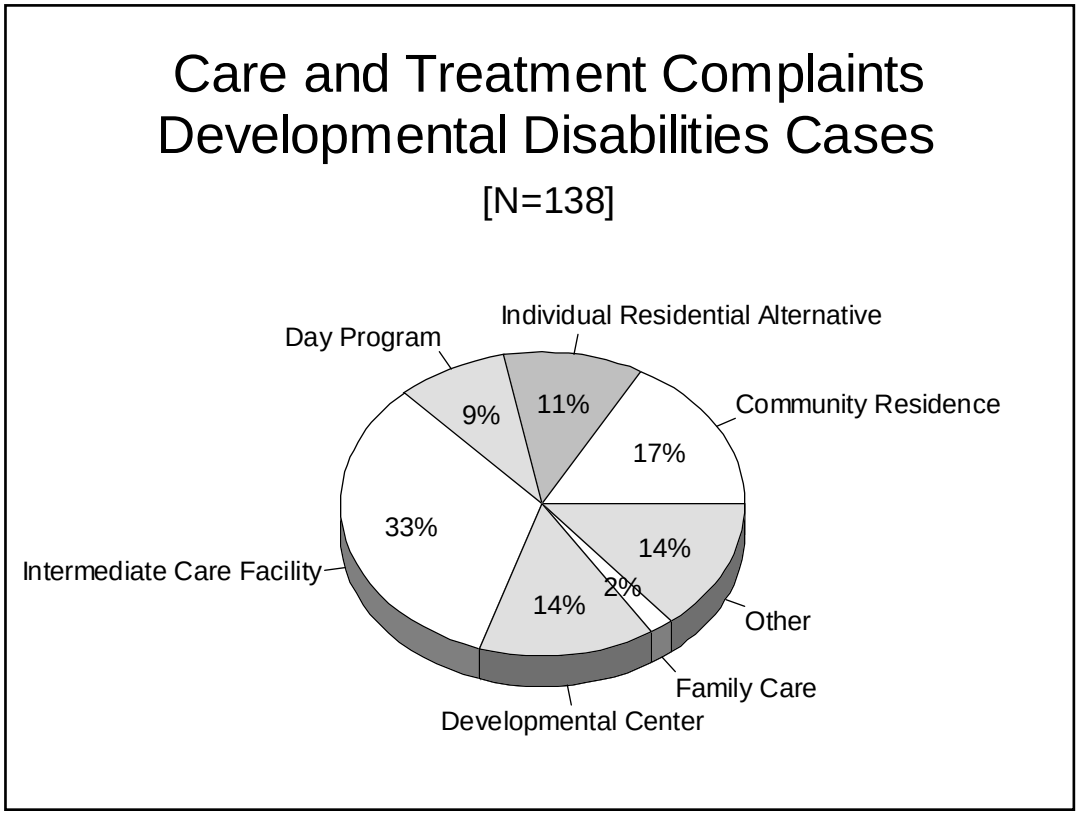
In its ongoing interactions with adult psychiatric center via the conduct of individual case investigations, as well as a series of unnannoucned visits in the fall of 1995 to assess conditions at 11 centers, the Commission has found that much has changed for the better as a result of the enactment of Chapter 57 of the laws of 1988 and OMH's efforts.

Quality Assurance and Assistance in Individual Cases

The names and faces of people coming to the Commission for assistance change from year to year, and more of the Commission's work has moved out of institutions into community settings, but the concerns expressed remain remarkably consistent because they reflect basic, fundamental needs. Consumers and their advocates repeatedly voice the desire for a decent, clean place to live, the desire for necessary, competent medical and mental hygiene treatment, the need to be and feel safe where you live and work, freedom from abuse, and the right to be free of unnecessary restraints and limitations imposed by programs, plans and medication. The case examples that follow illustrate these themes and the Commission's work on behalf of the people who brought them to our attention.

- An anonymous complainant alleged that an IRA for children was out-of-control. A CQC unannounced visit found the home's walls scribbled with crayons, carpets dirty and stained, all closet doors unhinged, the fire escape blocked by an unhung heavy wooden door, and numerous electrical plates missing from light switches. Six of the seven children had no day program or school program. None of the staff were tracking the behaviors targeted in program plans.

  At our urging, both Protection and Advocacy Services and the DDSO became involved. As a result of all of our efforts, the environmental concerns were corrected, the children were enrolled in summer camp, school placements for the fall were secured and behavioral programs were implemented.



- A patient at a psychiatric unit of a large municipal hospital and his friend complained about his being uncared for in a shabby environment. A CQC unannounced visit confirmed the allegation. Staff provided minimal guidance to patients — patients were not encouraged to take part in activities or to perform personal hygiene tasks. Recreational supplies were lacking or broken — no books, magazines or newspapers, no tapes for the VCR. The unit lacked sufficient furniture, so patients shared dressers and bedroom chairs and kept their clothing in plastic bags. The only liquid available between meals and snacks was tap water from the bathroom.

  A CQC return visit confirmed that the hospital had addressed the problems. It had ordered new lounge and bedroom furniture. Group therapies were planned, and a recreational and occupational therapist were delegated responsibility for recreational supplies and activities. Training on maintaining therapeutic environment was provided to staff.

- CQC, the OMRDD, and the Willowbrook Task Force combined efforts to improve living conditions at an ICF run by a voluntary agency. Unprotected radiators at 105°, severe vermin infestation, open containers in the refrigerator, a filthy kitchen and bathrooms and the unsanitary disposal of latex gloves, shoving them into the radiators, placed the 12 residents with severe mental retardation at risk.

  Approximately seven months after discovering the deplorable conditions, return visits verified that corrections had been made. Lighting had been improved, the residence had been cleaned and painted, new furniture was purchased, vermin were no longer evident, and the radiators had been insulated and enclosed.

Concerns about the adequacy and timeliness of medical and psychiatric care commonly cited poor evaluation and assessments, lack of follow-up of consultants' recommendations and/or abnormal laboratory values, and lack of timely response to the emergence of symptoms or in cases of medical emergencies were examples of typical complaints in a series of cases. For example:

- A distraught mother called the Commission alleging that her eight-year old son had received a totally inadequate mental health evaluation at a Comprehensive Psychiatric Emergency Program (CPEP) where she brought him with a police escort. She maintained that he was released with nothing more than a recommendation to return to the mental health clinic which regularly treated the youngster. The CQC review of the record verified the evaluation was cursory and did not follow the hospital's CPEP protocol. Only the child had been interviewed, not the mother; no physical exam had been done on the youngster; and, no determination had been made as to whether release to the parent represented a risk to the child.

  In response to our letter noting these deficiencies, the hospital replied that the physician in question was no longer employed there, and all CPEP personnel were retrained in CPEP policies and procedures.

- Concern about the drop in weight to 63 pounds of a woman with profound mental retardation prompted a call to the Commission. The CQC review revealed that the woman had left the developmental center in April weighing 86 pounds (her ideal body weight was 70-82 – she was 4 feet 8 inches tall), and had dropped to 75 pounds in August and to 63 pounds by November. Finally alarmed, the nurse ensured the woman was seen by her physician who ordered blood work and a chest x-ray. Both were negative. CQC ensured that corrective actions addressed both this woman's care and treatment and the systemic deficiencies which allowed this substantial weight loss to go undetected. Nutritional supplements were added to the woman's diet, and staff were instructed to provide her assistance, if necessary, to ensure she ate a sufficient amount at meals. Finally, the agency initiated a protocol requiring the monthly or more frequent weighing of residents.

- The Commission received a letter expressing appreciation for our assistance in aiding an agency in finding a nursing home placement for a man whose medical disabilities had worsened, forcing him to become a virtual prisoner on his residential unit. In addition to meeting his medical and physical therapy needs, the nursing home provided the gentleman with opportunities for activities and meals with other residents — activities he had rarely enjoyed in the previous two years.

The Commission received several complaints on behalf of persons living in IRAs who had formerly received a significant portion of their care from nurses before the residences were converted from ICF's. In these instances, family members worried about the care for their medically frail son or daughter, and staff members were anxious about performing medical procedures for which they felt ill-equipped. Corrective measures included:

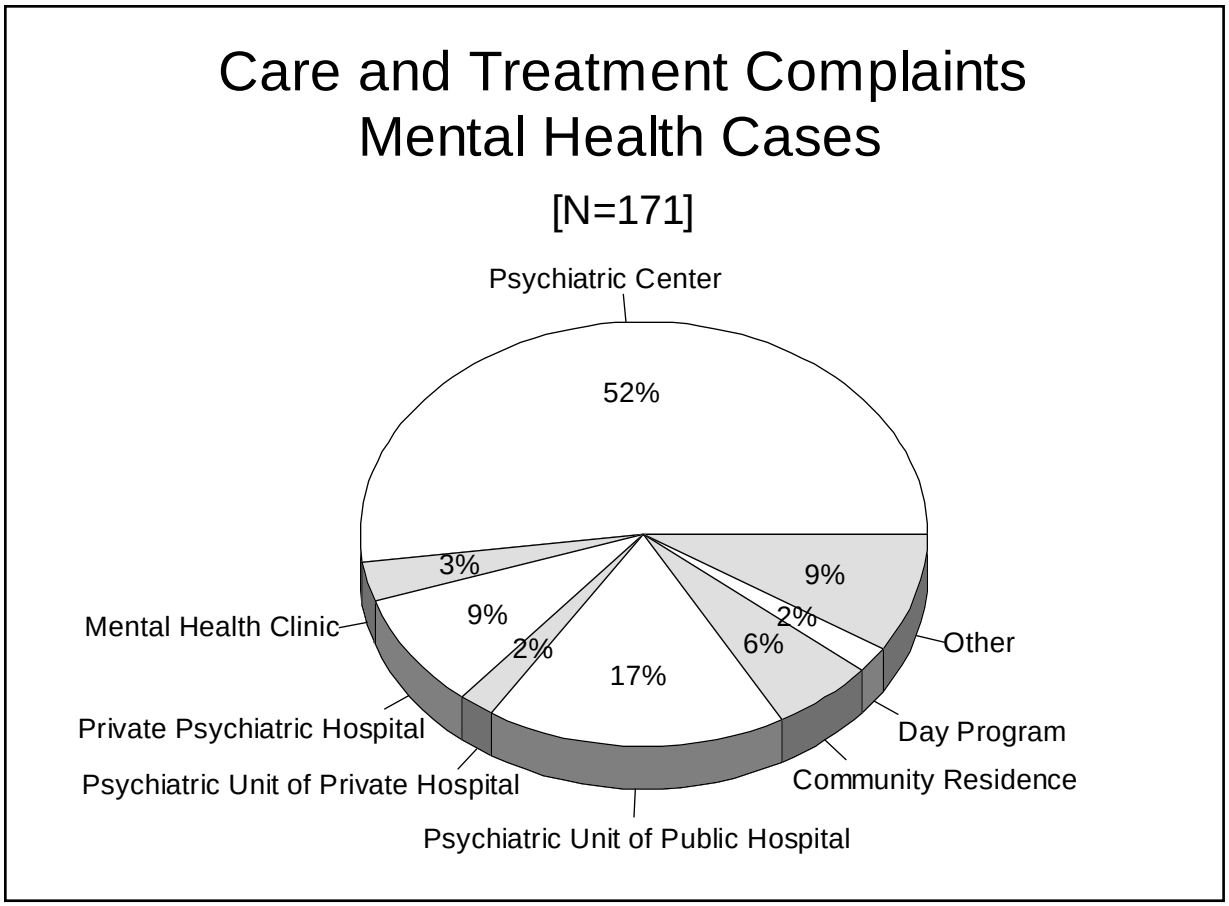
- Tube feedings and tracheostomy care were resumed by nursing staff after the Commission found that direct care staff training had been inadequate in one IRA;

- Unit dose medication packaging was initiated to reduce medication errors;

- Each resident was assigned to a primary care nurse whose responsibility it was to monitor his/her status.

One of the fundamental responsibilities of any program is to ensure the safety of consumers to a reasonable and appropriate degree. From the consumer's point of view, the ability to feel safe is basic to a satisfactory quality of life. While safety results in large measure, from the actions of sagacious program staff, the following anecdotes illustrate how clear and thoughtful policies and procedures can make a significant contribution to guiding staff actions and to ensuring the well-being of program participants.

- The psychiatric unit of a general hospital allowed two or more patients on 1:1 status to be supervised by the same staff person until a potentially fatal incident occurred. Two teenagers, both assigned to 1:1 supervision by the same direct care staff person, attended a discharge



party for a fellow patient. Each went to an opposite side of the room, forcing the staff member to accompany one and leave the other. The unescorted youth punched another knocking him unconscious. The victim suffered an epidural hematoma and required emergency neurosurgery. He recovered. The hospital's policies and procedures now require that staff performing 1:1 supervision of a patient be assigned no other duties.

- At a residence for adults with developmental disabilities a male resident used force and intimidation on several occasions to engage others in sexual activity. A CQC review of assessments of the man's capacity to consent to sexual activity revealed that although clinicians concluded he had the capacity to consent, they also concluded that he had no understanding of another's right to say, "no." The program has changed its guidelines to clarify that the understanding of another's right to refuse sexual contact is a concept essential to the ability to consent to sexual activity.

The failure to provide conscientious attention to the supervision of persons with potentially serious behaviors, such as aggression, self-injurious behaviors, and pica was the subject of several complaints to the Commission, as their behaviors jeopardized their own safety and development and the safety of others:

- A young woman in a developmental center who had a long history of pica was taken to the ER complaining of abdominal pain. An x-ray revealed an irregular mass in the stomach. The surgeon removed a large brown bolus composed of decomposing latex gloves, strips of cloth, pencil fragments and a plastic pen cap. The young woman had received 1:1 supervision during all of her waking hours for many months prior to the medical emergency. It was impossible to determine which staff were at fault. In response, the OMRDD sent a consultant to the developmental center to review and update the woman's behavior plan and staffing needs.

- A six year-old severely hyperactive child in a developmental center was supposed to be kept at all times "within arm's reach" to prevent his biting other residents. During an evening activity the youngster was found with another boy's thumb, index and middle fingers in his mouth, having already bitten off the youth's fingernails.

  A CQC review revealed that the six year-old had been left unattended on a potty chair for 10-15 minutes, during which time the incident occurred. Further investigation determined that the staff member responsible for him was also responsible for three other children, making her vigilant care of him impossible. The developmental center reassessed the needs of all children and reassigned staff accordingly.

Finally, the misuse of restrictive techniques for non-serious, non-emergency situations both violates consumers' rights and fails to teach positive behaviors. The Commission addressed these issues in cases similar to those below:

- The children's unit at a psychiatric hospital was routinely bear-hugging children in an infection-control blanket (padded blanket with pockets where staff place their hands used to wrap and restrain children) in the evening to calm them before bedtime. Once the Commission advised the administration that this was occurring, staff were required to stop the practice immediately and were instructed to use the infection-control blanket only for its intended purpose.

- The behavior plan of a young man with severe mental retardation required that he spend his time alone in his room except for meals and infrequent trips to the community with 1:1 staffing. This forced isolation was an attempt to prevent the young man from biting others. The Commission was successful in securing a more creative and more productive behavior plan to address the biting behavior. An oral stimulation program was written by an occupational therapist and staff increased their ability to discern the young man's pre-aggressive/pre-biting behaviors and were better able to intervene before he actually became aggressive.

Watching Over the Children

The Commission's work on behalf of children lies in two principal areas: the review of allegations of abuse and neglect (those involving residential programs come to the Commission from the State Central Register *(SCR)*), and the review of care and treatment issues usually brought to our attention by parents or other advocates dissatisfied with the services being provided to a child.

During the report period the Commission received 147 child abuse/neglect allegations from the State Central Register and completed the investigation of 123. In 111 cases there was insufficient credible evidence to determine that the child was physically harmed (beyond minor injury), seriously emotionally harmed or placed at substantial risk of physical harm by the misdeeds of an identified staff person. In 12 cases (10%) sufficient credible evidence was found to "indicate" the case, and the involved staff person was advised of his/her due process rights.

Beyond identifying staff whose actions have harmed youths or placed them at substantial risk of harm, Commission work on SCR cases provides an opportunity to review the quality of life for youths in all residential settings (except family care) operated or certified by the Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities. Thus, regardless of whether a case is indicated or unfounded, the Commission is able to make recommendations or call for a plan of correction aimed at systemic deficiencies or problems in the treatment of a single child. This opportunity to effect positive change in the care children receive is reflected in the following case examples.

SCR Child Abuse Cases Opened

July 1, 1995 - June 30, 1996

Total number of SCR cases opened = 147

OMH Cases Opened = 87

OMH	
Children's Psychiatric Center	37
Community Residence	6
Children & Adult Unit of Psychiatric Center	14
Art. 28 Hospital	7
Art. 31 Hospital	5
Residential Treatment Facility	17
Other	1

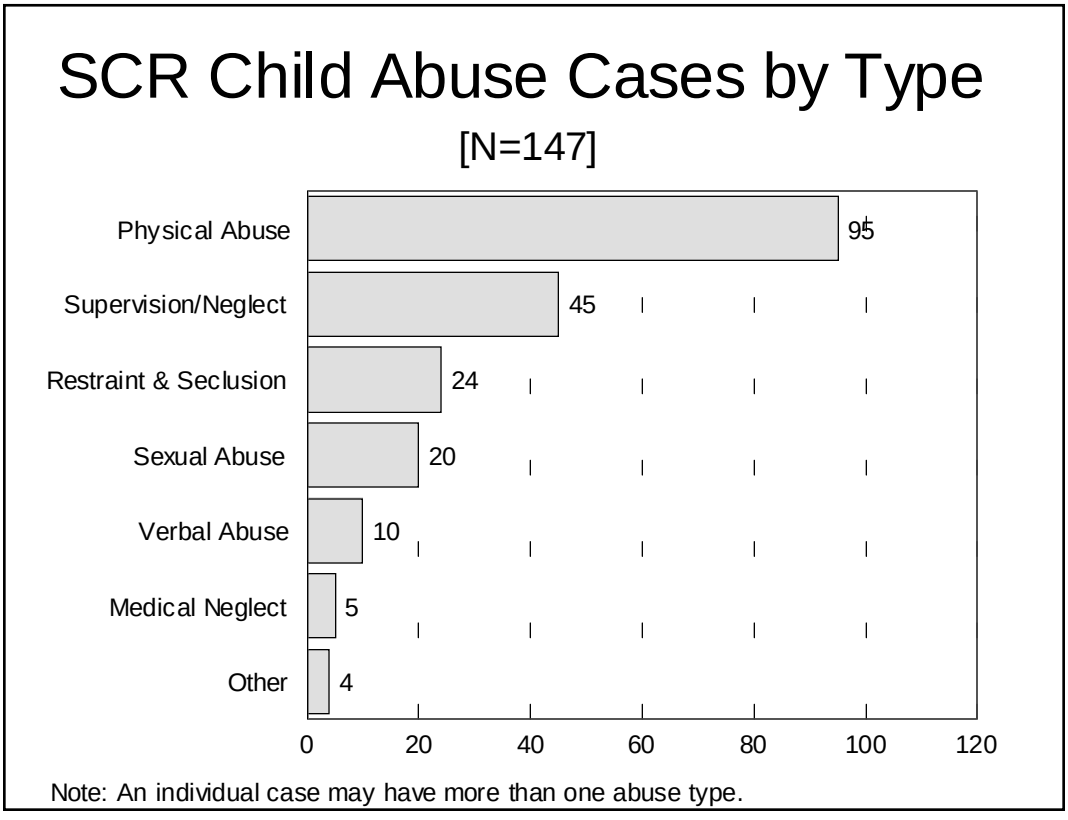
OMR Cases Opened = 60

OMR	
Community Residence	3
Developmental Center	7
Intermediate Care Facility	35
Individualized Residential Alternative	13
Other	2

Case Examples

- Two adolescent boys residing in an IRA, one with mild mental retardation and the other autistic and severely retarded, were inadequately supervised by staff and were found naked together in a bathroom stall. The two staff who discovered them separated the boys, but did not attempt to learn if they had been involved in sexual activity. The boys were then left unsupervised yet again. The mildly retarded boy eloped with the autistic child into a snowstorm, led the scantily clothed peer away from the residence and abandoned him. The youth was unable to find his way home again. Other agency staff happened upon the autistic youth before he suffered serious injury. Although the children involved could not provide reliable testimony, Commission interviews of staff and the review of physical evidence were able to verify that the two responsible staff had placed the boys at risk of serious harm, and they were indicated for neglect.

- In an unfounded case, a 17-year-old female patient in a children's psychiatric center with a history of suicidal behavior gouged her wrist and legs in a ward bathroom with a shard of glass she found on a bedroom floor, suffering lacerations which required 19 sutures to close. The Commission unfounded the allegation because our investigation found that the staff person assigned to watch her also had to supervise four other children and, in any case, hospital rules regarding the observation of children while they used the bathroom were vague. In response to our recommendations, the psychiatric center retrained staff and modified supervision policies at the hospital to help ensure adequate staffing and supervision.



- Investigation of the alleged excessive use of restraint and STAT IM medications on a 16-year-old girl with severe mental retardation and atypical psychosis during a 13-day CPEP emergency admission found that orders for four-point restraint and medication were necessary and appropriate. However, we criticized the length of her stay in the CPEP, where space was extremely limited and there was an absence of therapeutic and recreational activities. In its response the hospital agreed that, in the future, CPEP patients who were not ready for discharge 72 hours after admission would be admitted to the appropriate inpatient service.

- An adolescent boy with moderate mental retardation became agitated at his community residence and bit a staff person. The staff person proceeded to curse, taunt, and provoke the youngster, eventually throwing the boy to the floor and unleashing a barrage of punches to the child's head and body. The subject was arrested and fired by the facility, and also was indicated for child abuse. In addition, the Commission noted that neither of the two part-time staff on duty had been trained in Strategies in Crisis Intervention and Protection (SCIP), the OMRDD approved program for managing out-of-control consumers, even though they had been employed at the residence for 10 months and 15 months, respectively. The agency agreed to ensure that all new employees are trained in SCIP and other consumer rights issues in a timely manner.

- During an unfounded SCR investigation, a Commission staff person was told by a child that overnight staff at the children's psychiatric center sleep at night and children roam the ward at will. Senior facility staff felt certain that this could not be occurring, so the Commission investigator returned for a surprise 3:00 A.M. visit along with the facility Coordinator of Special Investigations. They found the security officer for the center sleeping and a therapy aide asleep on the ward. Fortunately, none of the children on that ward currently required increased supervision to prevent dangerous behaviors. Beyond alerting administrators to the need to ensure that staff remain vigilant through the night, this incident heightened administrative sensitivity to the value of listening carefully to children's complaints. There are now weekly meetings of various groups of patients to listen and respond to children's reports of conditions on the living units.

Reviews of the Care and Treatment of Children

The Commission has long responded to concerns brought by parents and advocates regarding the services children receive in residential and other programs licensed or operated the Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities. In addition, Commission staff often initiate follow-up reviews to ensure that programmatic deficiencies discovered during investigations of allegations of abuse/neglect are corrected.

The Commission completed 60 reviews of care and treatment involving children during the report period. Problems were discovered with the quality of

staff supervision in approximately 30% of these cases. Somewhat less frequently, the Commission recommended changes in agency policies and procedures, criticized medication practices or advised programs on how to improve the quality of internal investigations. The case examples cited below demonstrate the Commission's commitment to the provision of quality care, as well as persistence in working with a facility or family to resolve problems.

- During a visit to investigate an allegation of child abuse, investigators found that the living unit of a residential treatment facility (licensed by OMH) was dirty, roach-infested, and in disrepair. Children had insufficient clothing and their personal hygiene was not receiving adequate attention. Also, staff commonly gave children harsh consequences and restrictions for minor infractions of the rules. This prompted recommendations to remedy these deficiencies and a series of return visits by Commission staff to ensure the completion of corrective actions. New carpeting was installed, the living unit was repainted and walls are now attractively decorated. Furniture was purchased for day rooms and bedrooms. Children at the facility now have adequate clothing and hygiene supplies, and staff assist them when they need help maintaining their belongings and keeping clean and groomed. Finally, new management staff appointed by the parent agency formed a task force charged with setting uniform standards regarding what constitutes misbehavior and therapeutic, non-punitive responses.

- Commission staff received numerous complaints, including several SCR allegations, involving the quality of residential services at an agency serving developmentally disabled children. Visits to the children's ICF revealed evidence that incident reports had been destroyed and oversight agencies weren't informed of allegations of abuse. Facility investigations were inadequate and serious incidents were not presented to the agency's Incident Review Committee. The agency lacked policies and procedures regarding important elements of care and treatment i.e., supervision requirements for children, and we found significant delays in providing therapeutic services to the children. In response to our recommendations, the agency hired a Quality Assurance Consultant and drafted new incident reporting/review policies and new policies for the supervision of residents. The incident review committee was restructured and is now meeting more frequently; there is an improved mechanism for tracking incident investigations, and the OMRDD is monitoring the agency closely. Finally, bedrooms were modified and other measures taken to enhance the ability of staff to supervise children.

- A 7-year-old boy residing in a developmental center became familiar to Commission staff during two SCR investigations. The child suffers from Fetal Alcohol Syndrome, severe mental retardation, and is hyperactive and non-verbal. He lived with his mother and then his grandmother until their deaths, when his aunt was appointed legal guardian. She was forced to place him in the developmental center because of his hyperactivity, aggression and various health problems, but she no longer believed that the developmental center was the best place for her nephew. The aunt wished she could have kept him home

with her but was unable to obtain the after school and home health care assistance she needed. A Commission staff person informed the aunt of services available through the Home and Community-Based Medicaid Waiver, and worked with the family and the local DDSO to complete the application for home-based services. Once approved, various in-home supports were instituted to allow the child to live with his family again. These included residential habilitation, occasional respite care and home health aide services.

Many Commission reviews of care and treatment involving children are initiated in response to calls from parents or other advocates concerned for a child's safety or dissatisfied with some aspect of his/her care. The two cases summarized below detail instances where we criticized facility medication practices (a deficiency found in approximately 20% of Commission reviews of children's care during the report period), or were critical of the quality of treatment planning for the child (a problem noted in about 18% of Commission reviews).

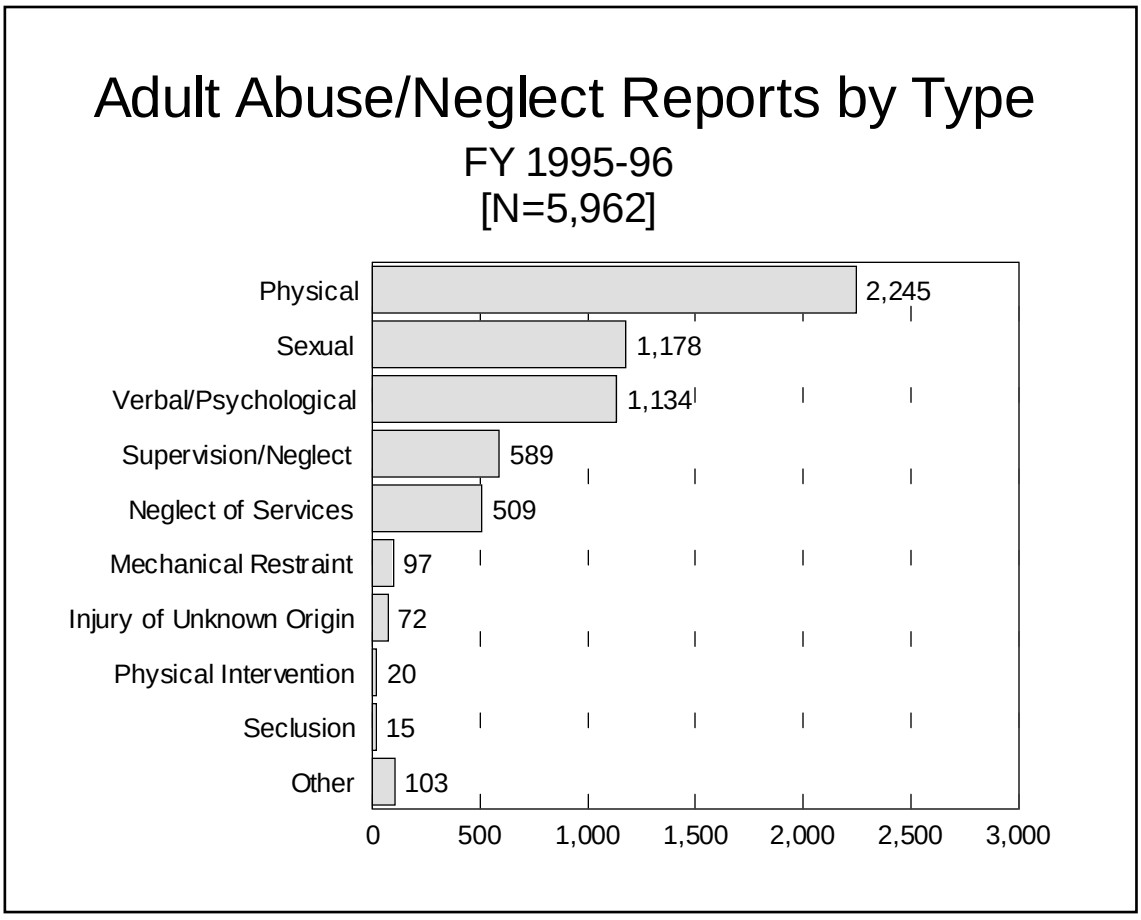
- A Mental Hygiene Legal Service attorney asked the Commission to review the treatment of a 17 year-old male patient after finding him alone twice in one day sitting rigid on his bed with shallow, labored breathing, unresponsive to her voice, with his tongue protruding from his mouth. She believed her first report to a nurse regarding the child's condition had been ignored as the child was not treated for his symptoms until she summoned the psychiatrist. Several days later, the attorney could find no documentation of the incident in the child's record. Our review discovered that the child was assigned to "close supervision" and the Commission disputed the hospital's determination that nothing of importance had occurred which would have necessitated additional physician documentation. The hospital's revised response acknowledged the breakdown in supervision and lack of required documentation. Nurses and physicians were counseled and retrained and the hospital agreed to work with nurse supervisors to ensure that "close supervision" orders are effectively implemented whenever ordered.

- A Commission investigation confirmed the complaints of the mother of a girl staying on the psychiatric unit of a community hospital who reported that clinicians had not performed necessary assessments or medical tests, and made no arrangements for her daughter's aftercare. Our review found problems with the treatment of this child and other patients, including incomplete medical histories, poor treatment documentation and incomplete reviews of patient progress, no written rationales for prescribed medications, treatment plans which did not address fundamental needs (i.e., histories of sexual victimization) and inadequate discharge planning. The hospital accepted the Commission's findings and has developed new policies and procedures to ensure that patient assessments and reviews are thorough, full histories are obtained, and adequate discharge plans are formulated. A consultant was also hired to train staff on indicators of victimization for persons in all age groups.

Monitoring Adult Abuse and Neglect

In the report period, the Commission received 5,962 reports of allegations of abuse or neglect of adults, which facilities and agencies licensed or operated by the Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities are required to report in accordance with 14 NYCRR Parts 524 and 624, respectively. Commission staff review each of these reports and assign a code according to the severity of the incident, which determines the extent of the review it will be given. Of the 5,962 reports, more than 20% or approximately 1,200 cases are assigned a more detailed review which requires, in the most serious cases, that a Commission investigator examine the agency's complete investigation of the allegation and issue a letter of findings.

A main objective of this work over the years has been to provide guidance to programs on how to improve their investigation of serious incidents. Through this process, the Commission seeks not only to effect a positive outcome for the individual(s) involved in the specific incident, but also to assure the protections afforded to all program participants. In addition, the work enables the Commission, through maintenance of an extensive database, to identify systemic problems and solutions. The following case examples illustrate the Commission's activities and accomplishments in this endeavor.



- The Commission was notified by the director of quality assurance for a downstate agency that a resident of one of their group homes had been receiving a non-FDA (Food and Drug Administration) approved medication (Mogadon) to control her seizure activity. This occurred over the prior 16 months without the agency administrators' approval or knowledge, but with the assistance of the residence's nursing staff who had been receiving the medication from the individual's parents and administering it four times per day. The agency was in a quandary. Aware of the parents' wishes and potential life-threatening withdrawal symptoms, the agency did not want to stop administering the medication. However, the agency appreciated its vulnerable legal position if it continued to administer a drug which did not have approval from the FDA. Without a resolution to this issue, the agency would have to discharge the young woman, an option which neither her parents nor the agency wanted to exercise.

  The Commission suggested that the agency contact the FDA to discuss obtaining a waiver or other options to "legalize" the medication. The agency, after numerous contacts and filings with the FDA, informed us that the individual's treating physician was able to obtain FDA approval of an Investigational New Drug Application, thus allowing the medication to be continued. The agency acknowledged the Commission for providing guidance and technical assistance, and for patience through the approval process. Additionally, the agency is confident it is prepared to manage a similar issue in the future.

- The Commission was notified that a female resident of an ICF had tested positive for a sexually transmitted disease (chlamydia) during her annual gynecology examination. The agency initiated an investigation of possible sexual abuse, since the woman was not known to be sexually active and was not able to provide consent to sexual activity. The agency's investigation, as well as a parallel investigation conducted by her day program provider, were unable to identify any source for a sexually transmitted disease. The investigation found that upon receipt of the diagnosis, the woman was treated with antibiotics prior to re-testing. The agency responded to the incident with appropriate recommendations for closer supervision and for retraining staff on the indicators of sexual abuse and client protection.

  The Commission, however, noticed that within the investigation report, the agency had cited clinical trials which indicated false-positive results were present within the general population and that re-testing is indicated for individuals not known to be sexually active. The Commission's review also observed that the test performed in this case was not designed to rule out suspected sexual abuse since it had the potential of yielding a false positive if foreign substances were present in the sample (i.e. blood, fecal matter, etc.). This was critical since the woman was, at times, incontinent. The Commission communicated these concerns to the provider.

The agency responded to our findings, stating that all agency medical staff were retrained on testing procedures for sexually transmitted diseases, which included a requirement for a follow-up gynecological examination and retesting prior to the initiation of antibiotic treatment. This measure will ensure that an individual is not prescribed unnecessary medication, or exposed to the ordeal of a sexual abuse investigation needlessly.

- The Commission was notified that as a result of a fall, a man living in an Intermediate Care Facility was hospitalized with a ruptured right eye which required surgical removal. Commission review of the investigation uncovered serious concerns regarding the method of escort/guidance, which did not follow the recommendations by the physical therapy department. Additionally, the recommendation regarding the form of escort had been made in March; however, training of direct care staff did not occur until six months later, and after the man's accident.

  The Commission determined that this inappropriate escort, in the absence of appropriate staff training, likely contributed to the man's fall and subsequent loss of his eye.

  The agency initially responded that the technique employed during the escort (hand at wrist and back), although not specifically outlined in the physical therapy recommendations, was appropriate citing a note that the least restrictive technique be used, and that the physical therapy department would make "a greater effort" to ensure that the training of direct care staff regarding treatment recommendations would occur in a timely manner.

  The Commission found this response inadequate and requested that the agency provide timetables and develop quality assurance mechanisms to ensure that training and implementation of physical therapy recommendations be timely. In response, the agency reported that the physical therapy department will now provide an additional orientation to all new and current staff which will discuss and define the terminology, treatments, and the role of physical therapy. In addition, a physical therapy inservice reply form will be completed whenever specific recommendations are made following an assessment which identifies what training, both staff and client, is required to implement the recommendations.

- The Commission was notified that suspicious bruises had been discovered on a non-verbal resident of a State-operated Individualized Residential Alternative program. The facility's investigation report concluded that, while it appeared these marks were not self-inflicted and that the individual had been struck by a wire-hanger device, the allegation could not be substantiated, since there were no witnesses or other evidence to support the allegation. The facility determined that a staff member had breached her duty by failing to document that she had observed the marks the previous evening, and it took steps for disciplinary action.

The Commission's review could not pinpoint the likely time the injuries were inflicted, due to the staff member's breach of duty and because the photocopy of the body check sheet was incomplete and illegible. A request for a clearer copy could not be accommodated, since the original body check sheets were routinely discarded after six months.

The Commission recommended that the facility take steps to prevent the destruction of original materials essential to special investigations. The facility Chair of the Special Review Committee responded that he would ensure that complete copies or original documents are submitted with all investigations and would recommend that all client records be maintained for a one year period. Such measures will not only improve the quality of investigations, but also allow for a comprehensive annual review of all aspects of client care. Additionally, all staff were trained on body check sheets, with emphasis on ensuring completion.

In some cases, the recommendations offered by the Commission have assisted programs in identifying omissions in treatment plans or capacity to consent to sexual activity assessment tools. Some case examples which illustrate this point are:

- The Commission reviewed a voluntary-run agency's investigation report of an allegation that a female resident of an ICF had been forced to engage in sexual activity with a male friend during an unsupervised visit to his home. The Commission investigation uncovered several concerns. The woman's clinical record indicated she had not been assessed for capacity, even though her treatment team was aware that this significant relationship had developed. Additionally, the Commission found no provision in her plan for staff to provide an opportunity for discussion following an unsupervised outing.

  In response to the Commission's findings, individuals have now been assessed for capacity to consent to sexual activity by their appropriate teams, with particular attention to those individuals involved in relationships, or who have demonstrated areas of vulnerability. Additionally, the agency stressed with all staff the encouragement of discussion following an outing as a key component of protective oversight.

- After receiving a second allegation of client-to-client sexual abuse involving the same two individuals with profound mental retardation within a three-month period, the Commission requested to review the agency's treatment plans regarding sexuality issues for these two individuals. The agency submitted a comprehensive policy for assessment of capacity to consent to sexual activity, which referenced obtaining third party consent (from a legal guardian, parent) for this purpose.

  The Commission pointed out that surrogate consent for sexual activity is not recognized in law. We also determined that the policy lacked a provision concerning the development of relationship and socialization skills as a component of sexuality training. The agency made compre-

hensive refinements to their policy and incorporated language to reflect all the Commission's recommendations, and stated that the issue of third party consent would be addressed through an extensive clinical and administrative review to determine an ethical, clinically sound, and legally acceptable solution.

The Commission regularly provides recommendations and guidance to assist programs in improving their investigative process. Examples:

- The Commission's review of an allegation of sexual abuse filed by a patient of a county mental health outpatient clinic found serious flaws and deficiencies in the investigation process. As a result of the Commission's findings, the clinic revised its procedures to ensure that multiple interviews by several staff are avoided and the victim is interviewed by only the investigator, perhaps with the consumer advocate present. Additionally, procedures were implemented to ensure the incident is immediately reported to the special review committee investigator, who is charged with the responsibility to classify the incident, notify all appropriate agencies (including law enforcement) and conduct an investigation.
- A Commission review of a sexual abuse allegation by a resident of a community residence in Brooklyn against a male staff member found that the investigation report was deficient. The agency took corrective steps to avoid "dividing up" an investigation among several staff, to include as a routine component of investigations credibility assessments specific to the allegation(s), and to revise the Incident Review Committee minutes format to ensure relevant and comprehensive information is included.

Protecting Lives by Investigating Deaths

During the 1995-96 annual report year, the Commission reviewed the deaths of 1,895 mental hygiene service recipients and, with the assistance of its Mental Hygiene Medical Review Board, investigated 252 deaths which appeared to have occurred under unusual circumstances or due to other-than-natural causes.

In selecting deaths for investigation, the Commission gives priority to individuals who were receiving inpatient or residential services (i.e., individuals who were most reliant on the state or its licensees for their day-to-day care) and outpatients who recently made the transition to living independently or with family.

The purpose of the investigations is to protect the living by improving, through recommendations when indicated, the care provided to individuals living in state-operated or -certified facilities or transitioning to more independent living.

In the course of the 1995-96 death investigations, Commission staff reviewed the care provided by 200 different mental hygiene facilities, as well as several dozen general health care institutions which provided the decedents' medical care. Examples of outcomes include:

- At a large New York City hospital, a 49 year-old woman died of a pulmonary embolism most probably caused by prolonged immobility due to catatonia. In response to the Commission's and Medical Review

Board's recommendation, the hospital developed a protocol for the prevention of pulmonary emboli due to deep vein thrombosis. The protocol identifies at risk patients (e.g., severely depressed bedridden patients, catatonic patients, individuals in restraints for long periods, etc.). The protocol also identifies prevention strategies, ranging from range of motion exercises and use of elastic stockings to anticoagulant medication therapy.

- A 38 year-old relatively healthy man with profound mental retardation choked and died at his program during his mid-day meal. The staff member on duty responded appropriately by summoning help and initiating the Heimlich maneuver and CPR. The problem was, she was the sole staff person on duty with seven very active clients, some of whom, including this man, had a history of eating difficulties and choking; a second staff person had been reassigned to go on an outing. In response to the Commission's findings and recommendations, the facility realigned staff schedules to increase supervision at meal times. The agency also reduced the number of individuals eating at any given time by creating an extra meal period. Now the minimal staff-to-client ratio at mealtime is 1:4.

- A 19 year-old resident of an IRA program became suddenly ill, experiencing 14 episodes of diarrhea. On-duty staff contacted the nurse who at one time covered the house. She ordered Kaopectate; however, she did not come to the IRA and examine the resident as she (the nurse) was on maternity leave. (The agency had no protocol in place for assuring adequate nursing coverage for its residential programs when nurses are off-duty on extended leaves.) The next day, the resident was found dead. As no autopsy was done, it could not be determined if more timely and aggressive medical intervention might have saved the individual. However, the facility agreed with the Commission's and Board's recommendation and created policies to assure that all its homes have adequate nursing coverage at all times.

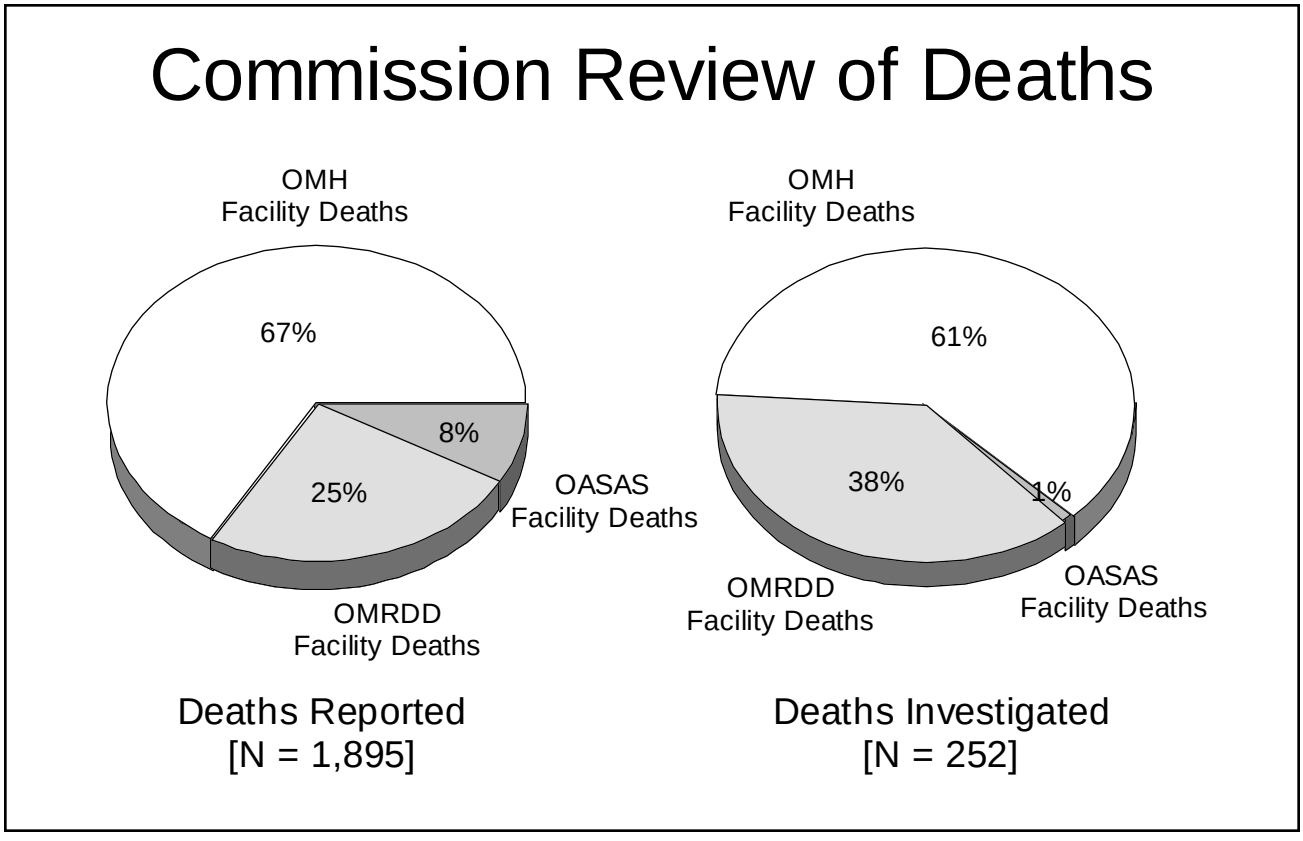
- Quality Assurance peer review processes were revised at a state psychiatric center following the Commission's investigation of the sudden death of a 65 year-old long-term patient. Upon autopsy, the pathologist could only speculate on a precise cause of death as being: a possible drug (Haldol)-induced pulmonary edema, or a possible fatal cardiac arrhythmia, or a possible myocardial infarction less than a few hours old.

  The Commission's investigation revealed that the patient did not receive her annual EKG which should have been performed 4 months prior to her death. Additionally, it was found that the patient had been maintained on a regimen of Haldol and Lithium for four years with no improvement in her mental status which her psychiatrist consistently described as unstable. Despite no improvement in her symptomatology, her psychiatrist made no attempt to adjust her medications, try alternative medications, or consult with his peers to discuss different treatment options.

  In response to the Commission's findings, the facility initiated a peer review process in which the care of all long-term care patients is reviewed and discussed at least annually.

- Better training on the side effects of medications and controlling for such was provided to staff of both an upstate HMO and a community residence which relied on the HMO for medical care for its clients. This followed the Commission investigation of the death of a 21 year-old woman diagnosed with bipolar disorder and prescribed Lithium. In May 1996, the resident became ill with flu-like symptoms (vomiting and diarrhea). Residence staff informed the HMO which advised them to monitor the client. Five days into the illness, with the symptoms persisting, the client was seen at the HMO. At that time no laboratory tests for Lithium levels were conducted, nor were adjustments to her medication made, nor were staff advised to monitor her intake and output, despite the GI distress and volume depletion which could lead to Lithium toxicity. On day 7 of her illness, the client was admitted to a local hospital with Lithium toxicity, dehydration and renal failure. She subsequently succumbed to pneumonia.

The deaths of these five individuals and the Commission's investigation into them are just a handful of examples of how care for the living can be improved through the review of death. In each of the above cases, as well as the other 247 deaths investigated in 1995-96, the involved facilities were formally informed of the Commission's findings, and recommendations - if indicated, via a letter or short report. However, to ensure that the lessons learned by one facility, through a tragedy such as death, are studied, considered and replicated by other facilities, the Commission published a series of case studies, *Could This Happen In Your Program?* distributed to all New York State facilities. The series, drawn from the Commission's death and abuse investigation files, won a national award in October 1995 in the National Association of Mental Health Information Officer's National Media Competition.



The SDMC Program: Assuring Efficiency and Quality in Consent Procedures for Major Medical Treatment

Over the past eleven years, the Surrogate Decision-Making Program (SDMC) has been successfully implemented in twenty counties across the state. Through June 30, 1996, SDMC has handled 3,414 cases and provided timely decisions regarding major medical treatment for individuals with mental disabilities residing in facilities licensed by state mental hygiene offices. Prior to the SDMC program, treatment was often delayed for weeks and months in the courts because of legal difficulties in obtaining informed consent for patients and residents deemed incompetent to give consent. Besides avoiding the costs of the court processes, the SDMC program provides a context for personalized decisions related to major medical treatment for individuals with mental disabilities.

During the reporting period, the SDMC panelists heard 319 cases, resulting in decisions for 337 major medical treatments. There are 352 dedicated volunteers who serve on the SDMC panels, which are composed of a health care professional, a lawyer, a former patient or relative, and an advocate [see the complete list of panelists in the Appendix]. The SDMC Program is able to facilitate timely medical care to a significant number of individuals, due in large part to the generosity of these volunteers. They are responsible for determining whether the individual is capable of providing informed consent, and, if not, whether there is an existing authorized surrogate to provide consent or refuse treatment based on the best interests of the individual. If there is no such surrogate, the panel makes the decision to consent or refuse the proposed medical treatment.

It is the responsibility of Commission staff to administer and oversee this important program. These staff must review and process all applications for medical treatment, recruit and train panelists, conduct outreach and information activities for health care providers, parents, spouses, and adult children of clients, guardians and correspondents to clients, and provide legal assistance through the Commission's counsel's office. During the past year, Commission SDMC staff conducted training sessions for 60 new panelists and 13 refresher trainings for existing panelists. In addition, eleven training sessions were conducted for provider staff to assist them in improving the quality and efficiency of the paperwork and procedures for submitting a case, so that the time element may be decreased even further. [The average processing time for cases during the past year has been less that two weeks: 12.55 days].

The reputation of the quality and efficiency of the SMDC program has spread to all parts of the state and beyond. Communities and judges in the central and western part of the state are anxious for the SDMC program to expand to their regions as well. It is the long-range goal of the program to fulfill that wish.

Promoting Accountability and Responsibility

New York State like the rest of the nation is experiencing profound changes in the organization and delivery of health care services because of the growth of managed care and the shift of treatment from inpatient to outpatient settings. As New York's Medicaid system has become increasingly expensive when compared to other states, the Commission has conducted studies on ways to make the mental hygiene system more affordable and efficient without compromising the state's commitment to providing quality care to dependent populations.

During this annual report period, the Commission has met the challenge to manage performance outcomes from the state itself and publicly funded not-for-profit corporations running community-based programs under state licensure. By examining old ways of financing programs, the Commission has found ways to curtail unnecessary spending. Changes are occurring as a result of the expanded use of managed care to control over-utilization of services, reducing excessive reimbursement to high cost programs through Medicaid cost containment, replacing state funding with federal revenues, and controlling overspending through tighter controls on administrative costs. At the same time, the Commission, by coordinating its activities with federal and state agencies, has continued to focus on the prevention of fraud and abuse through the prosecution of wrongdoers and the recovery of unwarranted public fund payments.

Curbing Fiscal Abuse

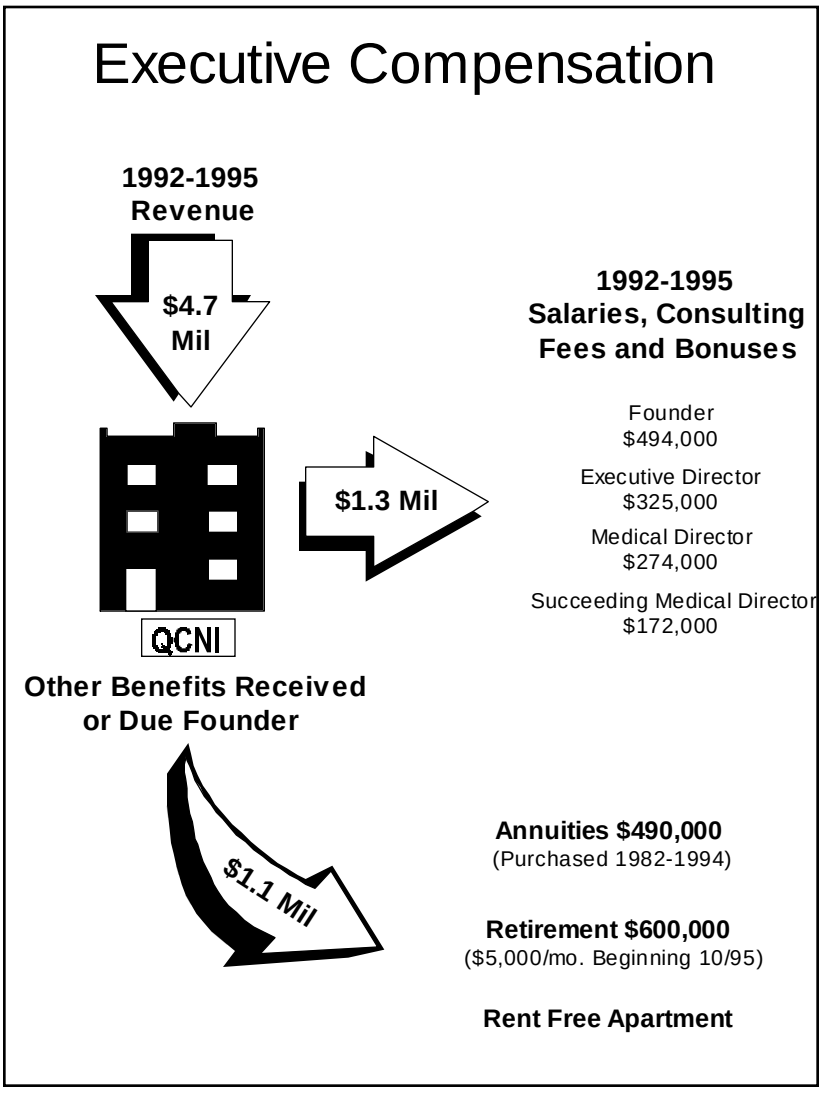
Fiscal Abuses at Queens Psychiatric Clinic

A Commission investigation of financial and programmatic practices of the Queens County Neuropsychiatric Institute, Inc. (QCNI), a not-for-profit clinic serving primarily low income clients with Medicaid funds, revealed some $600,000 in improper Medicaid billings, the diversion of agency assets to senior executives, concealment of financial irregularities by the agency's CPA, the failure of its board of directors to carry out its fiduciary responsibilities to protect the agency, and serious problems in the quality of the high-volume clinic services.

The Commission's October 1996 report *Profit Making in Not-for-Profit Care: Part III, The Case of Queens County Neuropsychiatric Institute, Inc.,* uncovered a not-for-profit agency certified to provide care and treatment to persons with mental illness, but which subordinated its avowed beneficent purpose "to become an engine of personal enrichment for its corporate principle." The Commission's report found major deficiencies in the areas of:

- **Medicaid billings:** There were $600,000 in improper clinic Medicaid billings out of $3.2 million claimed for psychiatric services from 1992-94 because records failed to meet federal and state legal requirements on documentation and legibility.

- **executive compensation:** excessive compensation and large, unjustified and unauthorized payments were made to the founder, who spent substantial amounts of time at his Florida residence, and compensation of other senior executives was questionable. From 1992-1995 almost 28 percent of the program's income went to its senior executives, and almost a half-million dollars in agency assets were misappropriated by the founder between 1982-94. The founder also had a rent-free apartment in the clinic building, and was granted a minimum of $600,000 in retirement benefits, which substantially weakened the not-for-profit agency's viability.



- **medical director:** the medical director was simultaneously employed as a full-time psychiatrist at the state-run Bronx Children's Psychiatric Center, enrolled there in its Extra Service Program for additional work, and employed by QCNI or paid as a consultant. He received compensation of $249,000 in 1994 and $229,000 in 1995 from QCNI, a private hospital, and the state for work weeks averaging 83 hours. There were many periods when he reported working at two different locations at the same time, working more than 24 hours in a single day, suggesting that he could not have worked all the hours for which he was paid.

- **board of directors:** the board failed to oversee the agency and protect its assets, and failed to comply with laws and regulations (e.g., annual independent audits and approval of business transactions with agency executives) to prevent dissipation of corporate funds and assets for the benefit of agency executives.

- **CPA misconduct:** QCNI's CPA firm participated in a scheme to redirect public funds intended for services to the agency's founder; attempted to conceal his misappropriation of $490,000 through improper accounting entries and by assuring that an audit had been done and that the financial statement were not misleading when, in fact, no audit was performed; and, failed to accurately report employee compensation to state and federal tax agencies.

- **quality of services:** there was no evidence that many of the patients were even eligible for mental health services; no treatment plans in a third of the cases reviewed; missing medical status information which placed patients on psychotropic drugs at risk of harm; illegible treatment records; and chronic treatment and record deficiencies which were not addressed by supervisors.

The report identified, as in several previous investigations, common ingredients characterizing such diversions of public funds to private profit as including:

- A dominant person in a position of leadership--in this case a psychiatrist who was the founder of the agency–who engaged in or directed financial decisions for his own personal benefit;

- A weak board of directors that either did not grasp its fiduciary responsibilities or failed to carry them out vigilantly; and,

- An accountant who failed to meet his professional responsibilities in conducting independent audits and in providing unbiased financial opinions. Instead, the accountant helped conceal from the board and the certifying agency – the Office of Mental Health – material financial transactions that diverted agency assets to the founder.

The Commission referred its findings to the Department of Law for recoupment of misappropriated corporate funds and reorganization of QCNI's board of directors; to the U.S. Attorney for the Eastern District of New York for possible criminal prosecution related to the theft of medical assistance funds; to the State Education Department for apparent gross violations of public accountancy; and to the Department of Social Services for recoupment of $600,000 in improper Medicaid payments received by QCNI.

Former Group Home Executives Arrested for Embezzlement

Leslie Wright and his wife Kay Wright, who were the executive director and president of the board of directors, respectively, for Community Living Alternative, Inc., a 10-bed intermediate care facility in Queens, New York, which operated as a home for mentally retarded adults, were indicted and arrested for the embezzlement of an estimated half-million dollars in Medicaid funds. This home was the subject of a Commission June 1994 report, *Missing Accountability: The Case of Community Living Alternative, Inc.*, which had found squalid conditions and financial abuse at the home.

The indictment was obtained on November 14, 1996 by the United States Attorney, Eastern District of New York, based on the Commission's referral, with assistance from the Federal Bureau of Investigation; Internal Revenue Service, Criminal Investigation Division; Department of Health and Human Services, Office of Inspector General; and Social Security Division, Office of Inspector General. Commission fiscal staff testified before the Federal Grand Jury which handed down the indictment.

From 1988 to 1992, CLA received $1.8 million in Medicaid operating funds from the state and federal government. According to the indictment, during this period, the Wrights embezzled an estimated $500,000 of CLA funds by writing checks to cash on CLA's corporate account, which they then deposited into their personal bank account. The proceeds were used to pay for various personal expenses. None of the money obtained through the embezzlement was reported as income to the Internal Revenue Service, nor was Leslie Wright's CLA salary for the years 1990 to 1992, totaling $124,700.

To facilitate the embezzlement, Leslie Wright used the aliases "Leslie White," and "Les White," and a false social security number. The aliases effectively concealed his marital relationship with Kay Wright, who, as president of the board of directors, was responsible for exercising oversight of CLA's spending. Further, the investigation revealed that, although Leslie Wright was required to submit annually to the state Department of Social Services a disclosure of ownership and control interest, including a list of CLA's directors, the lists were falsified. In fact, Kay Wright was the only board member.

Complaints by staff and relatives of CLA residents prompted an unannounced visit of the facility in 1992 by the Commission. Commission staff found the residents to be housed in squalid conditions and routinely fed cheap bulk foods. Subsequently, the Commission fiscal unit found that an unusually high percentage of CLA's expenditures were in the form of checks written to cash. And, when a subpoena was issued to Leslie Wright to obtain CLA's books and records, he abruptly closed CLA, padlocking the doors and fled to North Carolina.

The defendants are charged with fraud, embezzlement from a program receiving federal funds, money laundering and tax evasion. The government is also seeking to forfeit all the property of the defendants.

As this report goes to press, Leslie and Kay Wright have pleaded guilty to two felonies: conspiracy to defraud the federal Medical Assistance program and tax evasion. Richard Brown, the Certified Public Accountant for CLA, also has pleaded guilty to a felony count of lying to federal officials about his preparation of CLA's financial statements. Mr. Brown will be surrendering his CPA license for five years. Sentencing is scheduled for September.

Adult Home Administrator Sentenced

Based on the Commission's investigation of the HI-LI Manor Home for the Aged in Far Rockaway, New York, and referral of findings to the United States Attorney's Office, Beryl Zyskind, HI-LI's former administrator was sentenced to 30 months in prison for bank fraud in obtaining a $1.2 million loan and stealing funds from the mentally-ill residents, including a $122,658 check from the U.S. Veteran's Administration and over $10,000 from resident personal accounts.

Federal District Court Judge Edward R. Korman, at the November 14, 1996 sentencing proceeding, described Mr. Zyskind's crimes as "revolting," also ordering that Zyskind serve five years supervised release for the bank fraud and three years for the thefts. This sentence, the judge added, "should reflect...both the moral and legal consequences of what he did and the need to deter others from engaging in this type of activity." With respect to the charge of stealing the residents' personal monies, which entailed altering the balances on ledger cards to hide the thefts, the judge said Mr. Zyskind's conduct was "extraordinarily offensive and disturbing" since it affected the "most helpless disabled residents" of HI-LI Manor.

*Zyskind's sentencing brings to an end an extensive investigation begun by the Commission pursuant to the mandate of the State Legislature, which in 1989 directed the Commission to study the quality of care of at adult homes (*Adult Homes Serving Resident with Mental Illness: A Study of Conditions, Services and Regulation*, October 1990). This report revealed serious deficiencies at HI-LI Manor and at many other adult homes which serve predominantly persons with mental illness.*

The Commission's follow-up study of HI-LI Manor (*Exploiting the Vulnerable: The Case of HI-LI Manor Home for the Aged and Regulation by the NYS Department of Social Services*, May 1992) concluded that the deficiencies found in the earlier study were "directly attributable to decisions to divert a substantial portion of the available money to purposes unrelated to resident care." The Commission estimated that as much as 40 percent of the funds provided for the care of the residents was diverted through a pattern of improper fiscal practices at the expense of the welfare of the residents, while the facility for years remained in chronic non-compliance with DSS regulations for adult homes.

The investigation leading to the conviction of Mr. Zyskind was jointly conducted by the U.S. Attorney, Eastern District of New York; Federal Bureau of Investigation; the U.S. Department of Veteran's Affairs, Office of Inspector General; and the U.S. Social Security Administration, Office of Inspector General, and was assisted by staff of the Commission's legal and fiscal bureaus.

New Safeguards on Veterans' Benefit Payments

As a result of the Commission's investigation at the HI-LI Manor Home for the Aged which found that money belonging to mentally-ill veterans was not being properly safeguarded, the Inspector General of the U.S. Department of Veterans Affairs (VA) in early 1996 reexamined it procedures for safeguarding the management of VA monies by adult home administrators. These administrators act as VA-appointed fiduciaries for incompetent veterans residing at adult home facilities. The initiative focused on those adult homes where veterans had received large retroactive benefit payments. Veterans receive large retroactive benefit payments when they do not collect their monthly compensation payments for a long period of time.

The Commission's fiscal staff provided field support for the VA's proactive effort by conducting site visits to adult homes that had received large retroactive checks. The Commission found that the new mechanisms the VA put into place to safeguard the monies were working properly and that oversight by the local VA was rigorous and effective.

In a June 3, 1996 letter to the Commission acknowledging the coordinated efforts of the two agencies, the VA Inspector General noted that "The conviction of Beryl Zyskind has sent a very important message which has been clearly heard throughout the local adult home industry. That message is that government agencies will aggressively and relentlessly pursue and prosecute people who take advantage of the most vulnerable members of our society."

Private Psychiatric Hospitals Offer Improved Care and Cost Savings

A Commission study of private psychiatric hospitals in New York State suggests that, as the state's role in direct provision of inpatient psychiatric hospitalization diminishes with the downsizing and closure of state facilities, private psychiatric hospitals are a cost-effective alternative for children and elderly patients housed in state institutions, while offering potential annual savings of $14 million in reduced Medicaid payments by controlling the over-utilization of services.

The Commission's April 1996 report, Breaking with the Past: How New York's Private Psychiatric Hospitals Have Managed Since Managed Care*, found that, since 1989, there has been an almost 50 percent reduction in lengths of stay for private insurance patients at private psychiatric hospitals in New York State as a result of managed care controlling costs for private insurance patients, and with no adverse impact on quality of care. As managed care cost controls reduce their profit margins, private hospitals have become increasingly dependent upon Medicaid and Medicare-reimbursable patients to remain viable.*

The study of the role played and relative costs of the state's 11 for-profit psychiatric hospitals–operating under Article 31 of the State Mental Hygiene Law and serving 14,000 patients annually in the state inpatient mental health system–concluded that:

- private psychiatric hospitals offer high quality care to patients with commercial insurance, as well as to the growing number children and elderly who rely on Medicaid and Medicare. In contrast to state psychiatric centers and psychiatric units of general hospitals, where the Commission in previous studies found widespread patient inactivity, private psychiatric hospitals offer more programs and activities, had more psychiatrists meeting with patients, less use of restraint and seclusion, and much better follow-up with discharged patients;

- managed care has reduced lengths of stay almost by half, from 37 days in 1989 to 19 days in 1993 for private insurance patients, without affecting quality of care at private psychiatric hospitals. At the same time, without managed care's monitoring, Medicaid and Medicare average stays decreased only three percent and seven percent to 65 and 28 days, respectively. Lengths of stay for a comparable Medicaid population were 42 percent lower at general hospitals, however, suggesting that managed care can be successfully applied to this government assistance program;

- as a result of declining revenues and profits from commercial managed care initiatives, private psychiatric hospitals have been forced to turn to providing services to elderly and indigent mentally ill persons covered by Medicare and Medicaid. Under federal requirements, private psychiatric hospitals can only bill Medicaid for services to individuals under 21 or over 64. Revenue from this public source grew by 200 percent from 1989 to 1993 while Medicare income rose by 118 percent. If average Medicaid stays at private psychiatric hospitals were reduced to the levels of general hospitals, the Commission estimates annual savings of $14 million in medical assistance payments;

- though faced with declining revenues from managed care, private psychiatric hospitals have reduced costs by economizing, but the decrease in revenues has reduced profits overall, though the Commission found many "profits" disguised as costs through non-arm's-length management contracts; and

- with the downsizing or closure of state facilities, private psychiatric hospitals could help meet placement and treatment needs while offsetting the impact of managed care on the industry. Thus, the state would achieve cost savings from both managed care and state facility downsizing and further the public policy goal of privatizing.

The Commission recommended that OMH conduct audits and apply a managed care approach to Medicaid patients to ensure that cost-based Medicaid rates do not over-fund hospital operations. Such audits would help to ensure that licensees do not transfer operational responsibility to outside corporations to avoid diluting operational accountability as was also found in this study.

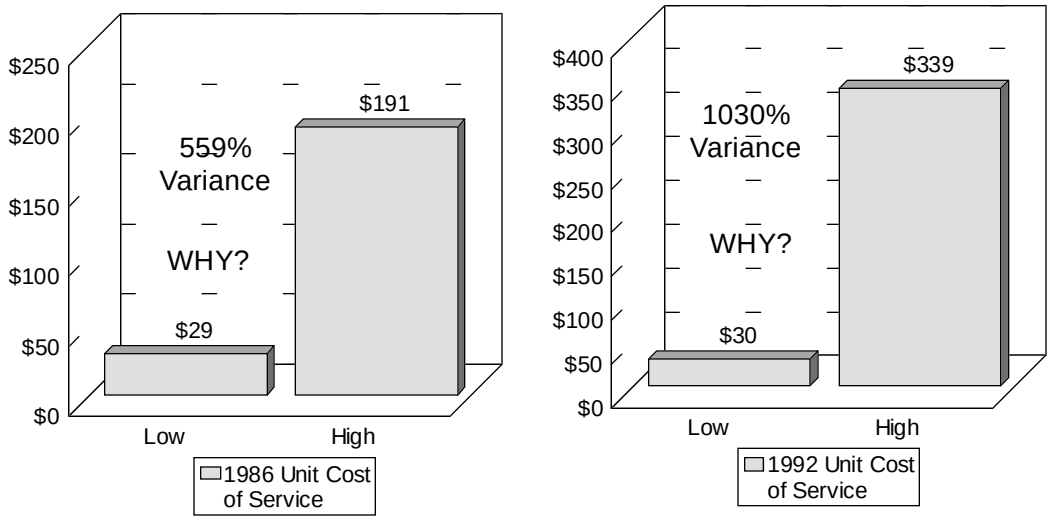
Wide Cost Variations at Psychiatric Clinics

A May 1996 study, *Why Do Psychiatric Clinic Costs Vary by 1030%?: A Review of the Efficiency of Freestanding Clinics*, found that 188 outpatient mental health clinics operated by voluntary agencies and counties in New York State had wide variations in the cost of clinic services, and identified the factors contributing to the high cost of the state's outpatient services. The review found that the "unit cost" of these clinics varied by 1,030 percent, ranging from $30 to $339 for a session between a patient and a clinician generally lasting 30 minutes to one hour. Such "free-standing" clinic programs are the largest category of outpatient programs, accounting for $217 million of the $1.1 billion New York State spent on outpatient mental health services in 1992.

The Commission found management practices of freestanding clinic programs substantially affected their cost-effectiveness and determined that four major factors affected the wide variation in the costs of clinic units of service:

- **method of payment of clinicians' services:** clinics utilizing primarily salaried staff had over double the unit costs of those using contract clinicians, who are paid only for services actually delivered. However, contract clinicians were less likely to furnish the comprehensive treatment and support services persons with serious mental illness need to function in the community;

Freestanding Clinics
Study Purpose: Why do costs vary?



- **clinician productivity:** programs whose staff averaged only one or two units of service of face-to-face patient therapy daily per clinician had unit costs 185% higher than clinics where staff averaged over five units of service daily;

- **hours of operation:** clinics open 40 hours/week or less had average unit costs 58% higher than clinics open over 60 hours /week, since longer hours permit scheduling during peak hours on evenings and weekends which are more convenient for some patients; and,

- **"no-show" rates:** clinics with higher no-show rates, which create unexpected gaps in clinicians schedules, thus reducing productivity, also had higher average unit of service costs than low no-show rate clinics.

As important as are the above relationships between provider management practices and their costs, it is of equal importance to note the following expected relationships which did not exist:

- the study found no correlation between the severity of mental disability of the patients served by clinic programs and the unit cost of service;

- examples were found of both county and voluntary agency-operated clinics regardless of contract or salaried staff, which were equally efficient, suggesting that auspice of service alone was not a significant factor in cost efficiency;

- despite a state policy supplementing base Medicaid fees for Comprehensive Outpatient Program (COPS) clinics, which agree to improve clinic services to seriously and persistently mentally ill adults and seriously emotionally disturbed children, non-COPS programs which did not receive these additional payment were found to serve higher percentage of such patients than COPS programs.

The Commission recommended that OMH require high cost clinics to implement cost reduction efforts and to gradually reduce subsidies to them to encourage efficiencies. The study estimates that holding unit costs to just 125 percent of the statewide average unit cost of $96 for a clinic visit could save $11 million annually.

OMRDD Provider Administrative Rate Reductions

A recurring factor in various Commission studies has been the excessive administrative cost being underwritten by the state through its funding systems at various voluntary run programs. The Commission's 1995 study (*Safeguarding Public Funds: A Review of Spending Practices in OMRDD Rate Appeals*) of the OMRDD system for processing appeals of Medicaid rates for intermediate care facilities (ICF) identified the ICF administration category as an area of abuse and overspending. In an effort to better control administrative costs and achieve budget efficiencies, OMRDD amended its ICF reimbursement methodology on July 1, 1996 producing $19.9 million in savings on an annual basis.

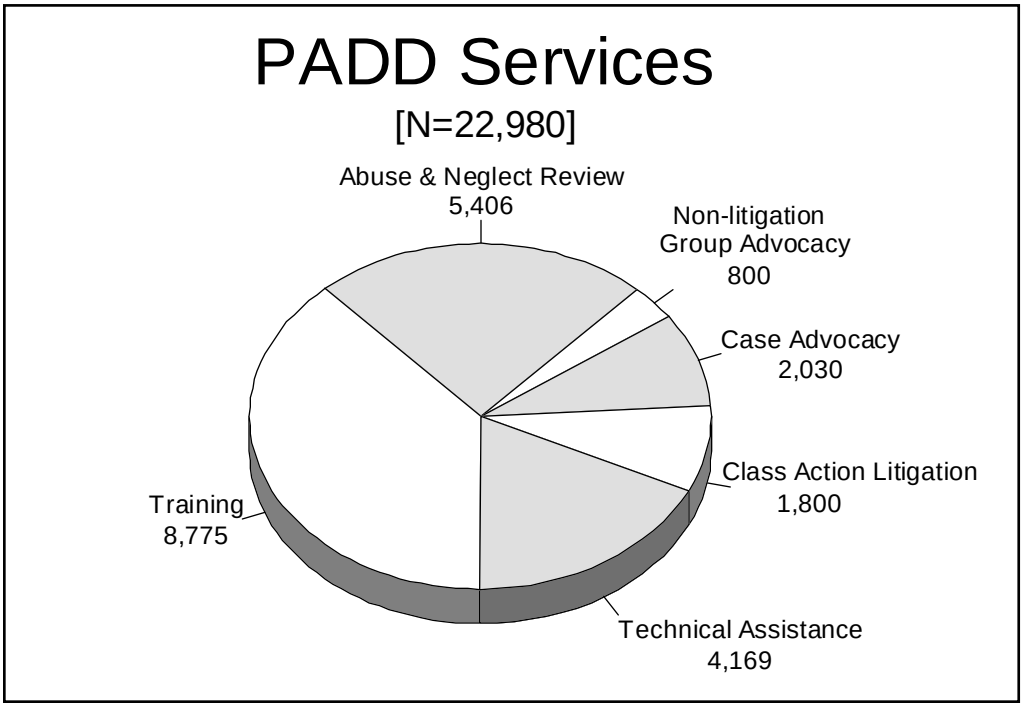
Protecting and Advocating

Individuals with disabilities are often vulnerable to abuse and neglect and can be denied civil rights. When Congress created the protection and advocacy programs, it acted to ensure that the rights of these individuals as specified in the United States Constitution, as well as each state's constitution and related laws, would be protected.

The Commission was entrusted with the administration of New York's protection and advocacy networks, because of its proven reputation for vigorous independent monitoring and advocacy. The activities and accomplishments listed below, which include a variety of individual case assistance, technical assistance, and legal representation, demonstrate the continued effectiveness of New York's protection and advocacy network.

Protection and Advocacy for Persons with Developmental Disabilities

Close to 23,000 New York State citizens with developmental disabilities were served by the New York State Protection and Advocacy for Persons with Developmental Disabilities (PADD) program this past year. These services included legal assistance and nonlegal individual advocacy and encompass a variety of educational and training programs and special efforts fostering community integration of persons with disabilities. The Commission also has been actively involved in advocacy for systems reform of services and programs for persons with developmental disabilities as well as the investigation of alleged abuse and neglect of institutionalized children and adults with developmental disabilities.



This was an especially productive time for the Commission's PADD program. Approximately 1,800 persons were represented in class action litigation. Case advocacy services were provided to 2,030 persons. Another 800 individuals were served in group advocacy, and 5,406 cases of alleged abuse were investigated by PADD staff. Over 8,775 individuals received training and there were 4,169 responses to requests for information, materials, referrals, and technical assistance services.

The strength of the New York State PADD program is in its unique blending of statewide and regional services. Its eleven regional offices provide a statewide network of accessible and individualized services to persons with developmental disabilities. Moreover, the Commission's other bureaus provide a perfect complement to these services, particularly, in the area of abuse and neglect investigation and policy studies. The Commission administers the regional PADD program from its central office in Albany through contracts with private, non-profit legal services and advocacy agencies. Services range from legal representation to nonlegal assistance and include training opportunities and informational materials.

The following are illustrative examples of PADD case activity.

Special Education Aide in a Parochial School

Following on the success of the Commission's Albany Law School (ALS) Protection and Advocacy for Persons with Developmental Disabilities (PADD) program in *Russman v. Watervliet Central School District*, the PADD office at Westchester Putnam Legal Services (WPLS) won an Impartial Hearing which ordered the on-site placement of a teaching aide for a special education pre-school student at St. Ann parochial school in Ossining, New York. The 2nd Circuit U.S. Court of Appeals agreed with lower Court Judge Con Cholakis in *Russman* brought by Albany Law School and ruled that while a consultant teacher and teaching aide "might add to the secular environment at St. Brigid, there is no evidence that the provision of a consultant teacher and teaching aide would add to the religious environment at the school". In the WPLS case, *In the Matter of JD v. Croton-Harmon School District*, the pre-school student with Down Syndrome needed only a teaching aide. The District argued that the service would add to the religious environment of the school despite the fact that the aide would provide no teaching at all. The Impartial Hearing Officer ruled that the aide could be provided on site at the parochial school without any fear of Church/State entanglement. The School District appealed the Hearing Officer's decision to the State Review Officer. This second stage special education administrative review ordered the retention of a teacher's aide at the St. Ann parochial school. The State Review Officer cited *Russman* again and reiterated that the use of a teacher's aide and consultant teacher on site at a parochial school did not violate the U.S. Constitution's prohibition against the entanglement of Church and State.

Community Placement

The Long Island PADD regional office, Long Island Advocates Inc. (LIA) was successful in returning a young man with quadriplegia back to the community after almost two years of wrangling with reluctant agency providers and ambivalent parents. The young man's rehabilitation had come to an end at the Blythedale Children's Hospital and he had to be placed elsewhere. The original plan was to have his parents' home modified for accessibility and that he would attend Hofstra college during the day. The plan for home modification became indefinitely delayed and it became apparent that the parents would be more comfortable with their son living somewhere else in the community like the dormitory at Hofstra. The staff at Blythedale became impatient with all the delay and they were faced with a mandate from Medicaid to find a nursing home. The advocates from LIA, along with the PADD Director from Albany, held a July meeting with all of the individuals (21) necessary to effectuate a placement back on Long Island. Hofstra arranged admission to its fully accessible dormitory, Vocational Educational Services for Individuals with Disabilities (VESID) arranged for Room and Board payment, the local State Developmental Disabilities Services Office (DDSO) arranged for primary medical care and referral to nursing services. The plan needed to be in place by September 5, the first day of college. The plan was almost completely aborted by an initial denial of Medicaid payment for 24 hours of nursing service but a New York State Department of Health (DOH) official assisted in gaining a compromise permitting the service. The young man was transported to Hofstra over the Labor Day weekend and he has been attending classes ever since.

Reasonable Accommodation

The Commission's PADD legal support unit in New York City, New York Lawyers for the Public Interest, won a favorable Medicaid Fair Hearing Decision challenging the denial of prior approval for a Handi-Move lift track, and remote control device. A woman with cerebral palsy needed the lift to realign her leg when it became dislocated from its socket. The dislocation happened several times per month and, in addition to severe pain, there was an increased risk of osteoporosis. The lift would allow her to move from her bed to her wheelchair on her own and to use the bathroom by herself. The Office of Health Systems Management (OHSM) had denied prior approval on previous occasions offering various arguments as to cost and that a power failure could cause a dangerous situation in that the lift would become inoperable. However, this time, the Hearing Officer overruled OHSM by ruling that the lift is medically necessary to realign the woman's leg and to allow her to use the bathroom when she is alone. According to the Hearing Officer, the ability to use the bathroom by oneself is a normal activity and Medicaid has to approve equipment which enhances the capacity for normal activities. This decision is extremely important in that it not only provides for greater independence for that individual but it saves the cost of added home attendant service at a minimum or, at a maximum, a nursing home placement.

Employment Reinstatement

The Commission's PADD office in Binghamton, Broome Legal Assistance Corporation (BLAC), intervened on behalf of a young woman with mild mental retardation who was terminated from a child care training class. At issue was the fact that this individual had some past history with the Department of Social Services (DSS) and therefore it was assumed that she was a risk as a potential child care worker. A review of past DSS files and the Central Child Abuse Registry by the BLAC attorney revealed no "indications" or history of child abuse. The woman was reinstated to the training program.

Adoption

In the North Country a Family Court judge asked for the assistance of the PADD office, North Country Legal Services (NCLS). At issue was the request to adopt four children by their foster mother. The children's parents had outstanding charges of child abuse. The father was serving time for abuse and the mother, who is developmentally disabled, had been found responsible for helping to contribute to the abusive situation. The mother now was remarried but her husband had no interest in caring for four children. The mother agreed to voluntarily release the children for adoption but the Family Court Judge was concerned about her informed consent. The Judge asked that the NCLS attorney counsel the mother as to her consent and assure the court that this was in the best interest of the children. Fortunately, it was apparent that the mother had her children's best interest in mind by releasing them for adoption with a family with whom they had been thriving. It was agreed that the adoption would be open and mom would have visitation.

Protection and Advocacy for Individuals with Mental Illness

Since it was established in 1987, and administered pursuant to Public Law 99-313, the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program has continued to be a vital force working on behalf of individuals who are mentally ill who come to us with complaints of discrimination, lack of services, abuse, neglect, or other violations of their legal rights. Since 1987, the New York State PAIMI program has served more than 95,000 persons through a combination of individual assistance, systemic advocacy initiatives, and education/training/outreach projects.

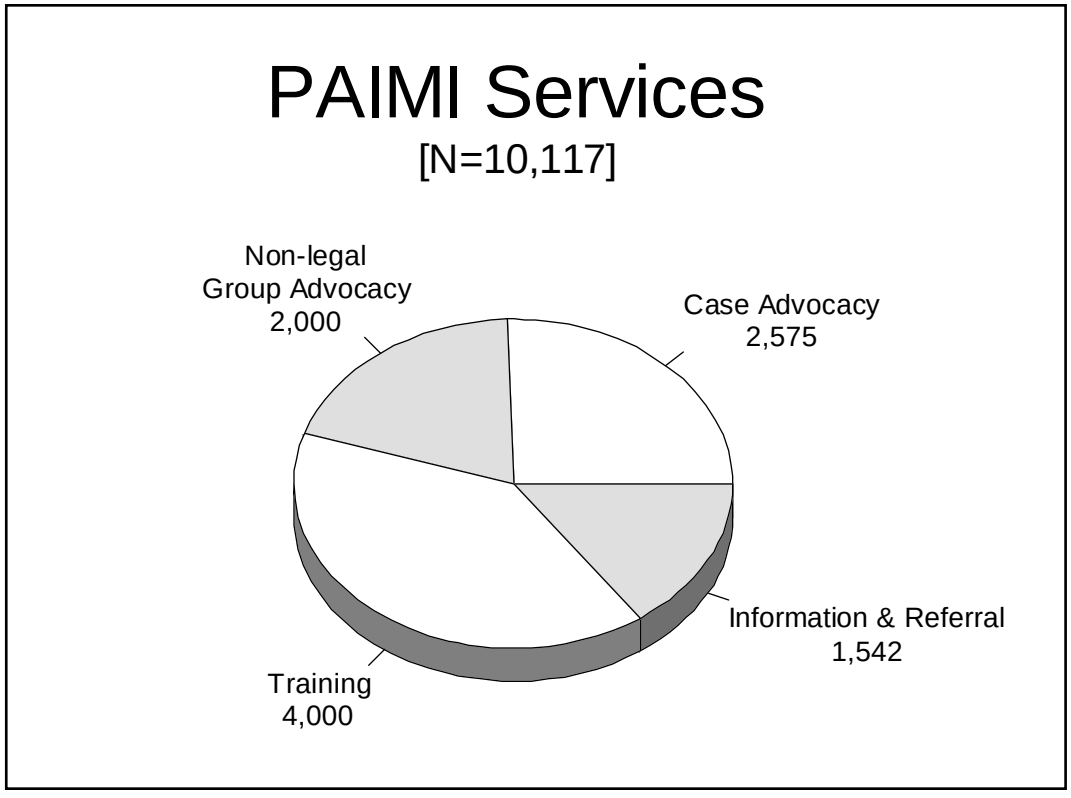
The federal mandate for the PAIMI program includes both the investigation of reported or suspected abuse and neglect and the provision of legal and non-legal advocacy services for eligible individuals. The work to accomplish the mandate from the federal government is carried out both by Commission activities such as investigation of patient deaths; reports of child and adult abuse in facilities which provide care and treatment for mentally ill individuals; response to complaints from recipients of mental health services and their family members; and through the advocacy efforts of a network of regional public interest legal offices located throughout New York State. Each compo-

nent serves an important function in working toward the goal that every individual who is served by New York's mental health system deserves to be treated with respect, care and dignity; and that an individual's constitutional rights do not change because they have a diagnosis of or are being treated for mental illness.

The Commission and its regional Protection and Advocacy office system will continue to work cooperatively with recipients of mental health services, their family members, and other advocates and service providers to ensure the protection of individual rights and the provision of quality mental health care.

During the past year, New York State's Protection and Advocacy for Individuals with Mental Illness (PAIMI) program has served a total of 2,575 individuals with mental illness throughout New York State who have been abused or neglected in residential treatment settings, or who have contacted us regarding problems they have identified related to their care and treatment or the violation of their legal rights. In addition to investigating individual complaints and finding resolutions, the PAIMI program has benefitted thousands of other persons throughout the state through its work in advocating for systemic changes in the delivery of mental health services. Systemic advocacy takes many forms, from participating on local and statewide task forces related to specific issues, to meeting with providers of New York State-licensed and operated programs as well as the state provider agencies regarding topics of concern, to pursuing litigation to resolve problems which cannot be solved by other means.

In addition to its individual and systemic advocacy work, the PAIMI program has provided 1,542 information and referral services for persons who contact us and whom we either cannot help or who would be better served by another



agency. The PAIMI program has also provided training regarding the rights of individuals in the mental health system and on specific related topics for approximately 4,000 persons.

Examples of specific types of assistance are listed below.

Parental Rights Assisted

- Disability Advocates, Inc.(DAI) was successful in reuniting a mother and her two children. The client had previously surrendered her parental rights to the children as a result of coercion by her mental health service provider. DAI represented the client in an attempt to revoke the surrender and regain custody of her children, who were awaiting adoption. After DAI brought a petition for custody in Family Court, the Department of Social Services agreed to return custody and guardianship of both children to their mother.

- Disability Advocates, Inc. has taken the lead, along with the Parents with Psychiatric Disabilities Support Project at the Mental Health Association in New York State, in assisting parents with psychiatric disabilities who are involved in the Family Court and/or social service system. This year, *Helping Yourself through Family Court Proceedings: A Guide for Parents with Psychiatric Disabilities* an informational brochure which was prepared by a staff attorney at Disability Advocates along with the director of the Parents with Psychiatric Disabilities Support Project, was published by the Mental Health Association.

- Legal Services of Central New York, Inc. assisted an individual who had been informed by her local Social Services office that her request for Medicaid coverage for her psychiatric appointments would not be approved unless and until she presented herself for an interview on an allegation of child neglect. After the involvement of the PAIMI program, by making a telephone call to the local Social Services office to point out that the client was being coerced, the issue was resolved and Medicaid coverage was provided. Additionally, the local office admitted that it would have been incorrect for the caseworker to threaten that approval for Medicaid was contingent upon an unrelated matter.

Employment

- The Mental Disability Law Clinic at Touro College successfully negotiated with the counsel for the Metropolitan Museum of Art in New York City to have the position of an employee who is mentally ill restored to him. The client had been terminated from his job by the museum after he experienced an episode of manic depression while at work. After commencing an EEOC action, but prior to filing a lawsuit, the client was restored to his position at the museum and paid several thousand dollars in back pay for lost time. The client was also returned to a higher salary level with full benefits.

Fair Housing

- Legal Services of Central New York, Inc. has taken on the case of an elderly woman with a mental illness who was forced to move out of the apartment where she had resided for fifteen years. The landlord's reason for demanding that she move out was her behavior spanning several months which was associated with a psychiatric episode. Their client was hospitalized in February, 1996 and remained an inpatient through September despite the fact that she had been stable and ready for discharge for several months because the apartment complex still refused to allow her to return to her home. An additional problem was that the apartment manager gave the woman unfavorable references when she applied for other living arrangements, thus exacerbating the problem. Even an application to a municipal housing authority resulted in a denial at first, but after further meetings and discussion, the client's application was finally accepted.

- New York Lawyers for the Public Interest, Inc. successfully prevented the imminent discharge of an individual with a psychiatric disability from his supported apartment program. The provider initially sought to discharge the resident without proper discharge planning, and without an eviction proceeding in court. After NYLPI's intervention, an agreement was negotiated with the residence to provide extensive assistance to their client to locate alternative housing. As a result, the client has found other housing and moved.

Interpreter Services for Deaf Individuals

- Neighborhood Legal Services, Inc. filed a complaint with the federal Office of Civil Rights on behalf of a deaf client who alleged that he was denied access to interpreters for his mental health treatment at an acute care psychiatric unit. The decision received from the Office of Civil Rights found that the hospital in question had failed to provide the client with sign language interpreters on a number of occasions during his hospitalization. The decision also stated that as a result of negotiations on this complaint, the hospital had voluntarily changed its policy and procedures on interpreters, making them acceptable to the Office of Civil Rights.

  The new hospital policy made some significant changes. It provided interpreters within 20 minutes of a request – and within 10 minutes if the request was from someone in an emergency setting. The policy also states that the request for interpreter services may be received from the patient, the family or representative of a patient, or from the provider of services. The policy also clearly states that charges for interpreter costs rest with the hospital and are not billed to the patient.

- In a similar situation, New York Lawyers for the Public Interest, Inc. has worked closely with New York City Health and Hospitals Corporation in developing policies and procedures for providing interpreter

services and other assistance to deaf patients in a timely manner 24 hours per day. Interest was stimulated at NYLPI after they were contacted by a deaf patient who had been held with no evaluation or treatment over a holiday weekend in the Bellevue Psychiatric Emergency Room because the interpreter services usually in place were not available due to the holiday.

Client Assistance Program

The Client Assistance Program (CAP) is a federal program administered by the Commission with the mission of promoting access to quality vocational and related services driven by consumer preferences and abilities. This is a fundamental tenet of the Federal Rehabilitation Act on the basis of which the Commission and its statewide network of participating CAP agencies assists individuals with disabilities secure quality vocational and other services related to employment, education, transitioning from school to work and self-support. As mediators, advocates, and legal representatives, CAP professionals employ an array of strategies to advance consumer access to effective rehabilitation and related services. CAP serves as a critical link to vocational services for many individuals who would otherwise find navigating the service delivery system frustrating and intimidating.

In a typical reporting period, such as the past year, consumer complaints vary, ranging from individuals seeking self-contained sheltered employment services to individuals seeking sponsorship for graduate studies leading to professional careers in medicine and law.

During the past year, CAP served over 6,200 New Yorkers with disabilities. More than 1,000 individuals received intensive advocacy case services. The statewide network of CAP advocates linked consumers with a vast array of vocational and related services by providing information and referral to over 1,400 individuals and demonstrated specialized expertise by providing technical assistance in over 764 cases. Over 3,000 individuals received training on their rights and responsibilities in the state's vocational rehabilitation and related services system.

CAP Services N=6,227	
Individual Case Services	1,063
Information & Referral	1,400
Consumer Trainings	3,000
Technical Assistance	764

Access to Computer Technology

Limited access to computer technology is a consistent consumer complaint and represents a fundamental challenge for the VESID service delivery system. Mr. M.'s case illustrates how consumers benefit from CAP's close working relationship with other New York State advocacy services. Mr. M.'s father contacted CAP after VESID had refused to provide a computer for his son. Mr. M. is a VESID consumer with Muscular Dystrophy attending college and majoring in computer animation. Mr. M. indicated that despite VESID's willingness to provide transportation, he was not gaining sufficient access to the computer labs on campus due to his demanding course schedule and limited lab hours. Mr. M. and his father had raised this issue with VESID and had received a letter from the senior VESID counselor indicating that under the American with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, the college was responsible for providing Mr. M. with a computer.

CAP met with the VESID District Manager in an attempt to negotiate a resolution and to avoid a fair hearing appeal. The VESID District Manager consulted with his senior staff and their technology expert, all of whom agreed that the university was responsible for providing the computer.

In the course of advocating for VESID sponsorship, CAP noted that the 1986 amendments to the Rehabilitation Act exempts assistive technology from similar benefit consideration. In addition, CAP noted that the regional CAP attorney also serves on the New York State Assistive Technology Advocacy Project and that the AT Project would be very interested in pursuing Mr. M.'s case. The AT Advocacy Project focuses on impact litigation to advance access to assistive technology for individuals with disabilities. The district manager indicated he would consult with VESID's central office. The following day CAP received notice that VESID agreed to provide funding for the computer.

Leaving Sheltered Employment

Ms. H. is a thirty-six year old VESID consumer who has mental retardation and a speech impairment. She had been in the same sheltered workshop placement for fifteen years. With support from personnel at her group home, and a case manager at the workshop, Ms. H. approached a VESID counselor for relocation to an alternative workshop or to a supported employment placement. The VESID counselor was extremely reluctant to consider alternative placements and admonished the case manger for advancing Ms. H's request.

CAP facilitated a meeting with all parties to review Ms. H.'s options. Following the meeting, the VESID counselor expressed a willingness to explore supported employment and requested the sheltered employment program to implement a behavior management program for Ms. H. A program of structured supports and feedback was initiated to assess whether Ms. H.'s inappropriate behaviors could be corrected. The behavior management program was monitored for six months and the results were excellent. Ms. H. has now been recommended for supported employment and she is extremely satisfied with this outcome.

Self Employment and Supports/VESID

The case of Mr. V. is an illustration of CAP's ability to assist consumers in negotiating a myriad of obstacles leading to a successful employment outcome.

CAP had previously represented Mr. V. at a fair hearing to secure VESID support for an assistive technology evaluation to determine whether music composer/writer was a feasible occupational objective. Mr. V. had a successful career in the music industry prior to being diagnosed with Multiple Sclerosis. The goal was deemed feasible with the use of a customized music computer and recording equipment. It took a full year with ongoing CAP intervention for delivery, installation, and training on the equipment.

Unfortunately, Mr. V.'s wife experienced serious medical problems and his M.S. exacerbated. To meet his need for more intensive supports, Mr. V. moved into a nursing facility. CAP assisted Mr. V. with the logistics of the move, with re-installation of the equipment at the nursing facility, in securing VESID sponsored repairs and with the purchase of a customized work table.

CAP then assisted Mr. V. in developing a Social Security Plan for Achieving Self Support (PASS) which provided Mr. V. with resources to market his material. Initial objections by Social Security to establish a PASS savings account at a nursing facility were overcome, and CAP linked Mr. V. with local resources to secure copyright protection for his work.

Mr. V. is now marketing his material independently and is engaged on a project to promote Long Island through the tourist industry and Chambers of Commerce.

VESID Overpayment and Service Suspension

In another case illustrating CAP's role in facilitating negotiated settlements, CAP assisted Ms. Q in negotiating a repayment plan to satisfy a VESID overpayment. Ms. Q. is a VESID consumer who is deaf and a resident of New York City. She relocated temporarily to Central New York to continue with her college studies when her home VESID district office discovered that she had been mistakenly awarded an overpayment of approximately $5,000 dollars in VESID funds. VESID suspended all support pending full repayment. Ms. Q. proposed a repayment schedule of fifty dollars a month which was unacceptable to the home VESID District Office Manager.

The western New York CAP office took the lead on this New York City case due to Ms.Q.'s temporary residence within their catchment area, and because the western New York CAP advocate is fluent in sign language.

CAP contacted the VESID District Manager and negotiated a satisfactory repayment agreement that allowed Ms. Q. to continue with her studies. An amount equivalent to VESID's typical room and board sponsorship will serve as repayment each semester until the debt is satisfied in-full. Ms. Q. will secure loans or alternative support for room and board in the interim. She will

continue to receive VESID support for tuition, fees, books and transportation assistance associated with her studies.

Training Program Dismissal

The case of Mr. Z. exemplifies CAP's typical role as mediator and negotiator. Mr. Z. is a 23 year old VESID consumer with significant learning disabilities. Following several warnings regarding punctuality, absences, and his inability to avoid conflicts with other consumers, he was dismissed from a VESID sponsored maintenance training program. The administrator of the training program was not willing to readmit Mr. Z. into the program, despite an appeal from his VESID counselor.
Following Mr. Z.'s request for assistance, the Manhattan CAP advocate identified a recently developed maintenance training program at the International Center for the Disabled (ICD). The program provided on-site counseling and problem solving supports for individuals engaged in on-site training.

Mr. Z. enrolled and excelled in the program which led to a placement at a local VA hospital. Unfortunately, Mr. Z. had an altercation with an ICD staff member over tardiness, and did not believe he had to answer to a line supervisor. Mr. Z. was also repeatedly accused of using foul language by his line supervisor. As a result, the program director was forced to consider dismissing Mr. Z. from the program.

Mr. Z.'s mother contacted CAP concerned about her son's possible dismissal from the program. CAP facilitated a meeting of all the parties and the program director discussed the program requirements and expectations with Mr. Z. and his mother. The program director was intent on establishing definitive guidelines for Mr. Z. to follow before she would allow him to return to the program. CAP suggested development of a contract to be signed by all parties concerned. CAP and Mr. Z. worked out a contract that was approved by the program director. Mr. Z. is currently back in the program, and to date, no further incidents have occurred.

The PAIR Program

The Protection and Advocacy for Individual Rights (PAIR) program is a legal and nonlegal advocacy program authorized by the Rehabilitation Act to provide authority and funds to states and territories to represent persons with disabilities who do not qualify for other existing advocacy programs. The Commission administers the program through contracts with regional offices. Typically persons with mental illness living independently in the community and persons with adult-onset disabilities are served in the program.

During the past year the New York State PAIR program served approximately 5,000 persons with disabilities, their families and advocates. Two hundred ninety-three persons were provided with legal representation or intensive case advocacy services. Another 966 persons were provided with information or appropriate referral and 3,741 persons were trained at 99 educational settings.

The following are examples of PAIR cases:

Supplemental Security Income Prerelease Program

Nassau Suffolk Law Services Committee (NSLS) in collaboration with its agency's sister program, Mental Health Law Project and LIFE - a mental health consumer-run program - has successfully instituted a process for persons with mental illness being released from the Kings Park Psychiatric Center. This process has resulted in individuals receiving SSI benefits within a few weeks of discharge, as opposed to six months or longer delays which were common previously. NSLS played a key role this year in developing new State mental hygiene legislation which incorporates this process. Moreover, Maureen McDavis, a PAIR and LIFE consumer advocate was awarded the Andrew Holub Achievement Award by the Federation of Employment and Guidance Services, one of New York's largest not-for-profit human services agencies, for her work on this prerelease program.

Accessible New York City Taxicabs

New York Lawyers for the Public Interest's (NYLPI's) PAIR program and Disabled In Action (DIA) devoted extensive efforts this past year to develop strategies to make taxicabs available in New York City that are accessible to people who use wheelchairs. Because of the difficulty of using public transportation, taxicabs play an important role in the transportation of individuals with mobility impairments. NYLPI and DIA have met and sought to work with a number of city and state agencies in an attempt to forge a coalition to support a workable proposal. Because taxis are much less expensive than ambulettes, accessible taxicabs would not only benefit many individuals, but could save money for Medicaid and the State Office of Vocational and Educational Services for Individuals with Disabilities, which now pay for ambulettes.

Disability Discrimination by a Physician Remedied

Disability Advocates, Inc. (DAI) was contacted by the parent of a deaf teenager who had requested, and was denied, an interpreter for an outpatient medical appointment. The parent filed a complaint with the Department of Justice, but it was not accepted.

DAI contacted the medical group and informed it that litigation would be commenced unless it agreed to provide sign language interpreters, post an interpreter policy in its waiting area, and advertise the policy in a local newspaper. After negotiating with counsel for the medical group, they agreed to all of DAI's requests, as well as to draft language for the interpreter policy and newspaper ad.

Illegal Discharge of Hospital Patient with Traumatic Brain Injury Prevented

DAI was contacted by a patient at St. Mary's Hospital in Troy, NY, regarding an impending discharge to a homeless shelter. He had traumatic brain injury, as well as a history of seizures, heart problems, asthma, and prior substance abuse. He also had just had a heart catheterization. The hospital made no discharge plans other than to place him in the shelter, where he would have to leave the facility between the hours of 8:30 a.m. and 4:00 p.m.

The client took eleven medications at ten different times of the day, and could not be compliant with medication in such an arrangement. Although the hospital was informed that it had not put together an appropriate discharge plan, it refused to delay the discharge pending an alternative placement.

DAI appealed the hospital's decision pursuant to the Public Health Law, and won a stay of the discharge pending the procurement of an appropriate facility. DAI found the client an apartment run by a program for individuals with a prior history of substance abuse. Outpatient rehabilitation services to address his traumatic brain injury and other health needs were also arranged for. He is currently doing well in his new home.

New York City Marathon Opened for Wheelchair Participants

Nassau Suffolk Law Services Committee (NSLS)PAIR program represented a client who is a competitive wheelchair athlete and who, along with numerous other competitors, has been denied access to compete in the New York City Marathon. The goal of this advocacy is to expand participation in the New York City Marathon to competitive wheelchair athletes similar to competition in the Boston Marathon and other National and International competitions. Several lawsuits brought against the New York Road Runners Club by competitive wheelchair athletes to require the Club to make the race accessible have failed, and the race has, to date, remained inaccessible to competitive wheelchair participants.

Final negotiations were completed with the New York Road Runners Club regarding the client's request for a reasonable accommodation to participate in the New York City Marathon. It was agreed that the client (and similarly qualified participants) would be provided with a starting position in the front of the race with a 12 minute early official start. Procedures for positioning the athletes at the start of the N.Y.C. Marathon are being handled by the Achilles Track Club, which reports that an additional approximately 90 wheelchairs will also compete, of which more than half will be in the competitive category (less than 3 hours to complete the marathon). This is the first time in the history of the New York City Marathon that there will be organized competitive wheelchair participation in the race.

Legal Interventions

In litigation, the protection and advocacy programs have a tool of last resort provided by federal statute to protect and enforce constitutional rights. Over the years the power to intervene by litigation has been used effectively in actions which resulted in protecting and advocating for the rights of individuals with disabilities. One of the great tests – and achievements – of the American legal system is its power to represent, and advocate for the rights and complaints of those who are particularly vulnerable, and, at times, stigmatized, abused, or outcast by others in society. The following are examples of legal actions pursued by the protection and advocacy programs.

PADD Legal Actions

Settlement Reached For Individuals With Developmental Disabilities In Psychiatric Centers

John S. and John R. et al v. Pataki, et al (NDNY)

This is a class action which is co-counseled between the Syracuse PADD office, Legal Services of Central New York (LSCNY) and Syracuse University Law Clinic. The named individuals are residents of the Hutchings, Binghamton and Mohawk Valley Psychiatric Centers. The suit alleges that the State has provided inappropriate care and treatment to the class members (including present and future residents) in violation of their substantive due process rights under the 14th Amendment to the U.S. Constitution.

During the course of the litigation, these advocates were able to achieve substantial results for many class members including re-evaluation by both the NYS Office of Mental Health (OMH) and the NYS Office of Mental Retardation and Developmental Disabilities (OMRDD). Residents were transferred to more appropriate and less restrictive settings. Those awaiting transfer were afforded more appropriate habilitation services and the special Multiple Disabilities Unit of Mohawk Valley Psychiatric Center was restructured and restaffed.

The final details of the settlement and the attorneys fees award are being completed. It is anticipated that all individuals found to be the legitimate

responsibility of OMRDD will be moved to appropriate settings. The significance of such a victory is that there has been no way to access the OMRDD system on an emergency basis and for that reason distraught families have sought psychiatric admissions out of desperation. The psychiatric center staff were unfamiliar with how to provide for the habilitation needs of these individuals with developmental disabilities. The suit will assure that once identified after emergency admission, these individuals will get appropriate temporary or transitional care and then move on to the more appropriate OMRDD system.

Applied Behavioral Analysis For Children with Autism Won in Federal Court

Nicholas Malkentzos on behalf of "MM" v. Barbara De Buono as Commissioner of the New York State Department of Health; The New York State Department of Health; The New York City Department of Mental Health, Mental Retardation and Alcoholism Services

The Commission's New York City PADD legal support unit, New York Lawyers for the Public Interest (NYLPI), was successful in finding the law firm of Weil, Gotshal & Manges to represent an aggrieved parent under the NYLPI Clearinghouse Program. The Clearinghouse is a consortium of forty prestigious New York City law firms which offers support to NYLPI. Each firm agrees to assume a number of cases *pro bono*. In *"MM"*, Weil, Gotshal & Manges won a full preliminary injunction from Judge Constance Baker Motley of the US District Court for the Southern District. The Federal Court reversed a New York State Department of Health's Hearing Officer decision which had denied the use of the controversial in-home Applied Behavioral Analysis (ABA) or Lovaas method for MM, a child with autism.

Judge Baker Motley stated that the defendants claims that the method was controversial and that allegedly, in the immediate area, there were no available "qualified personnel" as defined by State statute, did not preclude this family from finding their own trained college student practitioners and implementing a forty hour a week in home program. Citing the Supreme Court decision in *Florence County v. Carter*, Judge Baker Motley opined that MM's family could seek out a non-approved placement when the public placement is inappropriate for their child. In granting the full injunction, Judge Motley ordered that the defendants either provide the forty hours of in home ABA therapy, or reimburse the plaintiff for arranging the services. In addition, the plaintiff was awarded reimbursement for proven expenditures to date. This very significant decision is receiving widespread public interest, because there have been many denials of ABA therapy either under the rationale of number of hours involved (up to 40 per week) or because college students under the supervision of a trained special education teacher were considered as not "qualified personnel".

Parochial School Placement Sustained In U.S. Court of Appeals

Russman v. Watervliet Central School District

The Commission's PADD program for the Hudson region, Albany Law School(ALS) Disabilities Law Clinic, was victorious for a second time when the 2nd U.S. Circuit Court of Appeals upheld an earlier favorable decision by U.S.

District Court Judge Con Cholakis. In his July 6, 1995 *Russman v. Watervliet Central School District* decision, Judge Cholakis ruled that Colleen Russman was entitled to receive the special education services of a consultant teacher and teaching aide, on site, at the St. Brigid parochial school. These special education services were guaranteed under the *Individuals with Disabilities Education Act*, and while such services "might add to the secular environment at St. Brigid, there is no evidence that the provision of a consultant teacher and teaching aide would add to the religious environment at the school." The Circuit Court of Appeals agreed with the entitlement to services, and that there was no Church-State entanglement. There is only one final level of appeal for the School District and that is the U.S. Supreme Court. The Watervliet School District and the New York State School Boards Association are considering such an appeal, because it is their collective belief that "the court has opened the barn door enormously in terms of special education for private schools." For special education students, it means that, if they choose a private parochial school, they can receive their services on site rather than at some trailer on "neutral grounds."

Young Woman Seeks Reimbursement for Successfully Completed Training Program

Barbee v. VESID

This young woman with developmental disability had been accepted at the New York University Para Educator Center (PEC). Initially, she was told by the New York State Vocational and Education Services for Individuals with Disabilities office (VESID) that she could attend the PEC program in child care, but, later, VESID reneged stating that the program was longer than what is normally acceptable. The Westchester/Putnam Legal Services (WPLS) attorney brought an Impartial Hearing appeal which sustained the tuition payment for NYU. The Commissioner of VESID, however, reversed the Hearing Officer decision, stating there were other more suitable programs which were local to Westchester. WPLS brought an Article 78 appeal in State Supreme Court alleging that the Hearing Officer decision was supported by substantial evidence that local programs did not provide child care training, that VESID's reversal was arbitrary and capricious in that other similarly situated individuals statewide have been approved for the PEC program and finally that VESID exceeded the permissible scope of its authority on review by re-finding the facts rather than simply reviewing for errors in law.

The State Supreme Court dismissed on very narrow grounds of an error in the record. At oral argument before the State Appellate Division, the WPLS attorney stipulated the error, but argued that this did not change in any material way, the facts of the case and the fact Ms Barbee had successfully completed training and is employed as a teacher's aide gives testament to the fact that the program was appropriate and met all the elements of Ms. Barbee's vocational plan. This case is significant in that it might insure that the State VESID does not act so arbitrarily in the future and that individuals will receive training that will help them to be contributing members of society.

Experimentation on Incompetent Adults and Children Stopped
T.D. v. OMH

Two PAIMI offices, Disability Advocates, Inc. and New York Lawyers for the Public Interest, Inc., along with Mental Hygiene Legal Service, First Department have prevailed at the Appellate Division of State Supreme Court in their challenge to certain portions of the Office of Mental Health Regulations concerning research projects on human subjects. The lawsuit, *T.D. v. OMH*, focuses on physically intrusive experiments (such as drugs, ECT, surgery) involving persons who are deemed incapable of consent by OMH doctors. The lawsuit asserted that if an individual is incapable of giving consent, surrogate consent is illegal for experiments which offer no benefits to the subjects involved. The use of minors in research without parental consent is also challenged.

The plaintiffs sought and obtained a declaration that the regulations which permit such experimentation are unlawful. Since 1995 when the original State Supreme Court decision was issued, the Office of Mental Health twice ignored the Court's order and continued the challenged practices. After the issuance of restraining orders, the practices were finally stopped.

In December, 1996, the Appellate Court issued a unanimous decision which not only upheld, but more broadly interpreted, the initial decision, finding that the current regulations and practices "fail to provide for adequate notice and review procedures and therefore violate the due process clause of the New York State Constitution and the due process of the Fourteenth Amendment of the United States Constitution, and violate this State's common law as well as Public Health Law..."

Medicaid Ends Arbitrary Limits on Clozapine
Matter of Ruth X. v. Wing and DeBuono

New York Lawyers for the Public Interest, Inc., which serves as the New York City regional PAIMI office, has taken the lead in advocacy related to the availability of clozapine, which was heralded several years ago as a new miracle drug to treat schizophrenia. Originally, New York State Medicaid had refused to pay for clozapine at all, based on its cost, until NYLPI filed suit in 1991. In *Alexander L. v. Cuomo*, the State Supreme Court ordered New York to include clozapine in its Medicaid formulary. On February 1, 1996, the State dropped arbitrary limits on payment for clozapine for individuals on Medicaid. This useful development follows the success of another NYLPI lawsuit, *Matter of Ruth X. v. Wing and DeBuono.*
Starting in 1992, Medicaid refused to pay for clozapine for uses not included in the Food and Drug Administration-approved "labeling" for the drug. The "labeling" covers only patients over age 16 who are diagnosed with schizophrenia. ("Labeling" is material by which drug makers recommend their products to doctors. The FDA allows a use for a drug to be listed in labeling only if the drug maker submits to rigorous studies showing the drug is safe and effective

for that use. However, once a drug is approved by the FDA, doctors are free to use it according to their best judgement, including for purposes not listed in its labeling. This freedom is one way new uses for drugs are found. Drug makers often do not bother to submit new data to expand labeling, even as new uses of their drugs become widely accepted.)

The issue addressed in the *Ruth X.* case was the age of the patient for whom clozapine was being prescribed. Ruth X. was 13 years old and had been hospitalized for months and not helped by drugs other than clozapine. When she was given clozapine, she improved rapidly and was ready to go home. However, Medicaid denied Ruth's doctor's request for prior approval for payment for clozapine to continue on an outpatient basis, because use with a person her age was considered "off label" use. Ruth rapidly decompensated and her hospital stay was prolonged by 15 weeks, at a cost of $60,000 more in Medicaid payments than the State would have incurred by treating her as an outpatient with the requested clozapine.

NYLPI represented Ruth in a Medicaid fair hearing, but she lost. NYLPI filed suit for her, saying the denial violated the rule that Medicaid must pay for "medically necessary" drugs. Although the State tried to avoid a court decision by giving Ruth some of what she sought in the lawsuit, the Court rejected its attempt. This cleared the way for a ruling on the policy. Negotiations began and finally, New York State announced the end of the prior approval requirement, which also ended the "off label" policy as well.

Other problems have denied people on Medicaid access to clozapine as outpatients as well. Neighborhood Legal Services, Inc., the PAIMI regional office for the western New York region, successfully represented an individual in a Medicaid fair hearing who had been denied clozapine because her diagnosis was bipolar disorder rather than schizophrenia. In a case similar to that of Ruth X., North Country Legal Services, Inc., the PAIMI office in the northern region of the State assisted a 15 year old girl in obtaining clozapine despite the refusal of the hospital which was providing her treatment to accept the recommendations of a consulting child psychiatrist who had prescribed the drug for her.

As a result of ongoing advocacy efforts and the cooperation among advocates, recipients of mental health services, and their families; clozapine is finally fully available under New York State's Medicaid program.

Access to Treatment for Spanish-Speaking Patients

W.G. et al. v. Dvoskin, et al.

Disability Advocates, Inc. and Mental Hygiene Legal Service, Second Department successfully concluded a lawsuit, *W.G. et al. v. Dvoskin, et al.*, which was brought on behalf of all patients who spoke only or primarily Spanish at Rockland Psychiatric Center. The lawsuit was brought after it was learned that these Spanish-speaking patients who were unable to communicate in or understand English were being confined for treatment when the treatment team was unable to effectively communicate with them.

A settlement agreement was reached between the parties, which resulted in the creation of a second Spanish-speaking treatment unit at Bronx Psychiatric Center. The patients who moved from the Rockland facility to Bronx PC's Spanish unit have done remarkably well since they were transferred. One patient is expected to be discharged in the near future. An additional benefit of this settlement plan is that family members of these patients, most of whom live in the Bronx, can now visit their relatives more easily. Travel upstate to Rockland County had been prohibitive for many of them.

Challenge to "PRN" Medication Successful

Ruiz v. Acrish

Several years ago, the PAIMI program at Touro College's Mental Disability Law Clinic filed a class action lawsuit, *Ruiz v. Acrish*, which challenged the widely accepted practice of using PRN medications over the objection of patients "for agitation." The lawsuit was later joined by another PAIMI office, Disability Advocates, Inc. as co-counsel. The primary issue in this lawsuit was that the writing of PRN orders "for agitation" and the related forced medication led to violations of the right to refuse medication previously established by another lawsuit, *Rivers v. Katz*, several years previously.

After many years of litigating this issue, the lawsuit was finally settled. The settlement provided that:

- The NYS Office of Mental Health would adopt a policy that prohibits the writing of PRN for agitation orders in the form that they were currently being written. The new policy would require that such orders must be written "PRN for Agitation: to be given over objection only in an emergency." The Office of Mental Health agreed to keep this policy in force for at least five years after the court approved the settlement and an official policy directive was sent from the OMH on October 15, 1995.

- The Office of Mental Health would train all psychiatric center employees who are authorized to write medication orders or to administer medication about the provisions of the new policy.

- The Office of Mental Health agreed to monitor compliance with the new policy through its Quality Assurance program for one and a half years after the settlement and to provide plaintiffs' counsel with copies of the reports regarding the new policy for one year.

- The members of a subclass of patients at Harlem Valley Psychiatric Center would each receive a $100 settlement by executing a release, or they had the right to reject the settlement and bring their own lawsuit for damages.

Scope of Vocational Services
Cline v Gloeckler and Mills

VESID typically defines its role narrowly by limiting training and supports to those that lead to entry level employment. *Cline v Gloeckler and Mills* focused on clarifying the role of vocational rehabilitation, and argues that the Rehabilitation Act calls for services that are consistent with an individual's abilities and intended to advance career opportunities beyond entry level employment.

In *Cline v Gloeckler and Mills*, the western New York CAP legal services unit, Neighborhood Legal Services Inc., initiated an Article 78 complaint challenging the VESID Deputy Commissioner's reversal of a fair hearing decision favoring Ms. Cline. CAP argued that VESID's reversal of the fair hearing decision was not based on clear and convincing evidence that it was in violation of law or policy. CAP also challenged VESID's reversal based on their failure to notify Ms. Cline of their intent to review the hearing decision within the prescribed timeframes. The Albany County Supreme Court ruled in favor of Ms. Cline based on VESID's failure to comply with the prescribed time frames. This case was decided shortly after this reporting period ended.

Violation of the Randolph Sheppard Act.
Blind Vendors v. U.S. Postal Service

In the case of *Blind Vendors v. U.S. Postal Service*, the NYS Commission for the Blind and Visually Handicapped, blind vendors, and the Attorney General's Office filed suit in U.S. District Court challenging the policies and practices of the Postmaster General of the US Postal Services. New York Lawyers for the Public Interest (NYC CAP legal office) actively supported the litigation by filing an amicus brief.

Blind Vendors v. U.S. Postal Service successfully demonstrated that the U.S. Postal Service had denied blind vendors the revenues, profits and benefits due them from the operation of vending facilities on Post Office property. The Randolph Sheppard Act requires the U.S. Postal Service to establish one or more vending facilities for operation by blind persons "wherever feasible". The U.S. Postal Service had only established eleven Randolph Sheppard vending facilities in all of New York State. The settlement agreement will assure that the U.S. Postal Service is in full compliance with Randolph Sheppard requirements and will result in a significant increase in the number of employment opportunities for CBVH consumers statewide.

VESID Vehicle Modification Policy
Marshall v Switzer

Marshall v Switzer is another longstanding CAP case that successfully challenged a provision of VESID's vehicle modification policy that prohibits sponsorship

for factory-installed equipment. Mr. Marshall is a high level quadriplegic who was prescribed a series of vehicle adaptations that were achievable with factory installation i.e., power windows, heavy duty suspension, etc. The *Marshall* case took on additional significance when the lower court ruled, in response to VESID's motion to dismiss, that consumers of vocational rehabilitation services do not have an "individual" right to challenge a state agency in federal court under Section 1983 of the Civil Rights Act.

The Second Circuit Court of Appeals rejected this interpretation for recipients of vocational rehabilitation services, and affirmed "enforceable rights, privileges, or immunities within the meaning of Section 1983." The court ruling cited Title I of the Rehabilitation Act that requires states to develop a plan that "shall" provide, at a minimum, for the provision of specific vocational rehabilitation services. The court also referred to State Plan requirements that state vocational rehabilitation programs "shall" provide that an Individualized Written Rehabilitation Plan (IWRP) be developed for each eligible individual. The case was then remanded back to the District Court for resolution.

The U.S. District Court ultimately ruled that the VESID policy was inconsistent with requirements of the Rehabilitation Act, and directed VESID to amend their policies and compensate Mr. Marshall for costs associated with the prescribed factory installed equipment.

Education and Training

The work of the Commission's advocacy programs goes beyond individual case representation. Each office provides trainings, conferences, or small workshops to groups throughout assigned catchment areas. The topics are generated according to the needs of a particular group and trainings serve as a significant way of providing outreach. Individuals with disabilities, their family members, advocates, and others are provided with knowledge, skills, and self-confidence which adds to the quality of their lives. The following represents a sampling of these activities.

- **Educational Advocacy Training (EAT):** This very successful parent training continues on a statewide basis with the coordinator/instructor working from the Commission's central office in Albany. There are three levels of training beginning with a special education overview and moving on to CSE meetings and Impartial Hearings. In addition to the individual sessions, a Statewide conference sponsored by a number of advocacy agencies was planned for the spring of 1997.

  The EAT trainings have been enhanced with the addition of a bilingual instructor who will be training families in their native Spanish language. These special Spanish language trainings have identified other needs. For example, it has become apparent that Spanish language dominant parents could use the assistance of a bilingual advocate to help assure their full participation. Families are entitled to translators but these individuals serve no advocacy role. Consideration is being given to developing, on a trial basis, a cadre of bilingual volunteers to accompany families to the CSE meetings.

- **How to Develop An Individualized Education Plan (IEP):** This has been another continuing initiative from the WNYADD office in Rochester. It has been found that very few people understand how an IEP should be constructed. The WNYADD staff have developed very helpful guides to developing long and short range goals. This material and training has assisted many individuals on Committees on Special Education (CSE) as well as parents who find, at times, what is developed at CSE meetings is utterly incomprehensible.

- **Continuing Education for Foster Parents:** Long Island Advocates Inc. continues to assist the Department of Social Services Foster Care Unit in training minority foster parents about how to negotiate the special education system. Workshops were conducted in the morning and early evening to facilitate participation. Families are required to attend these sessions in order to meet continuing education requirements for their licensure.

- **Disabilities Awareness Program:** Each year a contest is held to encourage typical school age students to express in writing or through art their concepts of integration of individuals with disabilities. The schools are visited by representatives from the Commission who conduct a sensitivity training. Then the students are invited to send submissions for the contest. The submitted art work and creative essays are featured at a spring display at the Empire State Plaza in Albany. The individual winners are treated to a celebration which is frequently hosted by the state's First Lady at the Governor's Mansion.

- **Disability and the Law:** Featured this year in the ongoing series was a video entitled "Supported Employment: A Winning Option for All". Highlighting the benefits of supported employment, this one hour show explored the history of employment options for persons with disabilities and the federal laws which govern supported employment. The staff and participant interviews demonstrated the benefits of supported employment and the numerous options available within the program.

- **Medicaid Fiscal Assessment Training:** New York Lawyers for the Public Interest, Legal Services for the Elderly and the Association of the Bar for New York City conducted a training for *pro bono* lawyers, Legal Services, and Legal Aid lawyers on Medicaid fiscal assessment, the process by which Medicaid determines whether people should receive personal care at home or should be transferred to nursing homes. The training focused on the assessment process and how to represent clients in Medicaid fair hearings, State Court Article 78 proceedings and Federal Court. This training helped maximize the available legal representatives for an increasing caseload.

- **Minority Outreach:** The Minority Outreach effort continues under the coordination of Ms. Loretta Goff of the Commission's New York City PADD staff. Ms. Goff now divides her time between case advocacy and minority outreach training. She continues to be a consultant to the PADD Network of nine Statewide contract offices and she pre-

pares an annual workshop for the Advocacy Services conference. The focus of this effort is to prepare agencies to be culturally competent and to help entice and train individuals of various ethnic backgrounds into the service delivery system.

- **State University of New York (SUNY) Graduate Training:** The advocates from the PADD office in Rochester, Western New York Advocates for the Developmentally Disabled (WNYADD), conducted a two and one-half hour workshop for Masters-level teaching students at the SUNY campus at Geneseo. The session was interactive in which the students would pose questions on a range of issues, from special education law and regulations to various special education methodologies such as Applied Behavioral Analysis or Lovaas. Such a spontaneous method of instruction has helped to foster classroom discussion.

Appendices

1995-96 Publications

Shifting Costs to Medicaid: The Case of Financing the OMRDD Comprehensive Case Management Program, December 1995

Watching Over the Children: A Review of 1995 Commission Activities on Behalf of Children with Mental Disabilities, March 1996

Breaking with the Past: How New York's Private Psychiatric Hospitals Have Managed Since Managed Care, April 1996

Why Do Psychiatric Clinic Costs Vary by 1030%? A Review of the Efficiency of Freestanding Clinics, May 1996

A Brief Report on Active Programming in State Psychiatric Centers: Has Anything Changed? August 1996

Profit Making in Not-for-Profit Care Part III: The Case of Queens County Neuropsychiatric Institute, Inc., October 1996

Brochures – Could This Happen in Your Program? Series:

In the Matter of James Manning: A Case of Unrealistic Supervision Expectations

In the Matter of Becky Newman: A Failure to Communicate in Sexually Related Incidents

In the Matter of Joel Lang: A Failure to Ensure Implementation of a Discharge Plan

In the Matter of Donna Osborne: Providing Life-Saving Treatment Over Objection

In the Matter of Alanis Petty: When Investigations Miss the Basic Facts

In the Matter of Juan Garcia: Errors Spanning Three Shifts Lead to Death

In the Matter of Grace Maddux: Preventing Accidents During Activities of Daily Living

In the Matter of Sara Grand: Preventing Deaths by Timely Medical Care and Monitoring

In the Matter of Gail Foster: Dealing with Crime In A Residential Program

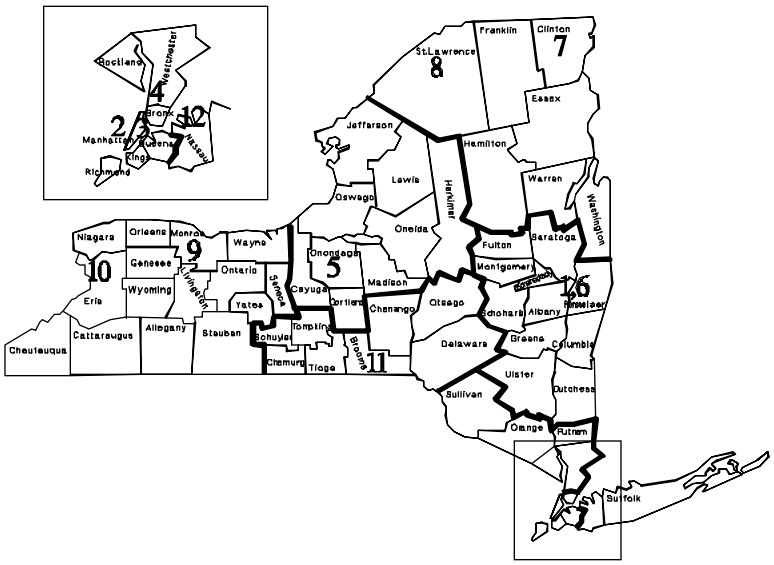
In the Matter of Linda Simon: Despite Late Reporting, The Incident Review Process Works

In the Matter of Amos Grace: Are Professional Staff Above Reproach?

In the Matter of Joan Stalker: Too Little, Too Late

In the Matter of Sharon Seaver: Chance Glance Thwarts Suicide Attempt

Protection and Advocacy for Developmentally Disabled Persons Regions and Offices



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

North Country Region

7. North Country Legal Services, Inc.
   100 Court Street
   Plattsburgh, NY 12901
   (518) 563-4022

8. North Country Legal Services, Inc.
   P.O. Box 648
   Canton, NY 13617
   (315) 386-4586

Western Region

9. Western New York Advocacy for the
   Developmentally Disabled, Inc.
   Medical Arts Building
   277 Alexander Street, Suite 500
   Rochester, NY 14607
   (716) 546-1700

10. Neighborhood Legal Services, Inc.
    495 Ellicott Square Building
    Buffalo, NY 14203
    (716) 847-0650

Southern Tier Region

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

Long Island Region

12. Long Island Advocates, Inc.
    Herricks Community Center
    999 Herricks Road
    New Hyde Park, NY 11040
    (516) 248-2222

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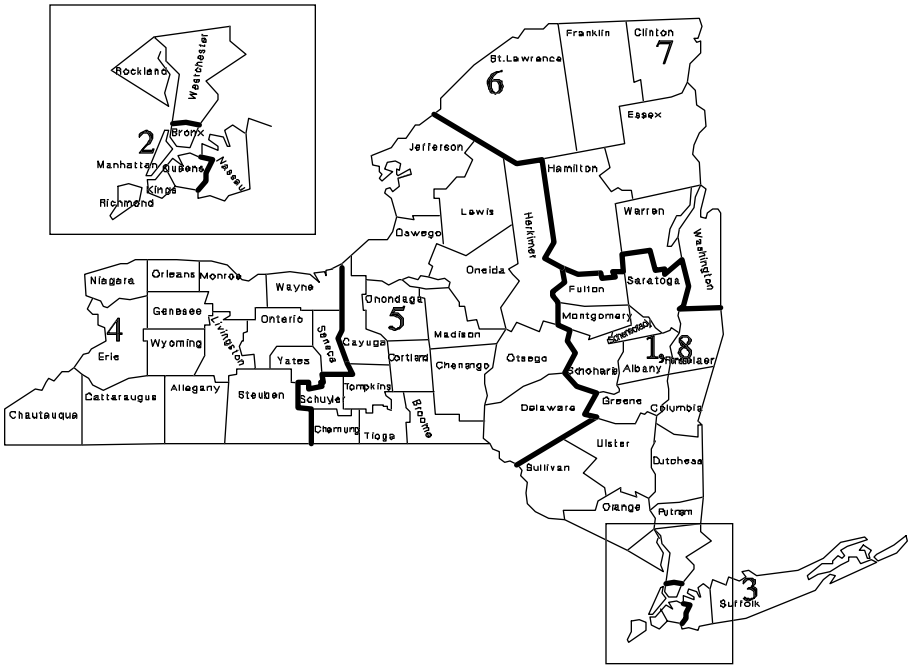

1. NYS Commission on Quality of Care
   Bureau of Protection and Advocacy
   99 Washington Avenue, Suite 1002
   Albany, NY 12210
   (518) 473-7378

New York City Region

2. New York Lawyers for the Public Interest, Inc.
   30 West 21st Street, 9th Floor
   New York, NY 10010
   (212)727-2270 (212) 727-2997 (TTY)

Long Island Region

3. Touro College
   Jacob J. Fuchsberg Law Center
   300 Nassau Road
   Huntington, NY 11743
   (516) 421-2244 ext. 331

Western New York Region

4. Neighborhood Legal Services, Inc.
   495 Ellicott Square Building
   Buffalo, NY 14203
   (716) 847-0650 (716) 847-1322 (TTY)

Central New York Region

5. Legal Services of Central New York, Inc.
   The Empire Building
   472 South Salina Street, Suite 300
   Syracuse, NY 13202
   (315) 475-3127

North Country Region

6. North Country Legal Services, Inc.
   38 Gouverneur Street, POB 648
   Canton, NY 13617
   (315) 386-4586 1-800-822-8283

7. North Country Legal Services, Inc.
   100 Court Street
   Plattsburgh, NY 12901
   (518) 563-4022 1-800-722-7380

Hudson Valley Region

8. Disability Advocates, Inc.
   155 Washington Avenue, Suite 300
   Albany, NY 12210
   (518) 432-7861

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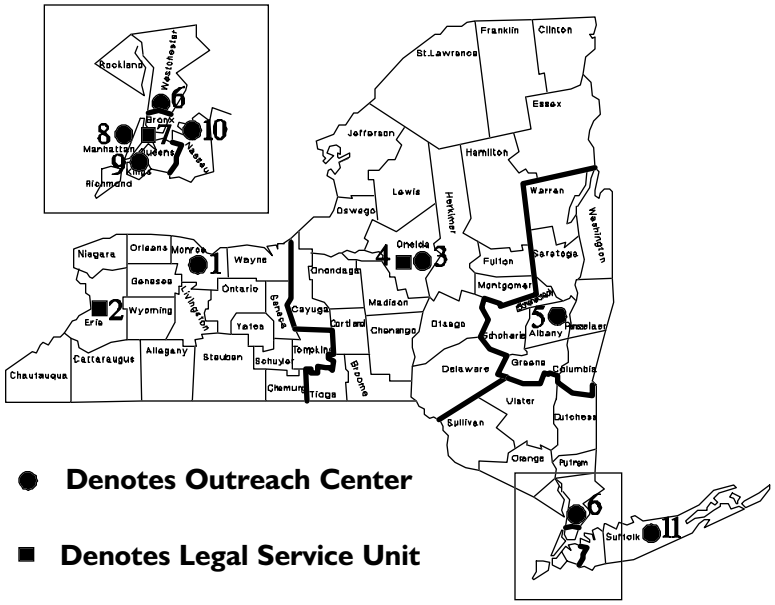

Western New York Region

1. Rochester Center for Independent Living, Inc.
   758 South Avenue
   Rochester, NY 14620
   (716) 442-6470 (Voice and TTY)

2. Neighborhood Legal Services, Inc.
   495 Ellicott Square Building
   Buffalo, NY 14203
   (716) 847-0650 (716) 847-1322 (TTY)

Central New York Region

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

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

Hudson Valley Region

5. Capital District Center for Independence, Inc.
   845 Central Avenue, South #3
   Albany, NY 12206
   (518) 459-6422 (Voice and TTY)

6. Westchester Independent Living Center, Inc.
   297 Knollwood Road
   White Plains, NY 10607
   (914) 682-3926 (914) 682-0926 (TTY)

New York City Region

7. New York Lawyers for the Public Interest, Inc.
   30 West 21st Street, 9th Floor
   New York, NY 10010
   (212) 727-2270 (212) 727-2997 (TTY)

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

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

Long Island Region

10. Long Island Advocacy Center, Inc.
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    999 Herricks Road
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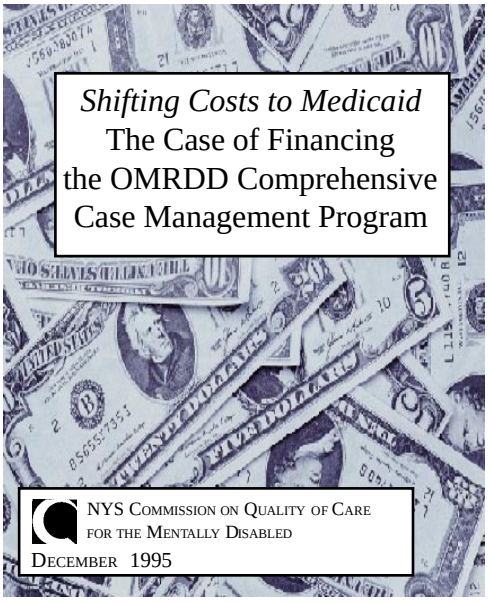

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