

NEW YORK STATE COMMISSION ON

QUALITY OF CARE

FOR THE MENTALLY DISABLED

ANNUAL REPORT

1998 - 1999

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

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The Commission's statewide toll-free number is for calls from patients/residents of mental hygiene facilities and programs, their families, and other concerned advocates.

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Foreword

Change again set the tone at the Commission this past year. In April, we moved our office to Schenectady. As any homeowner knows, moving can be both difficult and challenging. Fortunately, we were blessed with a great committee within our agency who incorporated the concerns of staff and kept us posted on the progress of the renovations. Their effort, coupled with a gracious welcome by Mayor Al Jurczynski, the people and the merchants of the City of Schenectady, provided for a smooth and efficient transition.

During the year, I had the privilege to visit throughout the state, meeting with family members, consumers, and providers of service. These visits provided me with an opportunity to witness firsthand what was happening in various regions of our state and to listen to the concerns and hopes of those we serve. I was gratified to hear consistently how grateful people felt for the compassionate and professional manner in which Commission staff responded to their issues and requests. The pages in this report provide the highlights of our work this past year, outcomes achieved because of the values expressed in our mission statement.

Since the creation of the Commission over twenty years ago, the mental hygiene system has been radically transformed. We have moved from a system marked by large institutions to smaller community-based residences, from a one-size-fits-all method of service delivery to a more person-centered approach, from a state-dominated system to one sponsored by voluntary, not-for-profit providers. The changes have been revolutionary. With these changes, new challenges arise for the role of the Commission.

To improve our efforts, we are in the midst of a process of strategic planning. While we will always continue to respond to the calls for help brought to our attention, we will also be exploring newer options that are in accord with a changing system. As catalysts for change, the Commission has to be open to a variety of ways to improve the quality of life for persons with disabilities. But no matter what form our efforts take, they will remain in fulfillment of our mission of ensuring excellence in the quality of service and protecting the rights of the citizens we serve.

I want to commend the members of the Commission, all our staff, and all of you for your assistance this past year. With gratitude for the past, I look ahead to the coming years with confidence and hope!



Gary O'Brien
CHAIR

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Ensuring and Advancing Programmatic and Fiscal Accountability...

“Ensuring and advancing programmatic and fiscal accountability within the State’s mental hygiene system through independent oversight,” and “Offering impartial and informed advice and recommendations on disability issues to government officials, program operators, individuals with disabilities and their families and advocates, and the public-at-large” are key objectives in the Commission’s mission and part of its statutory obligations.

During the past year the Commission was called upon to fulfill these mission objectives in various significant ways, including investigating the tragic incident of an individual with an extensive history of receiving mental health services alleged to have pushed a young woman to her death in a New York City subway station; monitoring incidents of alleged violent and sexual assaults in a psychiatric center; investigating and reporting on the numbers and treatment of homeless individuals with developmental disabilities; visiting and recording care and treatment of individuals with mental illness residing in adult homes; and making available to the public and provider community Commission staff experience and expertise on issues related to people with disabilities.

Findings and recommendations from these investigations and activities have resulted, the Commission believes, in “improving the quality of life for individuals with disabilities in New York State, and beyond.”

In the Matter of David Dix

In January 1999, David Dix (a pseudonym), an individual with an extensive history of psychiatric treatment, allegedly pushed a young woman to her death in front of a Manhattan subway train. The Commission and its Mental Hygiene Medical Review Board conducted an investigation to determine what mental health services Mr. Dix had received, to assess whether the services were adequate and appropriate, and whether they represented a cost-effective expenditure of public funds. This investigation concluded with a report, *In the Matter of David Dix*, which included recommendations for improving the care of individuals who are seriously and persistently mentally ill, whose histories include behaviors dangerous to themselves or others, and who are uncooperative with outpatient mental health services.

By the time he was 27, Mr. Dix had twice been admitted to a psychiatric center and had lived in a state-operated community residence and in an adult home. His nearly four-year stay in the community residence and adult home, during which time he required no hospitalization and where he received on-site services, including critical medication monitoring, represented the last period of stability in his life, prior to the January 1999 incident.

The two-year period after Mr. Dix left the adult home to live in an apartment in 1997 was marked by frequent visits to emergency rooms and numerous inpatient admissions, sometimes precipitated by his own requests for treatment and at other times by his aggressive behavior towards others. His treatment sources were multiple, the care uncoordinated, costly, and, according to the Commission’s Medical Review Board, often inappropriate in its failure to recognize his need for intensive, daily contact. Mr. Dix received 199 days of inpatient and emergency room services, on 15 different occasions, in six different hospitals from 1997 to 1999. Four different clinics provided outpatient services in this time period. In 1998 alone, mental health services for Mr. Dix cost over \$88,000.

Recommendations

In an effort to address the fragmented and often inappropriate care afforded Mr. Dix and identify available alternatives that have proven more effective and less costly, the Commission's investigation report concluded with the recommendation that the Office of Mental Health conduct a comprehensive assessment of current housing resources—including, but not limited to, state and voluntary community residences and supported living programs—and the current availability of Intensive Case Managers and Assertive Community Treatment teams to determine the need for additional residential and community support services for individuals whose serious and persistent mental illness has represented a danger to themselves or others or has resulted in frequent rehospitalizations.

Among a series of other recommendations, the Commission and Medical Review Board also recommended that all facilities discharging individuals with serious mental illness and a history of non-compliance with aftercare ensure, through training and supervision, that staff who prepare discharge plans are aware of and consider the full array of services in the community which may be needed to support the individual. Additionally, case managers should be assigned and held responsible for monitoring compliance with clinical recommendations and prompting additional interventions as they become necessary.

Kendra's Law

On August 27, 1999, Governor Pataki approved legislation (Chapter 408, Laws of 1999) inspired by the death of the young woman who was pushed into the path of the subway train.

The Governor, Senate Majority Leader Joseph L. Bruno and Assembly Speaker Sheldon Silver reached a three-way agreement on this legislation which they said has been “designed to protect the public and individuals living with mental illness by ensuring potentially dangerous mentally ill outpatients are safely and effectively treated.”

“Kendra's Law” authorizes courts to issue orders that require mentally ill persons who are unlikely to survive safely in the community without supervision to accept medications and other needed mental health services. Under this law, close family members, roommates, qualified psychiatrists, directors of psychiatric hospitals, and local mental health officials will be authorized to petition the courts for court-ordered community-based mental health treatment.

The new law has been supported by family members and other advocates, while former recipients of services and some legal advocacy groups and nonprofit community-based mental health agencies have opposed involuntary psychiatric treatment.

Governor Announces New Mental Health Package: \$125 Million in Expanded Mental Health Services

On November 9, Governor Pataki announced a comprehensive package of initiatives to strengthen New York State's mental health system, with more than \$125 million in new funding for expanded children and adult mental health services.

The cornerstones of the Governor's package of new initiatives include:

- more than \$52 million for new case managers and special Assertive Community Treatment (ACT) teams of field-based clinicians, increasing the number of persons served from 15,600 to 25,000;
- ensuring that individuals have access to services and stay on their medications;
- \$20 million for approximately 2,000 additional units of supported housing;

- \$8 million to expand special state-operated transitional residences to all five state psychiatric centers located in New York City;
- \$10 million to enhance oversight of community-based programs by the New York State Office of Mental Health (OMH).

In addition, during the coming year, the number of state psychiatric center beds will remain unchanged until there is a reassessment of bed needs for the future. This will help OMH ensure that no person in need of an institutional placement will have to wait for admission to a state psychiatric center.

The Governor's plan also includes 112 new community residence beds for children, using capital funding included in last year's enacted budget, as well as initiatives to provide additional community services that will support the early intervention and treatment of children and adolescents with serious emotional disturbances.

Oversight in a State Psychiatric Center

In June 1999, the Commission received a report expressing concerns regarding safety on a unit in a state psychiatric center. The complainant reported that both patients and staff were in danger on the unit due to low staffing levels, psychiatrists were not seeing and treating patients, and there was inadequate administrative response to allegations of rape.

The facility concurred with the Commission's identification of clinical and risk assessment concerns. The recommendations were implemented and the psychiatric coverage and administrative oversight were instituted on the problematic unit. Additionally, upon learning of the concerns at this facility, the Office of Mental Health initiated a statewide memorandum to all state psychiatric centers to ensure that the same recommendations were implemented across all New York State facilities.

The Commission visited the facility, reviewed records, incident reports, and trend data, and interviewed administrative and unit staff. Commission staff found that in the previous September a patient with a history of violence assaulted a staff member. This was followed by further assaults. The facility responded with an investigation and corrective actions, including reallocation of floating staff, improvement of their emergency response system, increased safety rounds, and hiring a new treatment team leader.

Most incidents of sexual contact were appropriately identified and reviewed through the incident management system. However, the Commission found there was one incident, which involved a patient with a criminal history of rape, that was not addressed in a timely or thorough manner.

Notwithstanding the improvements made by the facility, the Commission's review found significant problems in the area of risk assessment. Adequate clinical attention was not provided to patients with serious histories of violence. This lack of attention may have contributed to the occurrence of violent/criminal acts which resulted in harm to patients and staff. The Commission review identified areas requiring further administrative response and supported a number of the concerns identified by the original complainant. The most significant areas in need of attention included psychiatric oversight and risk assessment/identification.

The Commission recommended that the facility increase oversight and monitoring of unit psychiatrists by making them accountable to standards set by the clinical director; ensure that patients who are at a high

risk for violence are adequately assessed, and that patients who are at a high risk for sexual perpetration or victimization are clearly identified; that patients who require the more structured setting due to behavioral problem increases be formally assessed regarding pass and privilege levels, and that primary psychiatrists sign off on notes written by residents or covering psychiatrists to ensure that he or she has the entire clinical picture of the patient.

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Homeless Individuals with Developmental Disabilities

In August 1999, the Commission released *Report on Individuals with Developmental Disabilities who are Possibly Homeless* refuting media claims that there were scores of homeless, developmentally disabled persons known to the Office of Mental Retardation and Developmental Disabilities (OMRDD). The report also illustrated OMRDD's prompt response to individuals who are reported to be homeless and developmentally disabled.

Overall, the Commission found that OMRDD was correct in refuting the media's conclusion that 135 developmentally disabled people were homeless in mid-1998. It was also found that OMRDD responds quickly and creatively to the needs of such individuals.

In mid-1998, media reports indicated that there were 135 homeless developmentally disabled individuals statewide. As this figure was generated by a computer system of OMRDD, the DDP-4 Confidential Needs Identification System, the media reports implied that OMRDD was aware of the plight of these individuals, but not responsive to their needs.

OMRDD disputed the accuracy of conclusions drawn from its computer data, and indicated that it was vigilant in responding to the needs of developmentally disabled people whose homelessness was brought to its attention, as evidenced by its response to the 62 homeless people referred to its attention in the one year immediately preceding the media reports.

The Commission was called upon to investigate the matter. Commission staff reviewed a random sample of approximately 50 individuals drawn from 135 individuals cited by the media and the 62 referred to OMRDD within the prior year. Additionally, Commission staff interviewed Developmental Disabilities Service Office (DDSO) staff and, where necessary, voluntary agency staff from the 11 DDSOs where the sample clients lived. The multifold purpose was to resolve differences of opinion as to the veracity of conclusions drawn from the DDP-4 data; develop a profile of homeless developmentally disabled persons; assess the system's response to such individuals; and offer recommendations for improvement.

Overall, the Commission found that OMRDD was correct in refuting the media's conclusion that 135 developmentally disabled people were homeless in mid-1998. It was also found that OMRDD responds quickly and creatively to the needs of such individuals.

DDP-4 data are cumulative, span time, and are not necessarily updated based on changes in consumers' situations. Additionally, they reflect perceived, not actual, client needs, which are later verified. In reviewing the sample clients drawn from the DDP-4 data, it was found that 44% were either never

homeless or not developmentally disabled; that 32% were developmentally disabled and were homeless at some point between 1992 and 1998, but had been linked to residential services prior to the media reports; and that only eight percent were homeless and apparently developmentally disabled in mid-1998.

In reviewing a sample of the 62 clients brought to OMRDD's attention as being possibly homeless and developmentally disabled in the one-year period prior to mid-1998, it was found that about a quarter were neither developmentally disabled nor homeless. But of those who were, OMRDD and/or its licensees acted promptly to find placement and services.

The profiles of developmentally disabled and homeless individuals which emerged suggested formidable service challenges, a fact confirmed by service staff interviewed. They reported that the real problem presented by homeless people with developmental disabilities is not their numbers, but the complexity of their service needs, including concomitant serious mental illnesses, serious medical problems, difficulties with the criminal justice system, chemical abuse histories, and a significant percentage (22%) were parents of dependent children.

It was found that various DDSOs had developed different and innovative approaches in responding to the problem of developmentally disabled homeless individuals within their districts, models which perhaps could be replicated in other DDSOs. The Commission recommended that OMRDD explore this possibility.

The Commission also recommended that OMRDD work together with the Office of Alcoholism and Substance Abuse Services to develop treatment approaches for developmentally disabled individuals with chemical abuse difficulties. (OMRDD already has agreements with OMH on shared responsibilities towards individuals with mental illness and developmental disabilities.)

Adult Homes

As a result of legislation enacted into law in 1994, the Commission's jurisdiction was expanded to include oversight of adult care facilities where twenty-five percent or more of the residents were receiving or had received services from a mental hygiene provider. Based on a 1999 report by the Office of Mental Health, this authority provides the Commission with oversight authority of some 176 of the 453 adult homes in the state, and to nearly 9,000 residents with a diagnosis of serious mental illness living in these impacted homes.

The purpose of this project is to conduct systemic reviews of those adult homes where there is some indication of possible problems based on complaints received, deaths reported or referrals received by the Commission from advocacy programs.

With the recent transfer of regulatory oversight of adult homes from the former Department of Social Services to the Department of Health, the Commission decided to initiate a preliminary review of adult homes. From December 1998 to August 1999, the Commission's Policy Bureau coordinated the review of seven homes, five of which were located in New York City and two in Sullivan County. This review found four homes with very poor living conditions and three with mediocre living conditions.

Based on the results of this review, the Commission has undertaken a six-month pilot adult home oversight project. The purpose of this project is to conduct systemic reviews of those adult homes where there is some indication of possible problems based on complaints received, deaths reported or referrals received by the Commission from advocacy programs. To carry out this project, over 30 staff of the

Commission from every bureau of the agency have been trained to participate as members of field teams to assist in these systemic site reviews. It is the Commission's expectation that these reviews will allow the agency to address individual complaints, recommend improvements needed in the home, and identify underlying problems and exemplary practices among adult care facilities which impact upon the quality of life for persons with disabilities living in these homes.

Speakers Bureau

During the past year, the Commission made available to the public and provider community its staff experience for training and "targeted" presentations. Commission staff have a considerable number of years of experience in the fields of mental health and developmental disabilities. Many were practitioners and administrators before becoming staff for the Commission.

The Commission initiated this service not only to provide individualized, substantive training but also to give Commission staff an opportunity to expand their horizons and improve job satisfaction.

Commission staff have a considerable number of years of experience in the fields of mental health and developmental disabilities. Many were practitioners and administrators before becoming staff for the Commission. . . .The Commission's Speakers Bureau participants are all seasoned public presenters who already are well known to the provider community for their appearances at conferences and workshops.

Among the questions presented to agencies and consumer/parent groups who would utilize this service were the following:

- Does your staff need additional training on how to proceed with an investigation after an allegation of abuse?
- Have you considered all of the ramifications concerning *consumer sexuality*?
- Have you given parents sufficient and objective information about *Guardianship and Future Planning* ?
- Are all the members of your Board of Directors aware of their responsibilities and possible liabilities?

The Commission's Speakers Bureau participants are all seasoned public presenters who already are well known to the provider community for their appearances at conferences and workshops. The accompanying table lists an array of possible topic areas. However, presentations can be tailored to individual audience need. Forums can range from 90 minutes to two days and sites may be regional or more centralized.

There have been 29 presentations since the inception of the Speakers Bureau in September 1999, and Commission staff look forward to many more in the new year.

For more information and coordination of a future speaking engagement, call Bill Combes at (518) 381-7098, e-mail: billc@cqc.state.ny.us, or write to the Commission.

Speakers Bureau Topics			
Legal	Investigations	Fiscal	Life Planning
Surrogate Decision-Making	Child Abuse in Facilities	Board of Directors Training	Advance Directives
Rights of Minors in Decision-Making	Adult Abuse & Death Investigations	Current Legislation on Intermediate Sanctions	End of Life Decisions
Ethical Issues in Representing People with Disabilities	Sexuality & Consent	Diversion of Funds	Ethical Issues in Representing People with Disabilities
General Rights of People with Disabilities	Record Reviews	Not-For-Profit Pitfalls: Could This Happen to You?	Guardianship: Why & How to
Legislative Process	Restraint & Seclusion		Future Planning: Wills, Trusts, Estates
Americans with Disabilities Act & Section 504 of Rehabilitation Act	Could This Happen in Your Facility?		
Human Rights Law & Public Policy			

Ensuring Fiscal Accountability: More Specifics

The Commission's shared vision on improving the quality of life for individuals with disabilities sometimes requires it to look into the abuse or misuse of public funds at facilities where poor care and living conditions have been found.

Generally, the Commission's fiscal investigations begin as a result of input received from complainants (sometimes anonymous) and referrals from the Commission's Quality Assurance Investigations Bureau and other government agencies such as the State Medicaid Fraud Control Unit. The investigative process entails an audit of the program's finances and determination whether or not there has been any abuse or misuse of public funds. In addition, the Commission forms an opinion on board oversight and whether the programs operate in the public interest.

The Commission reports on its investigative findings in the form of reports, press releases and letters of findings and may include summary articles on its reviews in its newsletters and annual reports. The Commission issues its reports to the mental hygiene agencies certifying the programs, as well as other governmental bodies, to bring appropriate enforcement actions against the operators for fraudulently diverting public monies from client care to their personal enrichment.

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The outcomes which have been realized as a result of actions taken by the Office of Mental Retardation and Developmental Disabilities (OMRDD) include the replacement of an executive director and related family members who were personally benefitting from agency monies at the expense of the program's eight residents. The Commission's review of the program's dire living conditions prompted the OMRDD to intervene to improve the quality of life for the residents. Another successful outcome materialized when due to the issuance of the Commission's report, state contract agencies took immediate and appropriate action by terminating their contracts with the provider agency, which was illegally misapplying Medicaid funds, and awarded the contract to another provider committed to properly serving individuals with developmental disabilities. A third favorable outcome was the creation of a legitimate board to govern the agency's fiscal affairs, safeguard its assets, and expend its public monies for resident services. In addition, the Commission's reports and newsletters serve as a deterrent to other unscrupulous providers who may be contemplating improperly enriching themselves with agency funds.

Diverting Funds to the Detriment of Home Residents

After receiving an anonymous complaint, the Commission investigated and found credible evidence that the executive director of an OMRDD licensed not-for-profit corporation located in Queens neglected and exploited its developmentally disabled residents by depriving them of adequate food, shelter and services.

The root cause of the group home's dismal conditions was the failure of the board of directors to monitor the executive director's activities and hold her accountable for the management of the agency's operations.

The Commission's investigation, documented in its June 1999 report, *Abandoning Its Not-For-Profit Purpose: The Case of Project Independence of Queens NY, Inc.*, found that residents were living in a run-down roach-infested group home called an individualized residential alternative (IRA) and fed inferior diets consisting of mostly government surplus foods. Other program deficiencies included inadequate hot water, lack of personal hygiene items, an overpowering urine smell, unsafe fire alarm system and dirty and unsanitary facility conditions.

The root cause of the group home's dismal conditions was the failure of the board of directors to monitor the executive director's activities and hold her accountable for the management of the agency's programs. The board's abdication of its oversight responsibilities permitted the executive director to place 15 of her relatives on the payroll and to set her own salary, which amounted to \$114,000 in 1997, more than double (235%) the average salary of comparable executive directors.

The Commission's review also found over \$50,000 in undocumented credit card expenditures by the executive director and her relatives, including questionable trips to Florida, Haiti, and the Dominican Republic, and spending for personal items such as jewelry, clothing, and furniture. Additionally, the executive director misappropriated another \$35,000 in agency funds, which was used as a down payment to purchase a personal home. As a result, despite what would ordinarily be adequate funding for agency operations – over \$65,000 annually per resident in government funding – the agency was required to periodically obtain short-term loans to continue operations.

The Commission's investigation also criticized the agency's certified public accountant, who failed to consistently follow professional auditing standards, inappropriately issued "clean audit opinions," and failed to flag serious internal control weaknesses by issuing a "management letter."

As a result of the its report findings, the Commission has made referrals to the U.S. Attorney for the Eastern District of New York and the Federal Bureau of Investigation (FBI) for possible criminal prosecution related to the misappropriation of medical assistance funds. It also made referrals to the State Department of Law for possible violations of the N.Y. Penal Law and N.Y. Not-For-Profit Corporation Law to recover funds that may have been misappropriated, and to the State Department of Education Office of Professional Discipline because of alleged unprofessional conduct by the agency's certified public accountant. Additionally, OMRDD, in cooperation with the Commission, acted to preserve the health and safety of the program residents by monitoring the care provided to them, and by inducing the agency's board to replace its executive director and certain other family members.

Wrongful Diversion of Medicaid Funds to Housing Project

The Commission's review of the Independent Living Center of Amsterdam, Inc. (Center) began after the Department of Law, Medicaid Fraud Control Unit, referred a complaint concerning program and fiscal abuse at this not-for-profit agency, which was funded by the state to assist individuals with disabilities to pursue a more independent and active life in the community.

The Center illegally misapplied Medicaid funds to underwrite an ill-conceived housing development for the elderly, through a closely-held not-for-profit corporation called Veddensburg Village, which brought both corporations to the brink of bankruptcy.

In New York State, independent living centers are evaluated, overseen and primarily funded by the Office of Vocational and Educational Services for Individuals with Disabilities. (VESID). While their corporate mission is broadly and generally defined, independent living centers are expressly prohibited by state law from establishing or operating any kind of residential or housing facility. The Center was unique among living centers in New York in that it received two-thirds of its monies from Medicaid to provide services to individuals with developmental disabilities in family care homes certified by OMRDD.

The Commission's August 1998 report, *Diverting Public Funds: The Misguided Mission of the Independent Living Center of Amsterdam, Inc.*, describes how the Center illegally misapplied Medicaid funds to underwrite an ill-conceived housing development for the elderly, through a closely-held not-for-profit corporation called Veddensburg Village, which brought both corporations to the brink of bankruptcy. The dire situation prompted state action to end further diversion of funds, and prevent a lapse in services to disabled clients.

The investigation found that the Center misled state contract agencies by assuring them that no government monies would be used to develop Veddensburg, while it in fact was generating and then diverting funds for that purpose by overcharging state contracts \$58,000 for administration and misstating cost and expenditures used to establish government rates. In addition, the Center received and similarly diverted over \$45,000 in Family Support Service contract funds for services to under-served individuals with developmental disabilities, despite having no such clients. The Commission report also was highly critical of the Center's board of directors for failing to act as fiduciaries to protect Center assets and manage its affairs properly. It characterized the board as "careless" in its scrutiny of the illegal and improper transactions which placed the Center's programs at risk and allowed both its and Veddensburg's financial conditions to deteriorate to near insolvency. The Commission recommended VESID and OMRDD examine their internal monitoring mechanisms, which failed to detect the improprieties and growing financial instability.

Upon learning of the Commission's findings, state contract agencies took immediate and appropriate action. VESID terminated its contract with the Center effective September 30, 1998, in the meantime requiring a transition plan and cooperation in transferring operations to two other independent living centers. OMRDD simultaneously terminated its contracts and removed the Center's authorization to sponsor services for developmentally disabled individuals. The Department of Law notified Veddensburg's attorney and the elderly residents that no sales of housing units should have been made and asked that entrance fee refunds be offered to the residents.

In late 1999, the Resource Center for Independent Living of Utica, Inc. was awarded the VESID contract to continue and expand core services for individuals with disabilities in the Amsterdam area. In December 1999, the Attorney General filed a lawsuit against the former operators of Veddensburg Village to recoup the entrance fees of \$60,000 and \$40,000 paid by two elderly residents into the now-defunct retirement community.

Exploiting Medicaid Through a Shell Not-For-Profit

The Commission's investigation into the financial practices of a 10-bed group home near Hudson N.Y., licensed by the OMRDD for individuals with autism and other disabilities, found that a husband and wife team diverted over three-quarters of a million dollars of program funds for personal use through a shell not-for-profit corporation to conceal and distribute ill-gotten Medicaid proceeds.

The scam at the agency was facilitated by a fiction that a board of directors oversaw SNP and its finances, when in fact all decisions were made by Joseph Fricano, producing unauthorized expenditures for him and his family's personal benefit.

The Commission's January 1999 report, *Exploiting Medicaid Through a Shell Not-For-Profit Corporation: The Case of Special Needs Program, Inc.*, describes how Joseph Fricano, as executive director and board president, and his wife, Mary Ann Fricano, who was also an employee, used fraudulent documents and falsified board records to dominate and control the agency and remain undetected by OMRDD.

The public moneys siphoned off from January 1994 through July 1997 were spent primarily for unauthorized salaries, fringe benefits and leased vehicles. Mr. Fricano's salary rose from \$40,840 in 1987 to \$153,712 in 1996, and was projected to reach \$190,000 in 1997, through excessive unauthorized pay increases and fraudulent overtime, while reportedly working 20 hours per week at most. The Fricanos' took fringe benefits unavailable to other employees, such as a disability policy, special family medical, dental and vision coverage, and reimbursement for tuition and books. They also had exclusive use of two agency vehicles and "double-dipped" by taking \$6,000 in mileage reimbursement despite the fact that the agency was paying all auto expenses.

The Commission found over \$10,000 in questionable credit card purchases for jewelry, airfares, and other items including purchases made on the Home Shopping Network. In addition, the husband and wife reimbursed themselves over \$11,000 with agency funds, through petty cash and direct purchases, without adequate documentation to support the business nature of the expenditures. Also, over \$7,000 in agency funds were spent on memorabilia and collectibles. Finally, the Commission found evidence that the executive director filed false instruments stating he had no earned income to obtain disability benefits from the City of New York.

An excessive Medicaid rate of \$100,000 annually for each of the 10 residents allowed the couple to "milk" the program while still delivering "reasonably good services." The scam at the agency was facilitated by a fiction that a board of directors oversaw SNP and its finances, when in fact all decisions were made by Joseph Fricano, producing unauthorized expenditures for him and his family's personal benefit. During the Commission's review, OMRDD regularly monitored care at the agency and ensured creation of a properly constituted board of directors, including an OMRDD designee on the board.

Pursuant to its statute, when there was evidence that crimes may have been committed, the Commission gave notice to the appropriate law enforcement officials including: the Internal Revenue Service for possible excise taxes on "excess benefit transactions;" the U.S. Attorney for the Northern District of New York, and the Federal Bureau of Investigation for investigation of possible criminal conspiracy to misappropriate medical assistance funds; the State Insurance Department, Workers' Compensation Board and the NYC Inspector General for false disability claims; and, the State Department of Law to recover funds that had been misappropriated.

On November 3, 1999, Daniel J. French, the United States Attorney for the Northern District of New York, who accepted criminal jurisdiction of the case, reported that a nine-count indictment was returned by a federal grand jury in Albany on October 28, 1999 against Joseph Fricano. The indictment charged him with a scheme to defraud by maintaining a fictitious board of directors to oversee SNP and its finances, which purportedly approved decisions and policies, including those which financially benefitted Joseph Fricano, when in fact those decisions and policies were set by Joseph Fricano himself.

On November 9, 1999, Louis F. Allen, Special Agent in Charge, Albany Division, Federal Bureau of Investigation, reported that Joseph Fricano was arrested in Cocoa, Florida by the FBI's Orlando office. Mr. Fricano went to Florida after he abruptly left the agency at the onset of the Commission's financial review in mid-1997.

Providing Case-Specific and Systemic Investigative Services

Quality Assistance in Individual Cases

The Commission receives approximately 1,600 calls for assistance monthly on its 800 number. In addition, approximately 600 incident reports of possible abuse or neglect are mailed or faxed per month. Another 175 cases or so per month of deaths in New York's mental hygiene system are reported and looked at carefully for possible detailed investigation.

The Commission prides itself in being a place where individuals with disabilities, their parents, family members, or other advocates can call or write for assistance, be respected, listened to, and followed-up wherever and however possible.

The range of the calls for assistance can vary from a need for blankets in a facility or filthy environmental living conditions which must be improved, to serious incidents calling for immediate interventions to protect individuals from harm. The following are selected examples:

Environmental Conditions

- A Commission review was initiated in response to an anonymous complaint alleging substandard services at several residences run by a not-for-profit provider. Unannounced visits were made to three residences and, although the apartments were generally clean, they were undecorated, in need of repair and roach infested. In addition, cleaning supplies were left in the reach of consumers, and bumper and side pads were missing from several beds, creating safety issues. One consumer's mattress was so urine soaked, it had to be replaced immediately. Further, documentation of medical and nursing interventions was so poor, Commission staff could not determine whether or not consumers were receiving appropriate care.

In response to Commission staff findings, the agency made needed repairs, cleaning supplies were moved to an appropriate area, a new pest control business was hired, and the agency took steps under the direction of the health care coordinator to improve record keeping.

- The Commission received an anonymous letter stating that the environmental conditions of a residence and services provided to the consumers were inadequate and potentially dangerous. In addition, the letter alleged that the manager was involved in acts of fraud regarding consumer's personal finances, forged signatures on medical orders, and had obtained personal prescriptions using the name of a consumer.

In response, Commission staff made an unannounced visit discovering numerous deficiencies which compromised the health and safety of the residents. The residence was extremely dirty, personal hygiene supplies were poorly maintained, the kitchen was roach-infested, food was improperly stored, bathrooms lacked adequate supplies, and there was evidence that the menu was not followed.

Due to the serious conditions found, Commission staff contacted the Office of Mental Retardation and Developmental Disabilities' Bureau of Program Certification and referred the matter to them. OMRDD staff conducted their own site visit and, as a result, a 60-day letter was sent to the facility.

The agency subsequently submitted an appropriate plan of corrective actions to OMRDD, and a subsequent site visit by Commission staff determined that conditions have significantly improved at the residence.

Protection from Harm, Protection of Rights

- A mother called the Commission to complain that staff at a DDSO-operated IRA were unable to prevent her son from being sexually victimized by other residents at the facility. In response, Commission staff made three separate site visits to the residence where they were able to determine that, indeed, there were several incidents of sexual contact between three men at the residence.

Commission investigators discussed with the administration of the residence a number of issues including safety and supervision of residents, staff training, the need for medical exams, and the need to conduct evaluations of capacity to consent to sexual activity for residents. In response, all residents have updated capacity-to-consent determinations, sexuality counseling is available to residents, staff have received updated training in human relationships and sexuality issues, and supervisory policies have been tightened.

- A resident of a psychiatric center called the Commission to complain, among other things, that the level system in use on the forensic unit at the facility violated his rights because it did not allow him to make or receive telephone calls unless he was able to maintain a specific level. The Commission investigation clearly revealed that this was in violation of regulations. As a result of the Commission inquiry, the hospital's level system policy was modified.
- The Commission received a call from a woman complaining that she was discharged from the hospital with only an appointment for an admission interview for residential alcohol rehabilitation. The Commission found that, while the woman presented many challenges to the staff who attempted to arrange appropriate outpatient treatment services, the discharge plan made for her did not adequately address her needs for outpatient mental health treatment and was not in line with admission protocols at the residential alcohol rehabilitation program. In response, staff were trained in Mental Hygiene Law requirements for discharge planning and the hospital amended its policy to enter into formal, written agreements with other providers of psychiatric services to ensure proper discharge planning.
- The director of a Residential Treatment Facility (RTF) complained to the Commission that a 15 year-old young man was transferred inappropriately from a hospital's Comprehensive Psychiatric Emergency Program (CPEP) to the RTF. The young man had become agitated while waiting in the CPEP and was given injections of Ativan, Serentil, and Benadryl. He was then released from the CPEP and arrived back at his residence in a state of unconsciousness. He was then taken to another hospital where the treating physician had to wait approximately five hours for the child to become fully alert. He was subsequently admitted to a psychiatric unit for approximately six weeks.

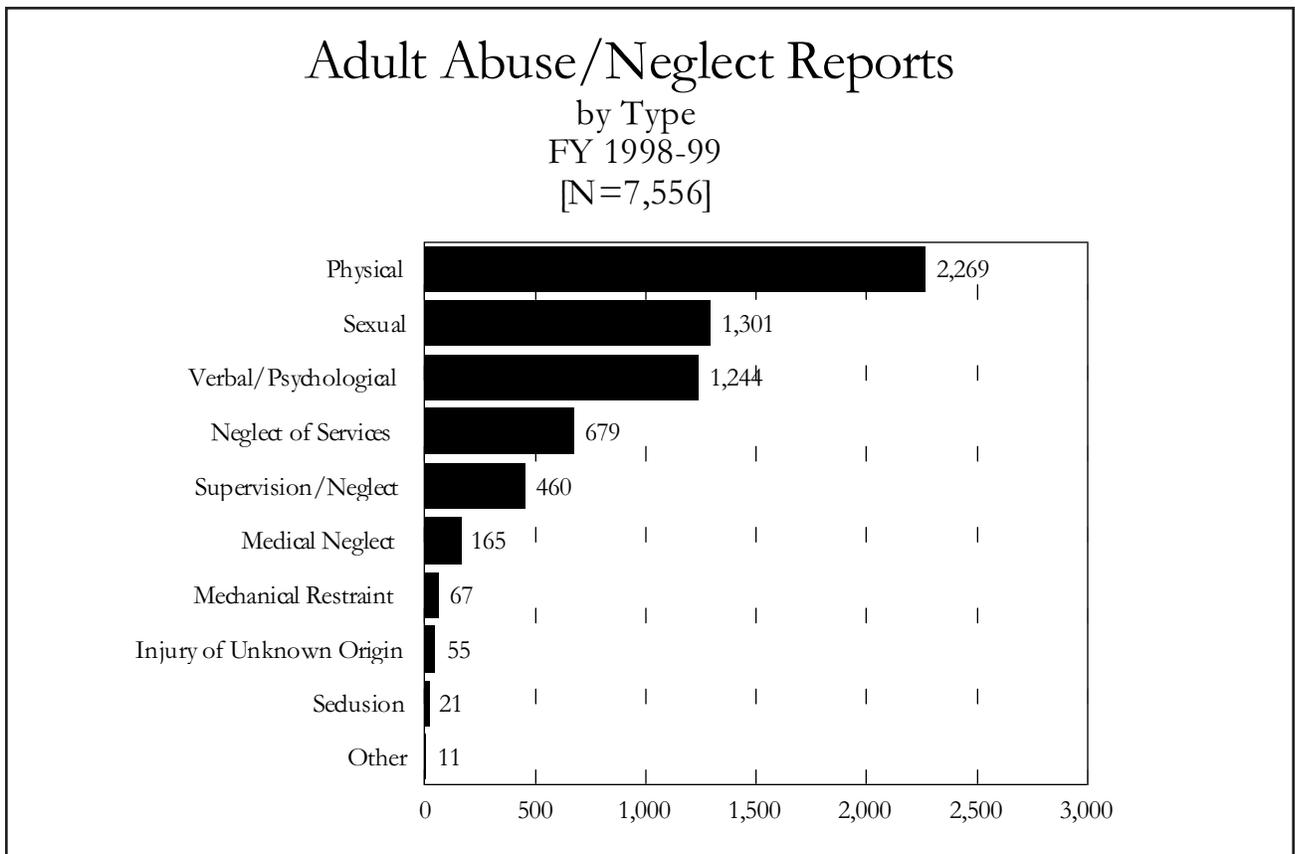
The Commission investigation revealed that the CPEP physician who treated the young man was most likely not aware that the RTF was ill-equipped to handle an acutely disturbed individual, and that the child received medications commonly used to treat acute illnesses. His state of disorientation was most likely an unusual reaction to the medication. However, Commission staff recommended that the CPEP rewrite its transfer policy to indicate that RTF's are not able to handle individuals in an acute stage of a psychotic illness. In response, the CPEP rewrote its transfer policy.

- The Commission became concerned when it learned that an agency was not forwarding investigations and abuse allegations in a timely manner. As a result, Commission staff reviewed agency procedures regarding investigations and the functioning of the Special Review Committee (SRC) and found

numerous deficiencies in policies and procedures. For example, staff were not adequately trained in conducting investigations, the quality of investigations was inconsistent, and they were not timely. Further, oftentimes program managers were not complying with recommendations made by the SRC. In fact, one manager “respectfully declined” to comply with several recommendations without further explanation.

Following the Commission’s review, the Office of Mental Retardation and Developmental Disabilities was requested to do an additional review, and, as a result, OMRDD provided the agency with investigations training, sexual abuse prevention training, and OMRDD staff provided on-site technical assistance to the SRC.

- The Commission received a number of calls from patients at a psychiatric center, who alleged that the facility was inappropriately using PADS restraints, a system of restraint in which an individual’s wrists are tethered to a belt around his or her waist, and the length of the tether can be adjusted. The Commission investigation revealed that PADS were routinely used at the facility as a preventive intervention. Although the hospital was in compliance with all other rules and regulations regarding the use of this treatment device, the use of PADS as a preventive intervention is clearly not in keeping with Mental Hygiene Law regarding the use of restraint. As a result of Commission findings, OMH asked the hospital to cease the use of PADS for preventive purposes.
- The Commission investigated an incident of sexual activity between hospitalized children, one nine and the other four years of age. The investigation revealed that the nine year-old was admitted with a history of fire-setting and sexual abuse. Although the child’s treatment plan addressed the need for him to discuss his anger over being sexually victimized, it did not address his sexual acting out. During the child’s hospitalization, it was learned that the nine year-old and the four year-old engaged in oral sex, at the insistence of the older boy.



The Commission investigation revealed several problems with the care received by the nine year-old. Although the hospital had prior knowledge of his history of sexual abuse, hospital staff provided him with no defensive strategies to help prevent future abuse. Sexual abuse was not addressed in his treatment plan either before or after the incident with the four year-old. The hospital did not consider the sexual histories of children in assigning bedrooms, nor did the hospital evaluate where the supervision of the children lapsed, allowing the incident to occur. However, most disconcerting to Commission staff was hearing hospital staff stating that it was their belief that a child who was a victim of sexual abuse could not be an aggressor. This evidenced the absence of fundamental information and understanding about the effects of sexual abuse and its various manifestations.

In response to Commission findings, the hospital developed a thorough staff training program dealing with sexually abused children.

Reviews of Health and Hospital Corporation Facilities

The Health and Hospitals Corporation (HHC) purports to be one of the largest providers of psychiatric services in New York City. There are eleven public HHC-affiliated hospitals within the New York Metropolitan region that provide such services on an inpatient basis. Over the years, Commission site visits to the psychiatric units of several HHC facilities have resulted in findings of problematic (sometimes egregious) living conditions, inattention to the personal care needs of patients, lack of appropriate programming resulting in pervasive patient idleness and the impassivity of staff. These findings prompted the Commission to undertake a larger review of the psychiatric units of the hospitals.

Between July 1998 and March 1999 the Commission completed 11 unannounced HHC hospital reviews. Commission staff reviewed environmental conditions, patient programming, and restraint/seclusion records at Harlem Hospital, Kings County Hospital, Lincoln Hospital, Jamaica Hospital, North Central Bronx Hospital, Bellevue Hospital, Woodhull Hospital, Metropolitan Hospital, Queens Hospital, and Coney Island Hospital.

Findings at these facilities varied. Some of the hospitals had numerous environmental deficiencies, including unsanitary conditions in the bathrooms, poor management of patient personal care supplies, lack of adequate clothing for the patients, inadequate privacy, and a variety of minor maintenance concerns. In addition, pervasive patient idleness and lack of meaningful treatment programs were seen as problems throughout the HHC hospital system.

In contrast, conditions at some hospitals, notably Lincoln Hospital, were excellent, with reviewers noting clean environments, generous staffing levels, adequate clothing and linens, and obvious attention to patient personal hygiene and hygiene supplies. Commission staff also found that hospitals with a treatment philosophy stressing the importance of patient programming appeared to be winning the battle over patient idleness and treatment stagnation.

Commission staff were pleased to report that comprehensive corrective plans have been submitted by all the hospitals reviewed in response to the findings. Substantial improvements were noted in some of the follow-up visits.

Watching Over the Children

Ever since the Child Abuse and Protection Act (CAPA) of 1985, the State Central Register (SCR) forwards to the Commission allegations of the abuse and neglect of children in residential care facilities licensed or operated by the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities. During the past fiscal year, the Commission opened 161 such cases.

Investigation of these allegations brings Commission staff into all types of residential programs for children with diverse disabilities: programs for children who are medically frail, children with symptoms of mental illness, children with autism and Prader-Willi Syndrome in community residences, children who have lived for years in long-term psychiatric settings, children who are profoundly mentally retarded, and youths with conduct disordered behaviors.

At the conclusion of each investigation, the Commission makes a recommendation to the Office of Children and Families Services to unfound or indicate a case. A case is recommended for indication when the Commission has determined that there is credible evidence that a named child has been abused or neglected, as defined by CAPA, by a named subject – an employee, volunteer, or consultant to the facility. In addition to arriving at recommendations, the Commission also uses the investigatory process to identify and recommend other corrective actions to further enhance the safety and quality of care afforded to children in residential care.

Following are case examples:

- The Commission investigated a child's allegation he had been choked by a staff member in a Children's Psychiatric Center. Commission staff shared with the Center findings that the employee had actually instigated the incident with the child and another staff member barred his co-workers from entering the incident area. The same employee also arranged retaliation toward the only other child who cooperated with the investigation. The resignations of both subjects were obtained by the facility.
- While finding some credible evidence that children had engaged in sexual activity in an IRA, no staff member responsible for the supervision of the children "committed, promoted, or knowingly permitted" (the SCR standard for "indication" of child sexual abuse cases) the conduct to occur. During the investigation, Commission staff shared concerns regarding the adequacy of resident supervision and the need for clarity in the agency's expectations around how staff members are to respond to discovered sexual activity among the children. The facility developed new policies and procedures including a clarified role for primary counselors to have specific resident assignments. The Commission also recommended that the treatment plan of the child initiating the sexual contact needed to be revised to ensure the safety of the other residents. The facility agreed and also developed a new activity schedule for the residents.
- An investigation of a child assigned to receive 1:1 supervision in a voluntary agency's ICF found that 1:1 supervision requirements were not consistently defined for staff assigned to this responsibility. Commission staff also found no clear policy which defined the various levels of supervision being assigned for the children. The investigation also revealed the agency's staff training program was poorly organized and employees were not being cleared with the SCR. The facility completed a comprehensive and systemic approach to correcting the above problem areas and several new policies and procedures were developed, not only for the residence under investigation but for all the residences operated by the agency.
- The Commission recommended "indicating" a report where Commission staff found that a child care worker in a private school had twisted a child's arm and caused a spiral fracture of the humerus. In completing the case Commission staff consulted a member of the Commission's Medical Review Board

SCR Cases by Program Type

April 1, 1998 - March 31, 1999

[N = 161]

<i>Office of Mental Health</i>	<i>69</i>	<i>Office of Mental Retardation and Developmental Disabilities</i>	<i>92</i>
Children's Psychiatric Center	17		
Children and Youth Unit/ Psychiatric Center	6	Community Residence	6
Private Hospital	10	Developmental Center	9
Public Hospital	6	Intermediate Care Facility (ICF)	41
Psychiatric Center (Adult)	1	Individual Residential Alternative (IRA)	24
Residential Treatment Facility	18	Private School	3
Community Residence	11	Other	9
		[= 3 respite; 6 Residential School]	

who confirmed the injury as a spiral fracture and noted the injury was consistent with the incident as it was described by the child. He emphasized it was highly unlikely that the injury was incurred in the manner described by the two staff witnesses. The Commission shared these findings with the facility and asked that the statement of the staff witness to the incident also be challenged.

- A child residing in a developmental center, ordered to receive 1:1 supervision, sustained multiple abrasions to her face and shoulders. Commission staff found there was no policy defining what 1:1 supervision entailed and that existing procedures of writing progress notes daily and completing body checklists were not followed by staff. The Commission requested under the Child Abuse Prevention Act that the facility submit a plan of correction addressing the issues within 30 days. The facility brought disciplinary charges against the subject and finalized a written 1:1 supervision policy that was given to all staff within 30 days.
- A patient residing on a children and youth services unit in a psychiatric center went AWOL while on a supervised trip in the community. Commission staff found that there were no written definitions of the type of supervision that staff were required to provide the children for either on-grounds activities or off-grounds trips into the community. In response, the facility instituted a process involving the Charge Nurse approving the purpose, goals, destination, and specific patients for the trip. A written policy was developed clearly describing what is expected of staff when supervising patients off the unit.
- Commission investigation of the alleged choking of an adolescent girl in a community residence found that a supervisor failed to make a timely report of the alleged abuse and the child was not medically examined promptly to document possible tell-tale signs of choking such as petechiae (reddish or purplish spots containing blood) in the sclera (eyeball coating). Commission staff also took exception to the program's use of physical restraint of this particular child who had a history of severe sexual and physical abuse. The Commission noted there was strong clinical evidence that the use of physical

restraint on such children often places them at risk of crisis. The Commission asked that her behavior plan be reviewed and a cautionary note about her past history of severe abuse be added. Finally, the Commission requested that all staff receive training in how best to treat and interact with individuals who have Post Traumatic Stress Disorder (PTSD) diagnoses. The DDSO reported that protocols had been established for the immediate medical evaluation of alleged abuse victims. Also, the child's behavior plan was revised and the use of supine control was eliminated. All staff were trained in PTSD and retrained in incident reporting requirements.

Children's Elopement Review

Each year, the Commission receives several reports of children eloping from mental health facilities. These reports come from a variety of sources: police authorities who locate a missing child, families who complain that their child was not well supervised, and licensed professionals who as mandatory child abuse reporters believe that the elopement was the result of staff negligence and that it presented a danger to the safety of the child.

In reviewing the reports, the Commission has seen cases in which children are missing from their facilities anywhere from several hours to several days; where no harm befalls the child to those where serious harm occurs; where staff complain that they are unable to prevent children from leaving to those cases where children complain that they ran away to escape overly harsh disciplinary practices. In order to better understand the nature and dimension of this problem, the Commission commenced a review of mental health residential programs during 1999. Through this review the Commission hopes to accomplish the following:

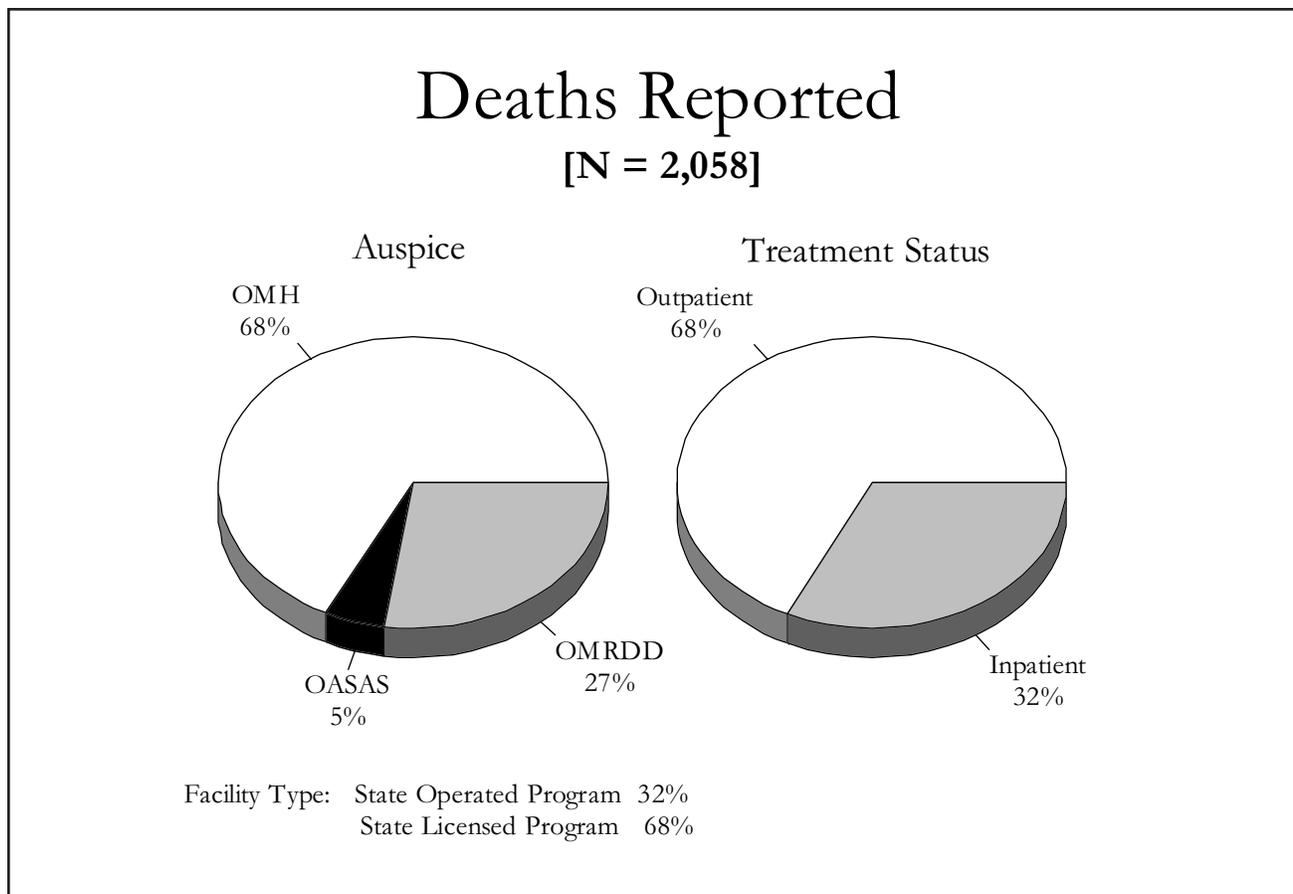
- establish the frequency with which children elope from mental health programs which are operated or certified by the Office of Mental Health;
- identify the elopement experience for children including the extent of harm, and reasons for elopement;
- develop a profile of facilities from which children elope which may identify environmental and other factors which pose a risk for elopement; and
- describe successful and innovative practices taken by facilities to reduce or prevent the elopement of children.

During this reporting period, the Commission has received survey instruments from nearly 75 mental health facilities including state psychiatric centers, Article 28 hospitals, private psychiatric hospitals, residential treatment facilities, and community residence programs. Through an analysis of the data received from these surveys, the Commission will identify those practices which help prevent children from eloping from a mental health program.

Monitoring Deaths

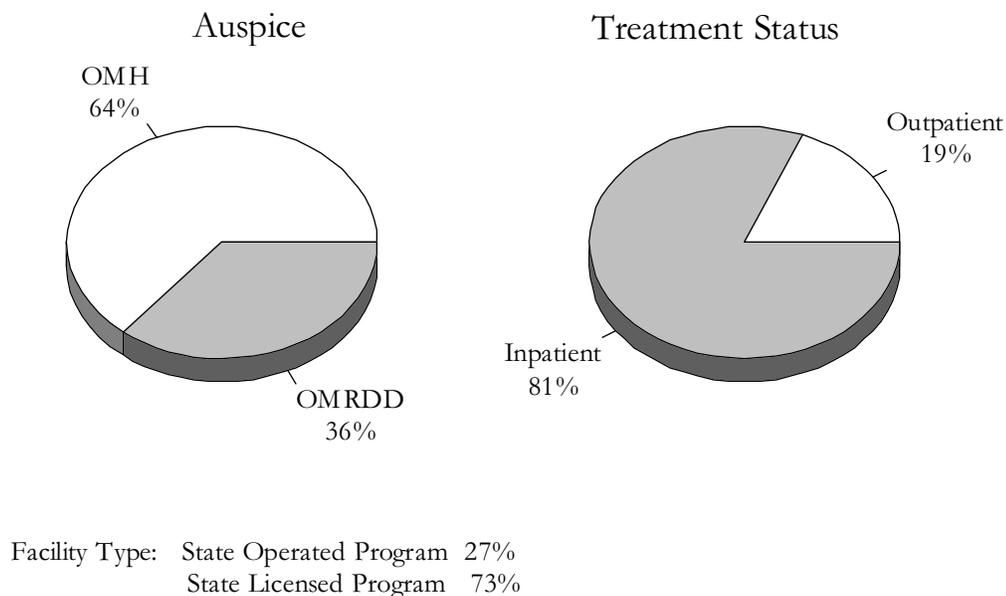
During the past year, the deaths of over 2,000 mental hygiene service consumers were reported to the Commission and its Medical Review Board for review. Of these, 181 cases were selected for investigation because the circumstances of death raised questions on the quality of care rendered by the treating facilities. In selecting cases for investigation, the Commission gives added attention to those individuals who depended most heavily on the mental hygiene system for their daily care and support. So while the majority of deaths reported to the Commission involved outpatients, i.e., individuals who live alone or with families and periodically visit mental hygiene clinics or day programs, most selected for investigation by the Commission involved inpatients or residents of mental hygiene facilities who relied on the State or one of its licensed or certified agencies for their care 24 hours a day. Additionally, the Commission flags for investigation those cases wherein death occurred shortly following the individuals' transition from inpatient/residential care to outpatient status, in order to assess the adequacy of plans for such transitions and connections with needed services.

The purpose of the investigations is to offer facilities recommendations for improving care where it is found needed by the Commission and its Medical Review Board, a panel of volunteer physicians with expertise in psychiatry, surgery, internal medicine, and forensic pathology. Although the Commission and Board communicate findings and recommendations directly to the involved facilities in letters, periodically investigation results are compiled as case study teaching tools and disseminated to all facilities. During the past year, the Commission released its second volume of these case studies, *Could This Happen in Your Program?*



Deaths Investigated

[N = 181]



Specific examples of the outcomes of deaths investigated by the Commission include:

- **Revised investigation protocols at a county hospital as well as better training for hospital staff in restraint practices:** In this case, a 42 year-old man died while being restrained on the floor by several staff. The facility conducted a cursory investigation into the event and, in doing so, failed to identify how staff physically held the patient. It also did not follow up on one vague report that a staff member may have used an inappropriate hold. The hospital completed its investigation before receiving the autopsy report, concluding that staff performed appropriately. The Commission's and Board's investigation revealed that staff indeed had used an inappropriate hold on the individual who died as a result of positional asphyxia caused by pressure on his back while being held face down on the floor.
- **Improved exchange of clinical information between a state psychiatric center and a local community hospital:** This change was prompted by the Commission's and Board's investigation of the sudden, unexpected death of a 39 year-old woman. It was found that the woman had died of a fatal arrhythmia possibly associated with the psychotropic medications she was receiving. Approximately one month before her death, the patient was hospitalized for four days at a community hospital for evaluation of a balance disorder. During this brief hospitalization, an EKG showed certain changes which should have triggered a careful review of the patient's psychotropic medication regimen. However, this important clinical information was not shared with the psychiatric center when she was discharged from the local hospital. Unaware of the EKG results, the psychiatric center started the woman on her pre-hospitalization psychotropic medication regimen and she subsequently died.
- **Improved clinic scheduling practices at a Developmental Disabilities Service Office (DDSO) and improved mortality reviews:** These improvements stem from the Commission's investigation of the death of a 66 year-old woman who lived in a DDSO-operated residence. In May she experienced

cold-like symptoms and was seen by her doctor. An initial and repeat x-ray revealed possible congestive heart failure and her physician scheduled her to be seen in the DDSO's cardiology clinic in early June. This appointment was not kept and no information why it was cancelled was maintained, nor was there any follow up to ensure that the primary physician was aware of the cancellation and that the woman would be seen by a cardiologist. Following the woman's death due to sepsis in late June, the facility's internal investigation or mortality review failed to address the missed cardiology appointment, the lack of documentation surrounding the cancellation, and the absence of attempts to ensure she received the recommended cardiac services in a timely fashion. These issues were addressed following the Commission's investigation and the agency revamped its scheduling and documentation practices as well as its standards for mortality reviews.

- **Improved notification to psychiatrists of significant changes in patients' behaviors so that psychiatric evaluations and interventions can be carried out as needed:** This change on the psychiatric unit of a general hospital was prompted by a Commission investigation into a homicide on the unit where one patient killed another with a fire extinguisher. The assailant in this case, who had a prior history of manslaughter, was admitted to the hospital for an acute exacerbation of his chronic paranoid schizophrenia. Upon admission, he appeared calm and non-threatening and was placed on a level of supervision requiring 15-minute checks. During his second hospital day his demeanor was much the same until about 3 p.m. at which point he became "hostile and threatening." Specifically, he stated he wanted to hurt someone in order to get out of the hospital and go to jail. This was followed by a threat to rape someone in order to get out. Psychiatrists were not alerted, and the patient's level of supervision was not changed. Later, in between 15-minute checks, he grabbed a fire extinguisher, ran into another patient's room, and assaulted him causing his death. Nursing staff who saw him run into the other patient's room pursued him, but were unable to reach him in time.
- **Statewide ban on a restraint technique:** Following the Commission's and Medical Review Board's review of a hospital's practice of placing towels over the mouths of patients who were restrained, to prevent biting or spitting, the State Office of Mental Health issued a statewide ban on the practice, which was employed by a number of facilities. The Office of Mental Health agreed with the Medical Review Board that this practice compromised patients' airways and was inherently dangerous.

Restraint and Seclusion: New York State Protections Lauded

In a September 1999 report, *Improper Restraint or Seclusion Use Places People at Risk*, the United States General Accounting Office praised New York State's efforts to protect individuals with mental disabilities who may be subjected to restraint or seclusion and to reduce the frequency of the use of these interventions. The GAO points to the New York State experience as a model for national reforms to ensure the safety and well-being of individuals with mental disabilities.

The GAO came to its conclusions following a national survey commissioned by Congress. Congressional interest in the matter was occasioned by a Fall 1998 *Hartford Courant* series, "Deadly Restraint," which reported on the restraint or seclusion related deaths of 142 individuals in the last 10 years.

The *Hartford Courant* reported that the 142 deaths were not truly reflective of the magnitude of the problem, as many states and the federal government do not monitor the use of restraint or seclusion or negative outcomes, such as death, arising from such. Yet most of the programs employing these interventions receive federal funds and each state has a federally funded Protection and Advocacy (P&A) agency designed to protect individuals with mental disabilities from abuse.

The GAO points to the New York State experience as a model for national reforms to ensure the safety and well-being of individuals with mental disabilities.

The GAO report sustained a number of the facts reported by the *Hartford Courant*, chiefly that restraint and seclusion, interventions used by many facilities serving people with mental disabilities, are hazardous to both service recipients and care providers, and that the extent of their use and risk of harm, even lethal harm, is unknown due to insufficient state and federal oversight.

The GAO also pointed to New York as one of the few states in the nation where use of these hazardous interventions are closely monitored through a combination of efforts by the state's licensing agencies, the Office of Mental Health and Office of Mental Retardation and Developmental Disabilities, and the state's Protection and Advocacy agency, the Commission on Quality of Care.

Among the practices cited by the GAO which made New York unique and which would serve as a model for the country were:

- The mandatory reporting of all deaths and allegations of abuse occurring in mental hygiene facilities to the Commission, New York's Protection and Advocacy agency, for review and investigation. This is required by NYS Mental Hygiene Law; most other states and the federal Protection and Advocacy program itself do not require the reporting of such events to an independent entity for review and investigation.
- Fairly broad access powers granted to the Commission for investigation purposes, including access to general hospital records, peer review records, autopsy reports, etc. These are granted under NYS law and most other Protection and Advocacy agencies do not enjoy such easy access.
- Careful monitoring by the state licensing agencies of restraint and seclusion use in facilities. Cognizant that use of these interventions is more a reflection of management practices at facilities than the clinical profile of the individuals they serve, the state OMH periodically publishes restraint and seclusion rates for its facilities so that they can review their practices and reduce their use of these hazardous interventions.
- Close cooperation and communication between the independent Protection and Advocacy investigating agency and the licensing agencies, which in New York has resulted in statewide reforms of restraint and seclusion practices.

Expansion of the Surrogate Decision-Making Committee Program

Governor Pataki's 1998-99 Executive Budget provided for the statewide expansion of the Surrogate Decision-Making Committee (SDMC) Program. This nationally award-winning program provides consent for medical treatment for people living in mental hygiene facilities. The Governor's Budget, which was approved by the Legislature, included \$525,000 to support statewide expansion of the SDMC Program.

Expansion of the SDMC Program - Counties added 1998-1999

- Nov '98 – Orange and Sullivan Counties
 - Mar '99 – Clinton, Essex, Franklin, Hamilton
Jefferson and St. Lawrence Counties
 - Jun '99 – Nassau and Suffolk Counties
 - Nov'99 – Broome, Chenango, Delaware, Otsego
Tioga and Tompkins Counties
-

The SDMC program is a volunteer-based and free alternative approach to the court system for obtaining informed decisions about major medical treatment for persons with mental disabilities who lack capacity to make an informed decision and have no willing or available legally authorized surrogates to act on their behalf. The program is available to both voluntary and state-operated providers of service. SDMC exercises its functions through panels of volunteers. From the list of over 500 volunteers statewide, four-person panels are convened within a region on an as-needed basis to provide consent or refusal of non-emergency major medical care and/or treatment. The panelists review declarations and hold hearings to evaluate documents and listen to testimony regarding the individual's capacity, the willingness and availability of a legally authorized surrogate and need for treatment. Panel members assist persons with mental disabilities by working to protect their autonomy and best interests in decision-making.

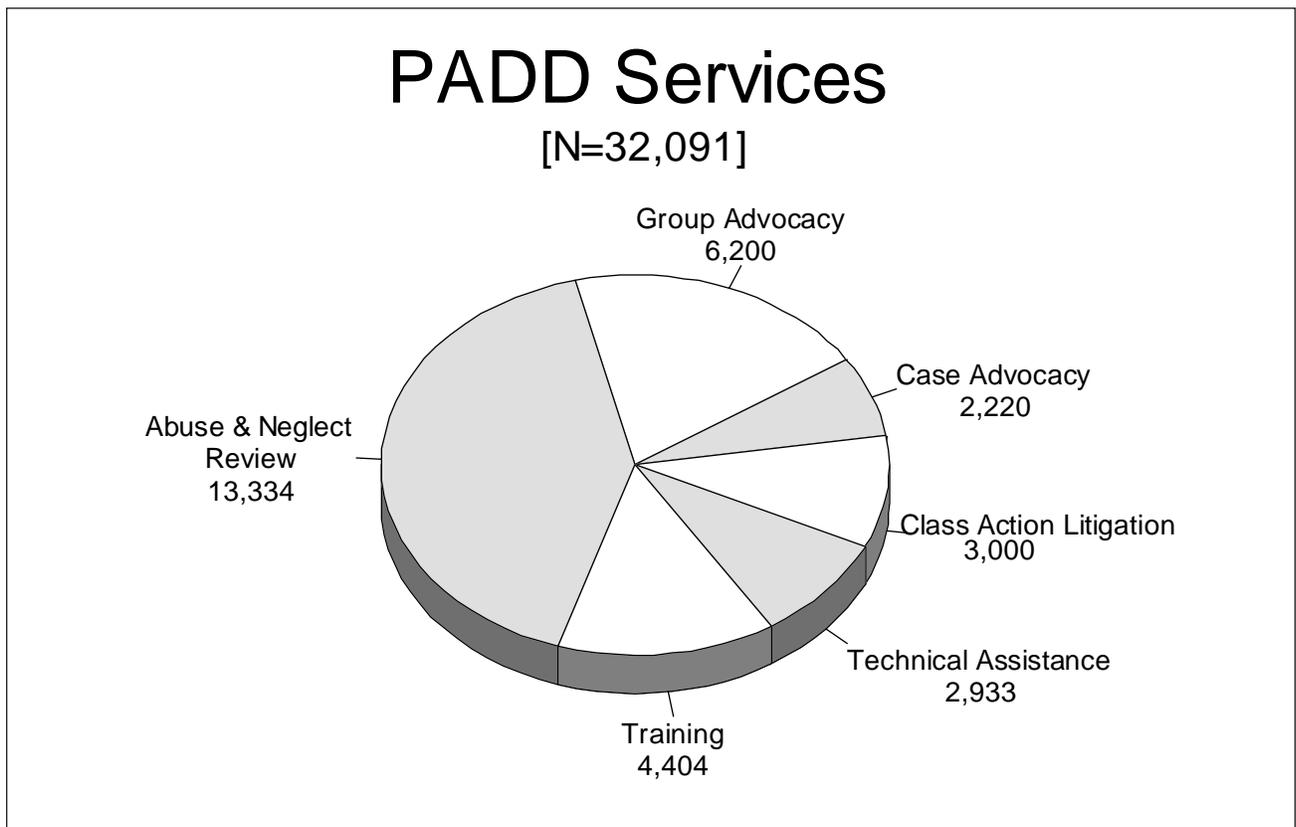
Since the inception of the program in 1986, over 4,800 cases have been brought to a panel for a decision. The average time from the time a case arrives in the SDMC program office, to the time it is heard by a panel, is 14 days. The vast majority of decisions are rendered on the day of the hearing, although panels have the right to ask for more information before making a decision. The SDMC program has also been proven to be more flexible than the court system and decisions have been made in as little as one day when an expedited decision is required.

The SDMC Program currently operates in 37 counties and is currently available in Bronx, Kings, New York, Richmond, Queens, Columbia, Dutchess, Orange, Sullivan, Putnam, Rockland, Ulster, Albany, Fulton, Greene, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington, Westchester, Nassau, Suffolk, Clinton, Essex, Franklin, Hamilton, Jefferson, St. Lawrence, Broome, Chenango, Delaware, Otsego, Tioga and Tompkins Counties. Eight (8) additional counties, in Central New York, including Cayuga, Cortland, Herkimer, Lewis, Madison, Oneida, Onondaga, and Oswego Counties will become operational on March 1, 2000. Further expansion plans are being implemented. It is expected that the SDMC Program will be operational statewide by June 2001.

Providing Advocacy Services

The strength of the Commission's Advocacy Services program is in its unique blending of statewide and regional services. The regional offices provide a statewide network of accessible and individualized services to persons with 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 programs from its central office in Schenectady 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 Commission on Quality of Care and regional advocacy offices are very fortunate in having an experienced group of legal and lay advocates. Their continued enthusiasm and willingness to challenge their own limits and the limits of the delivery system on behalf of persons with developmental disabilities is what continues to make the program a success.



PROTECTION AND ADVOCACY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Approximately 32,000 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 non-legal individual advocacy and encompassed 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.

Statistically, the PADD program provided the following services:

- Case advocacy services were provided to 2,220 persons;
- Another 6,200 individuals were served in group advocacy;
- 3,000 individuals were represented in class action litigation;
- Over 13,334 cases of alleged abuse were investigated by PADD staff;
- Additionally, 4,404 individuals received training;
- There were 2,933 responses to requests for information, materials, referrals, and technical assistance services.

Non-legal Individual Case Advocacy

Each of the PADD offices engages in non-legal advocacy to promote the rights of individuals with developmental disabilities. The offices have assisted large groups of parents of children with autism. These parents, who live throughout the state, wanted to use Applied Behavioral Analysis (ABA) for their children and the school districts balked at delivering such a service. In another issue, with the changes in childhood Supplemental Security Income (SSI) eligibility, came a large demand for representation. Each office developed procedures for handling large caseloads. With regard to residential need, parents of adults with developmental disabilities lobbied our New York Lawyers for the Public Interest (NYLPI) office to find a way to seek placements under the Medicaid program. Finally, a group of adults with developmental disabilities inappropriately placed in Westchester County shelters were in need of immediate placement.

Many times, after resolving an issue, the offices must monitor the situation to make sure that promises and settlement agreements are kept. The Buffalo office, Neighborhood Legal Services (NLS), is following the after-effects of a settlement reached with a Rochester college on granting *reasonable accommodations* for a person with developmental disabilities. The office at Westchester/Putnam Legal Services (WPLS) is ensuring the success of plans to move a woman with cerebral palsy from an inappropriate Office of Mental Health-certified program to an Office of Mental Retardation/Developmental Disabilities-certified home. The Albany Law School (ALS) program is monitoring the activities of a local Committee on Special Education (CSE) which has routinely violated state and federal regulations. ALS individual interventions have provided the necessary change, but there may be a need for a more systemic Office of Civil Rights approach.

The Commission is proud of the accomplishments of the PADD program over the past year, reflecting many hours of hard work by attorneys and lay advocates who strive to improve the lives of individuals with developmental disabilities. It is a credit to the creativity and dedication of all the staff within the statewide network.

There are hundreds of cases involving issues of concern for individuals and families which can be addressed outside the courtroom. Many cases may require the use of an impartial hearing or negotiation. Still others require the brokering of services in a coordinated way which will bring about a change in the life of the person with a developmental disability. The following case examples highlight the work of various PADD staff:

- **Albany Law School Assists Medically Frail Child To Receive Insurance Coverage at Boston Children’s Hospital (BCH):** The child’s HMO, Wellcare, was refusing an inpatient assessment at this out of plan provider (BCH). However, the child’s disability was so rare that Boston Children’s was the only facility capable of treating her. The ALS staff assisted the parents with a grievance appeal and got the approval of Medicaid to cover transportation expenses. The case was finally approved and the child received her very necessary treatment.
- **Long Island Advocates (LIA) Challenges Exclusion of Individuals under Age 21 from HCBS:** The Long Island Developmental Disabilities Services Office (DDSO) had routinely denied admission to the Health and Community-Based Waiver System for anyone under age 21. LIA had a client who was 19 years-old and could not be contained in the local school system. He was awaiting a residential school placement but no facility would accept him. The family was unable to assure the young man’s safety at home and the situation had escalated to dangerous proportions. The LIA advocate appealed to the Long Island DDSO and won approval to provide HCBS habilitation and respite service for the young man.
- **Western New York Advocacy for the Developmentally Disabled (WNYADD) Wins Continued Music Therapy for a Child with Autism:** At first the Monroe County Department of Health agreed to pay for music therapy for this two year-old child despite some controversy with the New York State Department of Health which administers the Early Intervention program. The State Department of Health did not consider music therapists as *qualified professionals* and it was at the State Department of Health’s urging that Monroe County reconsider its decision. After a year of providing the service, Monroe County terminated music therapy. With WNYADD’s help, the parents went to mediation which wasn’t productive. Then WNYADD asked for an Administrative Law Judge (ALJ) Hearing. The ALJ ruled that the music therapists were *qualified professionals* and directed Monroe County to reimburse the parents for music therapy and restore services which were provided previously.
- **North Country Legal Services (NCLS) Provides Representation in 47 Cases Challenging Childhood SSI Terminations:** The legal staff at NCLS provided assistance at every level of the Social Security Administration’s Appeals process. At the initial level before a non-lawyer Disability Hearing Officer (DHO), NCLS was successful in 25 cases. At the Administrative Law Judge (ALJ) hearings, 6 cases were heard but await decisions and another 8 cases remain to be scheduled before an ALJ. One case is being appealed at the Appeals Council after an adverse ALJ decision. In the remaining 7 cases representation was declined or the parent withdrew after an unfavorable DHO decision. In all the successful cases, the benefits were sorely needed to provide care and treatment for these children with disabilities who live in the more rural and poverty-stricken areas of New York State’s North Country.

Legal Intervention

The power to litigate has been the tool of last resort when other means of problem resolution prove unsatisfactory. Over the years, litigation has been used in reaffirming constitutional rights, and, in some instances, defining new rights for persons with developmental disabilities. This year the Commission’s PADD program was very successful in its litigation. The following is an example of one of the significant cases:

New York Lawyers for the Public Interest (NYLPI) Sets Precedent with the Help of Former PADD Attorney (*People v. Martin*)

When the call came into NYLPI’s Manhattan office that a Willowbrook Class member had been arrested in Utica, New York, an urgent call went to the PADD director to help find an attorney within 24 hours. Fortunately, a former PADD attorney from the Binghamton office now was in private practice in Utica and

he “juggled” his criminal court calendar to make an appearance on behalf of class member, Martin. Mr. Martin was charged with assault by the therapy aide who was assigned to his care during a field trip in Utica. The judge agreed to have the former PADD attorney assigned as Mr. Martin’s attorney, rather than a public defender, because of his background with individuals with developmental disabilities combined with his criminal defense expertise. NYLPI assisted in drafting a “Clayton Motion” to dismiss the case in the interest of justice. The judge was convinced that the therapy aide had not followed Mr. Martin’s treatment plan for dealing with problem behavior and, further, that the court was not the place to deal with clinical problems. The Office of Mental Retardation and Developmental Disabilities offered expert testimony and affidavits supporting the NYLPI/attorney defense that justice would not be served in prosecuting Mr. Martin. The OMRDD staff opined that it was not clinically appropriate for the criminal courts to be involved in the treatment of residential consumers. The case is significant because the public employee unions have been advising their members to file criminal actions when staff come into conflict with residents. In addition, there is a union-sponsored insurance policy which assigns benefits to staff “held hostage” on the job, which apparently requires the staff to bring criminal charges.

There was also PADD litigation concluded after many years and new initiatives which have expanded entitlement to services and benefits:

North Country Legal Services (NCLS) Saves Individual with Developmental Disabilities from Unfair Debt Collection

NCLS was approached by a local ARC to assist a client who had been sued by the Essex County Department of Social Services for an alleged Medicaid overpayment. NCLS argued a motion to dismiss on the grounds that the client’s lump sum insurance settlement in another matter did not factor into the alleged overpayment. Essex County withdrew the court case but referred the matter to a collection agent. The NCLS attorney made an affirmative defense under the Fair Debt Collection Practices Act requiring that all future collection activity be made through NCLS as the client’s representative. This action terminated any further collection attempts.

Albany Law School (ALS) Holds Hospital to its Promise (*Neale v.. Community Hospital of Schoharie County*)

As a result of a 1992 confidential U.S. District Court-ordered settlement in the *Neale* employment discrimination case, the defendant, a community hospital, had agreed to provide medical services without charge to residents with disabilities of Schoharie County for a period of one year. However, before all settlement obligations could be performed, the hospital filed for bankruptcy. This year, a successor hospital assumed control and sought to expunge the claims against it, including the ALS community services agreement. ALS filed objections in the U.S. Bankruptcy Court. ALS was one of many creditors making such claims, but the successor hospital agreed to honor the community service portion of the settlement and provide services to children with disabilities as contemplated in the agreement. Further, the hospital agreed to maintain records as to the recipients of service, services provided, and the cost of such services.

Neighborhood Legal Services (NLS) Wins Interpretation That Cost of Job Coach is a SSI Subsidy (*Nazarro v. Chater, U.S.D.C. WDNY*)

Neighborhood Legal Services (NLS) achieved residual benefits for individuals who receive SSI while working with the assistance of a job coach. In *Nazarro*, the U.S. Court of Appeals for the Second Circuit ruled that the use of a job coach could be considered as a subsidy and therefore the value of the actual wages would be lowered.

Education, Training, and Special Activities

The work of the Commission's PADD program goes beyond individual case representation. Each office sets an agenda for the year for providing trainings, conferences or small workshops to groups throughout the assigned catchment area. The topics are generated according to the needs of a particular group and trainings serve as a significant way of providing outreach. The following represents a sampling of Statewide PADD trainings.

North Country Legal Services (NCLS) Makes Inroads at the St. Regis Mohawk Reservation

After many years of bi-weekly visits to the St. Regis Mohawk Reservation, NCLS staff have developed a level of trust with the Native American residents. The turning point came about after one of the attorneys assisted a resident with an adoption. Later came an invitation from the Elders to give a presentation to the tribal members. As a result of these efforts, there has been an increase in requests for NCLS service from families on the reservation.

New York City Staff Continue Outreach to Diverse Groups

With the help of staff person Loretta Goff, the New York City PADD office continues its efforts to reach out to newly arrived immigrant groups. NYLPI has assisted in this effort by coordinating a *pro bono* initiative to help individuals with developmental disabilities to become citizens. This activity has helped in establishing linkages which will be used to notify families about the Governor's *NYS Cares* program which will eliminate the waiting list for residential services within five years.

New York City PADD Office Completes 17th Year of Guardianship and Future Planning Training

The New York City staff have completed over 300 trainings for parents and advocates on how to do an Article 17A guardianship petition *pro se* (without an attorney). Families report back their success in completing the petition, gathering the evidence and serving papers on all the relevant parties for the Surrogate Court hearing. In addition, families have been able to plan better for their son/daughter's future needs through the use of the Developmental Disabilities Planning Council publication: *Planning for the Future, A Guide for Families and Friends of People with Developmental Disabilities*. Although the goal of the number of trainings projected from last year has been met, the demand for trainings continues with each group of individuals who reach the age of majority (18).

New York Lawyers for the Public Interest Co-Sponsors New Training for Attorneys

NYLPI joined the Fordham University School of Law, Volunteers for Legal Services, Legal Services of New York City and Mental Hygiene Legal Service to present a conference on *Diminished Capacity In Civil Legal Services*. In addition, NYLPI has prepared a training for the next fiscal year which will prepare *pro bono* and other attorneys to assist in the representation of the members of the Willowbrook Class. The training will address the basic elements of the permanent injunction in the Willowbrook case, the role of the Consumer Advisory Board, rights of individuals under the OMRDD regulations, and the elements of a fair hearing. It is expected that a cadre of attorneys will be developed to help with the enormous 4,000 member caseload.

PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS

The United States Congress created the Protection and Advocacy for Individuals with Mental Illness program (PAIMI) to protect vulnerable individuals who are mentally ill. The PAIMI mandate is twofold: (1) to investigate either reported or suspected abuse and neglect of eligible individuals and (2) to provide eligible individuals with both legal and non-legal advocacy assistance to enforce their legal rights under all federal and state laws.

The Commission on Quality of Care, together with its six regional Protection and Advocacy for Individuals with Mental Illness (PAIMI) offices throughout New York State, provided protection and advocacy services for more than 1500 eligible individuals during the past year. Additionally, more than 10,000 individuals benefitted by systemic advocacy and class action litigation initiatives provided by the PAIMI system and 11,000 persons received training from the PAIMI system or were part of public information and awareness activities presented by the PAIMI system.

The following case summaries provide examples of the work of the PAIMI regional advocacy system.

Advocating for Prisoners with Major Mental Illness

Disability Advocates, Inc. is advocating for prison inmates who have major mental illnesses and who are not receiving adequate care and treatment in New York State Department of Corrections facilities. They have attempted to address both individual problems as they are presented as well as systemic problems which cause inadequate care.

For example, one inmate received antidepressive medication he needed after Disability Advocates intervened on his behalf. The New York State Office of Mental Health, which provides mental health care within prisons, had refused to provide him the medication because it was not on the Department of Corrections formulary, although the medication he was receiving caused unacceptable side effects. In addition, the inmate had not received any medication for several days when he was transferred from one facility to another. Because of delays in transferring his medical records, the receiving facility knew nothing of his mental health needs. After an attorney from Disability Advocates demanded an investigation, the Office of Mental Health agreed to provide the medication even though it was not on the formulary, acknowledged the errors in the transfer process, and implemented corrective measures to prevent future inmates from missing medications.

Eviction Prevented for Individual in Psychiatric Center

North Country Legal Services, Inc. successfully represented an individual who was hospitalized at St. Lawrence Psychiatric Center, but who had continued to pay her rent so she would have housing upon her discharge. During the course of her hospitalization, she received a letter from her landlord's attorney advising her that her lease had been terminated, that she was forbidden to return to the apartment, and that if her belongings were not removed immediately they would be placed in storage at her expense. The landlord also turned off all utilities in the apartment.

After intervention by the PAIMI attorney, the landlord restored the utility services and did not remove her belongings from the apartment. He did, however, commence a summary eviction proceeding against the client, but this was adjourned until she was discharged from the hospital. After her discharge, the client had adequate time to move to a place of her choosing.

Informed Consent and Protections for Subjects of Experiments

Since 1991, Disability Advocates, Inc. and New York Lawyers for the Public Interest, Inc. have been leaders in advocacy on behalf of both child research subjects and adults who are incapable of providing informed consent for participation in research. These two PAIMI offices, together with Mental Hygiene Legal Service, First Judicial Department, filed *T.D. v NYS Office of Mental Health*, challenging regulations

which governed human subject research that permitted experiments on children and adults with mental illness in psychiatric institutions. In 1995, the trial court invalidated the regulations of the Office of Mental Health because OMH lacked the authority to promulgate such regulations. The court also required that the NYS Department of Health approve or disapprove all non-federally funded experiments involving children and adults with mental disabilities.

In 1996, the Appellate Division affirmed the lower court decision and, in addition, ruled that the State's scheme for experimenting on psychiatric patients violated state and federal constitutions, state law, and longstanding public policy precepts supporting personal autonomy and bodily integrity. The Appellate Division decision, however, did not apply to federally funded experiments and less-than-minimal risk experiments. This narrow finding was appealed by the plaintiffs to the NYS Court of Appeals. In late 1997, the Court of Appeals dismissed the plaintiffs' appeal on procedural grounds. The decision left in place the lower court rulings which invalidated the regulations.

In response to the rulings in *T.D.* the Department of Health has convened an advisory panel to assist it in drafting regulations governing psychiatric research. All parties for the plaintiffs have provided comments to the advisory panel in response to several questions posed. The panel deliberated and recently released a report entitled "Recommendations on the Oversight of Human Subject Research Involving the Protected Classes," inviting comment on the recommendations from interested parties.

In addition to the *T.D.* litigation activities, New York Lawyers for the Public Interest and Disability Advocates have taken an active role in discussing experimentation on human subjects in other arenas. A complaint was filed with the federal Office for Protection from Research Risks concerning an experiment at New York Psychiatric Institute, a facility of the NYS Office of Mental Health. The experiment involves a fenfluramine challenge (fenfluramine was withdrawn from the market in 1997 by the FDA because of evidence that the drug caused heart valve damage in a significant percentage of people who took it) on healthy boys, mainly African-American and Hispanic, that subjected the children to significant risks and no possibility of benefit. The experiment appears to violate federal regulations governing experiments on children. A complaint was also filed regarding fenfluramine experiments on children at Mount Sinai School of Medicine. These experiments received widespread publicity. As a result of this intervention, the Office of Mental Health has agreed not to perform experiments involving fenfluramine in facilities which it operates.

Mother Assisted with Care for Daughter

Disability Advocates, Inc. was contacted by a mother who was a patient in a private psychiatric hospital. The mother expressed concern for her adolescent daughter, who also has a mental illness and resided in a Residential Treatment Center under the custody of the the Office of Children and Family Services. This Office had threatened to discharge the daughter to the mother's home when her mother was unable to provide the necessary care, and without the offer of necessary support services.

As a result of the PAIMI intervention and two family court appearances, all parties agreed to a plan to discharge the daughter into the mother's custody after she had been placed in a Job Corps program. This plan was satisfactory to everyone involved.

Isolated Student Receives Appropriate Educational Setting

Neighborhood Legal Services, Inc. assisted a teenage girl who needed a special education placement because she had been unable to function in a regular school environment for some time. After she was discharged from a psychiatric hospitalization, she was placed on home instruction and had little interaction with her peers. Recognizing a need for integration with peers as well as a need for special education services, mental health providers unsuccessfully advocated with the school district for CSE (Committee on Special Education) classification and placement.

After initial efforts failed, the child's case manager contacted the PAIMI program and an advocate participated in two CSE meetings on behalf of the client. The CSE's primary argument was based on an unwillingness to classify the client because she did well on standardized tests. However, failure to classify her would make her ineligible for special education placements. After much discussion and negotiation, the CSE agreed to classification and placement in a day treatment program. The client is doing well in that setting.

Inappropriate Discharge Prevented

At 4 pm on a Friday afternoon, Disability Advocates, Inc. was contacted by the parents of a child with mental illness who had just been advised that a private psychiatric hospital was about to discharge the child to the parents' home even though the child, the parents, and the treating physician believed that the child needed a residential placement. The parents reported that the hospital threatened to "hotline" them to Child Protective Services if they did not come to get their child. It appears that the push for discharge by the hospital was based on the amount of remaining insurance coverage.

After the attorney contacted the hospital, discharge was halted and assurances were made that the hospital would not make a report to Child Protective Services. The child remained in the hospital until the treatment team, the patient, and the parents agreed to an appropriate discharge plan.

Lack of Interpreter Service Addressed

Legal Services of Central New York, Inc. assisted a young deaf and mentally ill man who was brought to an emergency room because his emotional state deteriorated when he stopped taking his medication. No interpreter service was provided at the emergency room despite repeated requests by the young man and his family. The client was then admitted involuntarily to a psychiatric unit for one week, where he was provided with interpreter services on only two occasions during the entire week.

The advocate met with the hospital administrator, the chief nurse and the unit social worker to discuss the issue of interpreter services in general and his client's experience in particular. As a result, the hospital administrator agreed to make certain policy changes to accommodate the needs of individuals who require interpreter services.

Traumatized Child Assisted in Discharge

North Country Legal Services, Inc. was contacted by staff at St. Lawrence Psychiatric Center on behalf of a 14 year-old patient who had witnessed her father murder her brother. The father had been convicted and incarcerated based on evidence provided by the young girl. The trauma of witnessing the murder and her father's incarceration resulted in her hospitalization.

When the girl had been stabilized, discharge planning became a problem, since the staff were unwilling to discharge the girl to her mother (who apparently blamed her for the father's incarceration). The plan called for the girl to be discharged to a relative who lived outside New York State once legal custody could be arranged.

After interviewing everyone involved, the attorney developed affidavits to support a custody petition and obtained an Order to Show Cause transferring custody of the child to the relative. The psychiatric center then discharged the girl to her relative and coordinated her outpatient treatment in her new community.

Training and Public Awareness Activities

In addition to providing case investigation, legal and non-legal remedies for its clients, the PAIMI program sets a high priority on the provision of training to members of its constituency groups and on making members of the general public aware of the issues involved in its advocacy work.

During the past year, 1,979 individuals received training from PAIMI program staff. Another 9,000 persons received information from the PAIMI system. For example, training events included:

- Challenging Stereotypes through Legal Advocacy
- Legal Rights of Parents of Adults with Mental Illness
- Legal Issues for Parents with Psychiatric Disabilities
- Overview of PAIMI Program and Rights in Residential Facilities
- Overview of Advance Directives, Housing, and Family Law
- Housing Issues for People with Disabilities
- Pregnancy, Parenting, and Mental Illness
- Specific Changes Related to the *Balzi/Brogan* settlement
- Article 81 Guardianship
- Changes in SSI Rules

CLIENT ASSISTANCE PROGRAM

The Commission has been administering the New York State Client Assistance Program (CAP) since 1984. CAP is a federal program with the mission of promoting access to quality vocational and rehabilitation services driven by consumer abilities and preferences. In order to receive funds authorized by the Federal Rehabilitation Act, each state is required to have a CAP program to provide legal and advocacy services to persons receiving services.

The Commission and its statewide network of participating CAP agencies assists individuals with disabilities to secure quality vocational and other services related to employment, education, transitioning from school to work and self-support. For many individuals CAP serves as an indispensable link for accessing quality vocational and rehabilitation services. CAP professionals are mediators, advocates, and legal representatives who use an array of strategies, including administrative and legal remedies, to ensure effective rehabilitation and related services.

During the past year, 828 individuals were provided with intensive case advocacy services. In addition, more than 2,300 individuals were trained by CAP professionals on their rights in the rehabilitation process, and nearly 2,000 more individuals were provided with information and referral services, linking them to appropriate vocational and related services.

The following are examples of CAP cases.

Home Modification

Mr. E. was a consumer of the New York State Office of Vocational and Educational Services for Individuals with Disabilities (VESID) since 1996 and contacted CAP for assistance in resolving problems resulting from VESID-sponsored home modifications. Mr. E's multiple sclerosis had progressed to the point that he relied on a wheelchair for mobility and could no longer independently enter and exit his home, or utilize the bathroom facilities.

During the home modification process the contractor approved by VESID had dismantled the doorway to the bathroom at the outset of the renovation, rendering his entire home almost impossible to live in. Following several delays, the modifications were completed and Mr. E. signed off on the job, believing the work had been satisfactorily completed.

Soon after the modifications were completed, the bathroom started to leak, which resulted in damage to furniture in the living room and family room. CAP contacted the contractor and VESID in an effort to determine what was causing the leaks and who was responsible. When these efforts proved unsuccessful, members of Mr. E.'s family contacted their own insurance company which dispatched an assessor, who determined that the floor liner had not been properly installed and suggested that any licensed contractor should know it would leak.

Based on CAP's recommendation, Mr. E. and family members diligently documented the findings of the insurance company and their protracted effort to compel the contractor to rectify his mistakes and compensate the family for their losses. CAP lobbied the VESID counselor and business manager to determine that the contractor was at fault and to approve a second round of renovations. VESID ultimately concluded that the contractor was at fault and approved the additional renovations. There were additional delays in the second round of modifications and Mr. E. was about to request the fair hearing when the work was ultimately completed nearly a full year after the first round of modifications had begun.

Steps Toward Achieving Employment Goals

Mr. T. is a VESID consumer in his early 40s with a long history of psychiatric disorders. He approached CAP for assistance following VESID's denial to fund the costs associated with a series of certification tests necessary for him to complete network computer training and seek employment. Apparently, VESID had been slow in processing the vouchers for the certification tests and, as a result, Mr. T. personalized the delay and became extremely agitated. His demeanor when he contacted CAP was hostile and threatening. By this time he had also threatened his VESID counselor and communication had broken down.

CAP determined that the threatening behavior was simply Mr. T's way of releasing/channeling his anger and frustration. CAP worked with Mr. T. on his approach to communicating his needs and desires in a non-threatening manner. It took nearly two months before CAP considered Mr. T. prepared for a meeting between his counselor, the senior counselor, and CAP to calmly discuss VESID concerns and requirements. VESID viewed Mr. T. as having transferable skills and not requiring the additional training. With coaching from CAP, Mr. T. calmly demonstrated that, following an exhaustive search, he had secured alternative funding for his continued studies. He also secured alternative funding for transportation, books, and supplies. He documented his continued success in securing high-grades.

Realizing just how devoted Mr. T. was to achieving his employment goals, VESID approved defraying the costs associated with seven certification tests at \$250 each. VESID appreciated the apparent effort Mr. T. had undertaken to control his anger, improve his communication skills, and was impressed with his ability to continue to secure high grades.

Success in College

Mr. K. is a VESID consumer recovering from substance abuse. VESID sponsored Mr. K. in a human services training program at the International Center for the Disabled (ICD). Upon completion of the training, Mr. K. decided he would like to pursue a career as a drug/alcohol abuse counselor. His VESID counselor was reluctant to support any additional training because she felt that Mr. K. lacked the ability to successfully complete the course work and had completed training that should allow him to seek employment immediately.

The regional CAP Coordinator met with Mr. K's counselor to discuss the possibility of supporting him for a trial semester. CAP also suggested that VESID consider a college preparatory training program at a nearby university. The college prep program is offered during the summer and combines one college course with study skill development and discussion groups. The program provides students with ongoing feedback and, upon completion, VESID receives a comprehensive evaluation report.

Mr. K. performed extremely well and the evaluation strongly supported continued studies on the college level. VESID agreed to continued sponsorship and Mr. K. began full-time college studies at the university.

Achieving Vocational Goal

Mr. V. is a VESID consumer who was seeking additional training to pursue a career as a technologist or engineer's assistant. Mr. V. approached CAP for assistance after he had completed an associate's degree program from Devries Institute of Technology with VESID sponsorship. Initially, Mr. V. had entered the Devries program when it was a certificate program. During his study he required medical treatments that delayed his graduation. During the course of his studies Devries converted the program from a certificate program to a degree program. It was Mr. V's strongly held belief that he requires a bachelor's degree in computer engineering to reach his goal of technologist, or engineer's assistant. Mr. V. indicated he had approached the VESID district office manager with the request for continued sponsorship. Mr. V. reported that the district office manager stated that he could not honor the request and recommended that he contact CAP.

The regional CAP Coordinator supplied VESID with a vocational market analysis demonstrating that in order to secure employment as a technologist or engineer's assistant, the applicant must acquire a BA in computer engineering or a related major. Mr. V. also argued that, while his academic progress was delayed due to his medical treatments, the technological advances in the field necessitated more advanced training. VESID granted Mr. V. the additional sponsorship.

PROTECTION AND ADVOCACY FOR INDIVIDUAL RIGHTS PROGRAM

The Protection and Advocacy for Individual Rights (PAIR) program is an 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 also administers this 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.

The major goals of the system include the provision of assistance to people to secure their rights to accessible and affordable housing in the communities and neighborhoods of their choice, and the reduction of accessibility, communication and transportation barriers. Projects also increase the availability of supports enabling people with severe disabilities to participate freely in community life.

PAIR, in combination with CAP, and the programs authorized under DDA and PAIMI, allows P&As to serve all individuals with disabilities and provide a full range of legal services and advocacy.

During the past year, the New York State PAIR program served approximately 4,600 persons with disabilities, their families and advocates. Legal representation or intensive case advocacy services were provided to 532 persons. Another 1,469 persons were provided with information or appropriate referral and 2,626 persons were trained at 75 educational settings.

The following are examples of PAIMI cases:

Securing Housing/Safe Haven

Restoration Society, et. al. v. City of Buffalo, 98-CV-0041S(H) (WDNY).

Neighborhood Legal Services obtained a preliminary injunction in federal court against the City of Buffalo, under the ADA and Section 504, allowing an overnight drop-in center for homeless people with mental illnesses to open. The purpose of the center is to provide a safe haven for homeless people with mental illnesses and to attempt to link these individuals with community services in a nonthreatening manner, with the ultimate goal of providing permanent housing. Many of the intended clients of the program have historically been extremely resistant to such interventions and assistance.

The City of Buffalo had denied a special use permit to a nonprofit agency which was seeking to open the drop-in center based on classic “not in my back yard” pressure from the neighbors of the center. Prior to initiating the lawsuit, NLS appeared with the agency at several hearings before the City of Buffalo Common Council, as well as at community meetings, in an effort to obtain approval for the center without resort to litigation. When that failed, NLS filed a court action.

After several appearances in Court and a hearing on the motion, the Court granted a six month preliminary injunction to the agency, allowing the program to open. The Court found that NLS was likely to prevail on the claim that the City had impermissibly discriminated against the agency and its clients on the basis of disability in violation of the ADA and Section 504. Plaintiffs have since received two additional six month extensions to the preliminary injunction order and are negotiating settlement of the lawsuit with the City.

In the meantime, the program has been in operation for almost a year and is considered a huge success at providing a place for homeless people with mental illnesses to go to get off the streets at night. A large percentage of these people have accepted referrals to community service agencies and are no longer homeless, thus meeting the ultimate goal of the program.

Reducing Accessibility, Communication, and Transportation Barriers

During this year, New York Lawyers for the Public Interest began an Access Campaign with the intention of enhancing the public’s understanding of the importance of access for all.

A major part of the Access Campaign will be increased advocacy. This effort involves surveying facilities to make sure they are accessible and taking action to ensure that inaccessible places and programs are made accessible. The Access Campaign emphasizes the places that are important for the daily lives of people with disabilities, especially for those who are poor. These include stores, schools, post offices, government buildings, transportation services, medical services and other public accommodations that are part of everyone’s day-to-day life. The Access Campaign also plans to continue NYLPI’s work in supporting the rights of people with disabilities to services such as appropriate education and psychiatric treatment in one’s native language.

Community outreach and education are also a major component of the Access Campaign. Strategies include distributing easy-to-read information on the ADA, public service announcements and advertisements and increasing people’s awareness of assistance available to them, including legal assistance. Education is also aimed at the general public, including employers and architects. The Access Campaign seeks community feedback on a frequent basis to ensure that its work is helpful and effective.

Enabling Participation in Community Life

Lupo v. Wing, CV 97-0986 (E.D.N.Y.)

Plaintiff, represented by counsel from NSLS and the Touro Law Center, prevailed in his claim challenging the failure of the Suffolk County Department of Social Services (SCDSS) and the New York State Department of Health (NYSDOH) to permit recipients of Medicaid Personal Care Services (PCS) to go on activities of daily living performed outside the home, such as shopping and banking, with their PCS aides. Plaintiff challenged the defendants' restrictive PCS policies as violating the State Medicaid Statute and Title II of the Americans With Disabilities Act, providing for government programs and services to be offered in the least restrictive manner.

United States District Court Judge Thomas Platt ordered a stipulation of settlement in the case on February 4, 1998, pursuant to which plaintiff is permitted to go with his PCS aide on activities of daily living included on the plaintiff's PCS care plan, which include shopping, banking, haircuts, and other activities. The stipulation provides for the use of Suffolk County paratransit for the performance of activities performed by Mr. Lupo and his aide outside the home.

Education, Training and Outreach

Educational Advocacy Training

An important component of the Commission's statewide training program is the provision of specially designed workshops focusing on special education issues for PAIR clients. During this past year a variety of sessions were scheduled throughout the state. These sessions focused on advocacy skills for parents, including how to understand evaluations and assessments; how to write an Individualized Education Plan; and how to monitor a child's special education program. Many of the workshops were co-sponsored with other disabilities organizations such as the Learning Disabilities Association, the Parent Network, the Mental Health Association, the SUNYA TRAIID Program, and Taconic Resources for Independence, Inc.

Minority Outreach Project

The Commission's Statewide Minority Outreach Project continues its primary mission of assisting the Commission and its related advocacy partners to effectively serve the state's minority groups. Although housed in New York City, the Project serves as a valuable resource to all the regional PAIR programs.

Hispanic Outreach and Training Project

Complementing the Minority Outreach Project is a statewide Hispanic Project. The Hispanic Access coordinator has focused her efforts on making the State's Hispanic organizations aware of the Commission resources, and on the delivery of educational advocacy training.

National Association of Protection and Advocacy Systems Minority Award

In recognition of the Commission's outstanding minority outreach activities, the National Association of Protection and Advocacy Systems (NAPAS) bestowed its national minority outreach award to the Commission at the NAPAS annual conference.

Disability Awareness Program

The Commission on Quality of Care, along with nine other co-sponsors, has for the last several years conducted a statewide disability awareness program. This program is designed to provide information to students to help promote positive attitudes toward persons with disabilities. Over the years, Commission staff have conducted a variety of school presentations and activities for students including essay, art and photography contests. Judging from the more than 2,000 entries annually, the program has been a success in helping to focus attention on the many similarities among persons with disabilities and those without disabilities. Materials developed for and emanating from this project have been featured on the Commission's website.

Disability and the Law

Disability and the Law is an ongoing video series which deals with relevant issues in disability law. This award-winning series is co-produced by the Commission and the NYS Bar Association and broadcast on local cable television stations throughout New York. Videos are also available for purchase. This year featured shows were on guardianship and special education issues.

Appendices

STATE
OF
NEW YORK

STANDARD VOUCHER

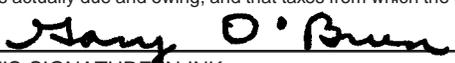
Voucher No.

ANNUAL REPORT 1998-99

1 PAY TO:	
Payee Name (Limit to 31 spaces) Commission on Quality of Care for the Mentally Disabled	
Address (Limit to 29 spaces) 401 State Street	
City & State (Limit to 24 spaces) Schenectady, New York	Zip Code 12305

QUANTITY	DESCRIPTION OF SERVICES-April 1, 1998 to March 31, 1999	Amount
57,114	Persons Served Through PADD, CAP, PAIMI & PAIR Networks	
18,058	1-800 Calls Received	
7,556	Reports of Suspected Adult Abuse Reviewed	
1,710	Recommendations Made	
451	Site Visits	
369	Surrogate Decision-Making Cases Reviewed	
266	Individual Quality Assurance Complaints Acted Upon	
181	Deaths Investigated	
148	Reports of Suspected Child Abuse Responded To	
7	Published Reports	
TOTAL EXPENDITURES FOR SERVICES		
State Operations		
General Fund		\$2,813,702
Special Revenue Fund - Federal		3,074,495
Special Revenue Fund - Other		1,946,271
Aid to Localities		
General Fund		\$ 195,070

<input type="checkbox"/> 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.	TOTAL	\$8,029,538
	Discount %	
	NET	\$8,029,538

 PAYEE'S SIGNATURE IN INK 1998-99 Date	Chairman Commission on Quality of Care for the Mentally Disabled Name of Company
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1998-99 Publications

Could This Happen in Your Program? A Collection of Case Studies Provoking Reflection, Discussion, and Action, Volume II, 1998.

Diverting Public Funds: The Misguided Mission of the Independent Living Center of Amsterdam, Inc., August 1998

Exploiting Medicaid Through A Shell Not-For-Profit Corporation: The Case of Special Needs Program, Inc., January 1999

Abandoning Its Not-For-Profit Purpose: The Case of Project Independence of Queens NY, Inc., June 1999

A Report on Individuals with Developmental Disabilities Who are Possibly Homeless, August 1999

Watching Over the Children: A Review of 1998 Commission Activities on Behalf of Children with Mental Disabilities, August 1999

In The Matter of David Dix, November 1999

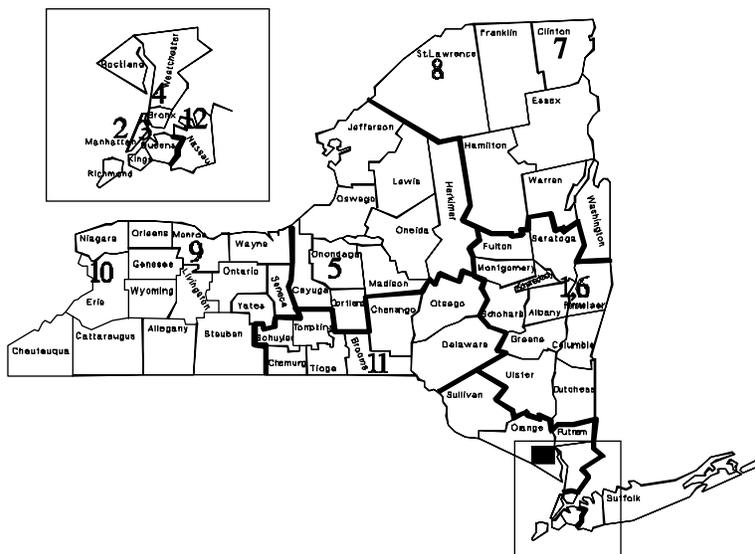
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1. NYS Commission on Quality of Care
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New York City Region

2. NYS Commission on Quality of Care
Bureau of Protection and Advocacy
55 Hanson Place, Room 1069
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(718) 923-4305
3. New York Lawyers for the Public Interest, Inc.
151 West 30th Street, 11th Floor
New York, NY 10001-4007
(212) 244-4664

Lower Hudson Region

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

Central Region

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

Upper Hudson Region

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.
295 Main Street
Ellicott Square Building, Rm 495
Buffalo, NY 14203
(716) 847-0650

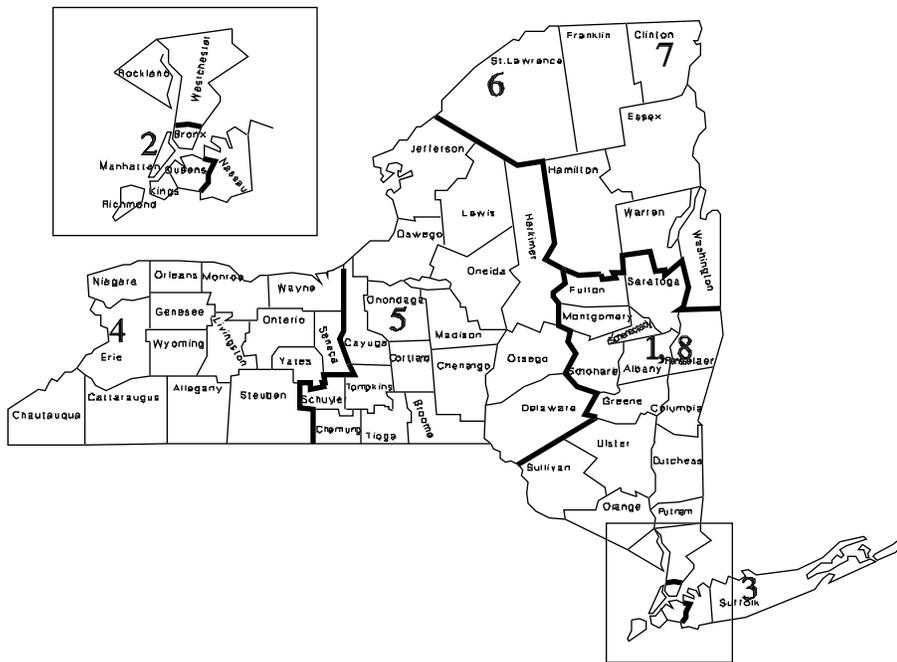
Southern Tier Region

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.
4250 Hempstead Turnpike, East Building, Suite 19
Bethpage, NY 11714
(516) 735-5466

Protection and Advocacy for Individuals with Mental Illness Regions and Offices



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151 West 30th Street, 11th Floor
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(212) 244-4664

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.
295 Main Street
Ellicott Square Building, Rm 495
Buffalo, NY 14203
(716) 847-0650 (716) 847-1322 (TTY)

Central New York Region

5. Legal Services of Central New York, Inc.
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472 South Salina Street, Suite 300
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(315) 475-3127

North Country Region

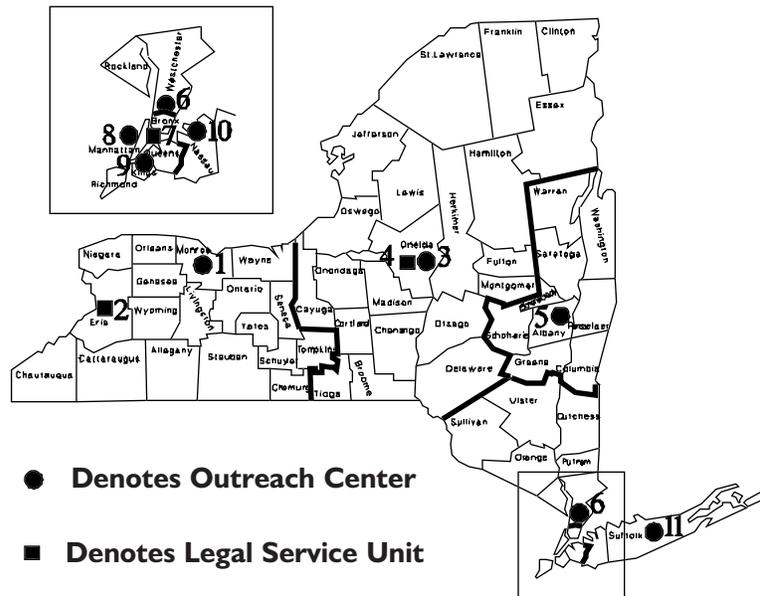
6. North Country Legal Services, Inc.
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Canton, NY 13617
(315) 386-4586 1-800-822-8283

7. North Country Legal Services, Inc.
100 Court Street, POB 989
Plattsburgh, NY 12901
(518) 563-4022 1-800-722-7380

Hudson Valley Region

8. Disability Advocates, Inc.
5 Clinton Square
Albany, NY 12207
(518) 432-7861

Client Assistance Program Regions and Offices



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.
295 Main Street
Ellicott Square Building, Rm 495
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.
855 Central Avenue, Suite 110
Albany, NY 12206
(518) 459-6422 (Voice and TTY)
6. Westchester Independent Living Center, Inc.
200 Hamilton Avenue
White Plains, NY 10601
(914) 682-3926 (914) 682-0926 (TTY)

New York City Region

7. New York Lawyers for the Public Interest, Inc.
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New York, NY 10001-4007
(212) 244-4664
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.
Herricks Community Center
999 Herricks Road
New Hyde Park, NY 11040
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11. Long Island Advocacy Center, Inc. (Satellite Office)
490 Wheeler Road, Suite 165C
Hauppauge, NY 11788
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NEW YORK STATE COMMISSION ON
Quality of Care
FOR THE MENTALLY DISABLED

MISSION STATEMENT

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

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

VALUED AND GUIDING PRINCIPLES

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

▶ Committed and Courageous Independence

We will carry out the agency's mission on behalf of individuals with disabilities undeterred by extraneous factors.

We will gather information and data independently, making findings and recommendations as we see them, consulting with but not controlled by outside parties.

We will be a voice for the often voiceless, "the everyman" disabled or not, singing praise where praise is due, explaining ways in which services could be improved and expressing righteous outrage when they are not.

▶ Compassion

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

▶ Integrity

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

▶ Respect

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