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NEW YORK STATE COMMISSION ON

QUALITY OF CARE for the Mentally Disabled

92 Rev. (4/82)

STATE OF NEW YORK

STANDARD VOUCHER

Voucher No.

PAY TO:

ee Name (Limit to 31 spaces) Commission on
uality of Care for the Mentally Disabled

ress (Limit to 29 spaces)
9 Washington Avenue

& State (Limit to 24 spaces)
lbany, New York

Zip Code 12210

ANNUAL REPORT 1993-94

QUANTITY	DESCRIPTION OF SERVICES--July 1, 1993 to June 30, 1994	Amount
41,781	Persons Served Through PADD, CAP, & PAIMI Networks	
7,862	Complaints Acted Upon	
2,677	Recommendations Made	
703	Site Visits	
330	Deaths Investigated	
376	Surrogate Decision-Making Cases Reviewed	
143	Reports of Suspected Child Abuse Responded To	
393	Reports/Month of Suspected Adult Abuse	
7	Published Reports	
	TOTAL EXPENDITURES FOR SERVICES	
	State Purposes	
	Personal Services	$2,975,112
	Non-Personal Services	954,718
	Special Revenue Fund - Federal	
	Personal Services	$ 971,184
	Non-Personal Services	2,132,776
	Special Revenue Fund - Other	
	Personal Services	$ 666,690
	Non-Personal Services	238,387
	TOTAL	$7,938,867
	Discount %	
	NET	$7,938,867

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.

Chairman
Title

PAYEE'S SIGNATURE IN INK

1993-94
Date

Commission on Quality of Care for the Mentally Disabled
Name of Company

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

Annual Report Editor
NYS Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, NY 12210-2895

Tel: (518) 473-6304

Foreword

As the mental hygiene system continues to evolve from an era where institutions predominated to one where care is provided in a variety of community-based settings, the challenges that are presented continue to evolve as well. Through changing philosophies of care and changing economics, the system is moving inexorably to a new post-institutional era that presents great opportunities for the persons being served, but that also exposes both individuals and the quality standards of the service system as a whole to new risks.

There are several emerging hallmarks of this new era that create both the opportunities and the risks:

- a willingness to innovate and experiment with new forms of services and supports to respond to needs *as defined by the persons being served*;
- a greater stated emphasis on consumer choice and empowerment;
- a new flexibility in process and a greater emphasis on achieving desired outcomes;
- a fuller commitment toward assisting persons with mental disabilities live in independent and quasi-independent residential settings;
- a greater recognition that many persons with mental disabilities can participate in regular work settings, with real paychecks, if provided needed adaptive equipment and supports;
- a concomitantly greater reliance on non-certified, settings to provide residential and day services;
- a dismantling of or de-emphasis upon statewide regulatory structures as a means of providing guidance on what is expected of employees and providers, accompanied by sharp cutbacks in governmental staff engaged in quality assurance and programmatic and fiscal oversight activities;
- greater reliance upon staff who have less training and experience in the provision of services and supports and who often also receive less onsite supervision of their performance by more senior or experienced staff;
- reduced staff training budgets, especially funding allocations for training the mid-level managers responsible for staff supervision and quality on the frontlines.

At the same time, the service system is poised to take a giant step into the world of managed care which promises better coordination to achieve improved quality of service and health status. Yet one of the fundamental objectives of managed care is to reduce and contain costs, which engenders concerns that in the quest to achieve fiscal goals, access to needed services may be denied or reduced.

Many of the activities of the Commission described in this annual report illustrate the tension between these opportunities and the risks that sometimes accompany them. As the ramifications of the changes in the system became clearer to us in our day to day work of responding to complaints of families and consumers, and in investigating allegations of abuse and neglect, the Commission decided to begin a wider discussion of these issues. We sponsored a Symposium on "Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities" to engage providers, state officials, consumers, families and advocates in thinking about how to take best advantage of the opportunities while minimizing unnecessary risk. A monograph collecting the views of the principle speakers at the Symposium was published and disseminated.

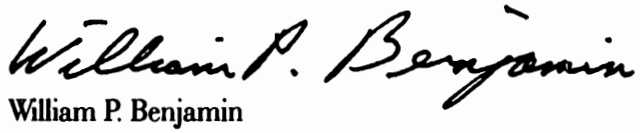
This year's activities reminded us once again of the wisdom of the state legislature in providing for independent oversight of a large human service system that

provides for the needs of a vulnerable group of New Yorkers. The cost to the state of independent oversight has remained below one tenth of one percent of the budget of the programs overseen. As deregulation and the other changes enumerated above take hold, the necessity for independent oversight will become an even more critical part of the safety net.

The Commission and its staff pledge to devote our best efforts to this mission.

Clarence J. Sundram
Chairman

Elizabeth W. Stack
Commissioner



William P. Benjamin
Commissioner

Contents

Fostering Choice, Maintaining Responsibility

Recent years have witnessed unprecedented change in the service systems for persons with mental disabilities. This change has been characterized by movement towards living in the community as opposed to the institution, an increased emphasis on consumer choice and empowerment as a fundamental value in redesigning services and supports for community living--with attempts to reverse a history of paternalistic decision-making, policies, and expectations for staff who provide the services and supports.

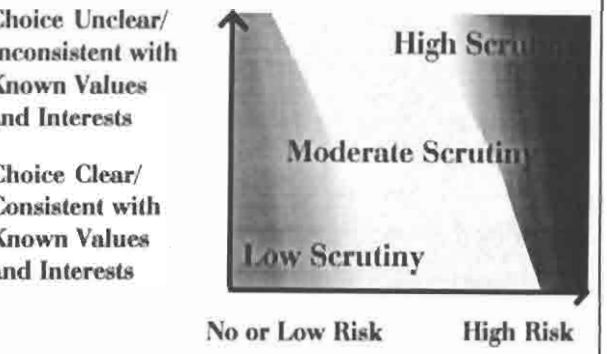
As an agency charged by law with investigating unnatural deaths and allegations of abuse and neglect on the one hand, and advocating for the rights of individuals with disabilities on the other, the Commission regularly confronts cases where tragedies occur and where negotiations around client choices have failed. The Commission continually wrestles with the issues of choice and responsibility, empowerment and protection--not as abstractions, but in the context of real lives and real dilemmas.

Commission investigations and activities listed below illustrate the delicate balance in preserving both sides of what appears at first glance as a dilemma: fostering independence and choice among individuals with disabilities, while, at the same time, insisting on recognition and acceptance of responsibility by individuals receiving services and their providers, in order to protect vulnerable people from harm.

Symposium on Choice and Responsibility

On June 21-22, 1994, a symposium on *Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities* was held in Albany to address these apparent dilemmas which advocates, clinicians, recipients of services and family members face as they try to honor the values for personal choice, self-determination and independence for people with disabilities while trying to face the responsibilities necessary for protection from harm. The symposium was co-sponsored by Disability Advocates, Inc. and the Commission. Funding was provided by the van Ameringen Foundation, Inc. and the NYS Developmental Disabilities Planning Council.

Framework for Assessing Decision-Making Capacity



During the two days of the symposium, approximately 850 consumers, self-advocates, service providers, lawyers, family members, and professional and lay advocates from 25 states discussed such controversial topics as: involuntary treatment, sexual expression among adults in group homes, what to do when consumer choices and provider's expectations do not coincide, and when persons with mental disabilities should be held responsible or excused for criminal behavior.

In the opening address, *Free Choice, Informed Choice, and Dangerous Choices: Who Decides and Who Is Accountable?* Clarence J. Sundram, Chairman of the Commission, advised the audience not to lose sight of their common sense in dealing with these dilemmas and proposed a framework to assist service providers and advocates in assessing when their intervention and protection is warranted.

Lead seminars on the first day were designed to provide *Conceptual Frameworks* of the values and legal precedents for choice and responsibility in specific issue areas: deinstitutionalization; sexuality; medical care; residential services; involuntary treatment; criminality; and day programs, work, and leisure activities.

Fourteen workshop sessions on the second day entitled *Practical Matters* focused on day-to-day problems in negotiating choice and responsibility in services for persons with mental disabilities. Using case studies drawn from the experiences of service providers and the Commission over the past few years, symposium participants were brought to the frontlines of service delivery and were provided the opportunity to respond to these case problems.

Designed to spark discussion among persons with different points of view, this symposium convened participants from many walks of life and all over the United States. Opening plenary speakers set the tone for the symposium. In addition to the Commission Chairman's discussion of the dilemma of honoring choice versus seeking surrogate decision-makers, Michael Kennedy and Darby Penney, representing the self-advocacy movement, offered strong advocacy for "choice," whereas the NYS Office of Mental Health Commissioner Richard Surles asserted that OMH cannot both provide persons with mental illness more freedom and independence in their lives and continue to assure them the same level of protection that had once been expected.

The symposium closed with the central theme of *Reconciling the Rights of Persons with Mental Disabilities and Expectations for Protection From Harm* with three long-time advocates in the field of mental disabilities and all with strikingly different points of view. E. Fuller

Torrey, advocated for a "grandmother test" of "common sense" and stated that the system had gone too far in giving individuals with serious mental illness decision-making powers. Judi Chamberlin countered, "Why do we take one group of people, those labeled 'mentally disabled,' and deny them the basic rights all other American citizens take for granted?" Attempting to bridge the gap between Torrey and Chamberlin, David Ferleger closed the symposium by asserting the need for choice but to do so with caution.

Participants gave high marks to the symposium; they praised the symposium for including the consumer perspective in the presentations, placing speakers with opposing views on the same panel, and for ensuring that presenters were well-organized and prepared. Criticisms generally centered on time constraints for the sessions or the lack of specific solutions or answers. Many, however, remarked that the symposium was a good beginning for needed future dialogue.

It is essential that we honestly ensure that we are eliciting authentic and informed choices of consumers, and that we adequately prepare everyone from agency managers on down for the new responsibilities they will have to shoulder in respecting these choices and, as importantly, in challenging them when they expose the individual to unrecognized dangers. The Boy Scout motto: "Be Prepared" would be a good first step in today's Quality Handbook.

— Clarence J. Sundram

One way of continuing this dialogue is through the use of the symposium monograph which the Commission published following the symposium. This monograph contains edited papers and case studies that address the tensions between increasing emphasis on recipient choice and empowerment, and the traditional responsibilities of service providers to protect individuals from harm. Authors include many nationally known leaders in the field of mental disabilities who have been directly involved in the struggle for civil rights of persons with disabilities. Requests for the monograph have come in from all over the United States, as well as Canada, England, Japan, and Australia.

Monitoring Progress in the Care and Treatment for Persons with Multiple Disabilities: Multiply Disabled Units

Care and Treatment for Persons with Multiple Disabilities: A Progress Report, the Commission's study of Multiply Disabled Units (MDUs) serving persons with both a mental illness and developmental disability, issued in August 1994, continued efforts begun by the Commission in its earliest days in one of the Commission's first systemic studies. In contrast to the findings of nearly 15 years earlier, the 1994 study found substantially improved conditions and far more opportunity to live and participate in the community for the residents. Site visits to eight MDUs and comprehensive reviews of the care and treatment of 69 residents from these sites amply demonstrated the progress that has been made in meeting the multiple treatment challenges presented in caring for this group of individuals.

The Commission's study focused on examining how well the MDUs meet the unique needs of this group to reduce inappropriate behavior, learn basic adaptive behavior, and reduce psychiatric symptoms. Also studied were how well residents are being protected by the incident reporting and investigation system. The use of psychoactive medication (including issues about consent for such medications), and the use of restraint, seclusion and physical intervention techniques were also examined as were the treatment planning and provision for residents' daily living needs.

In brief, the Commission's findings included:

- The MDU populations served by OMH and OMRDD were similar but the Commission found OMRDD's MDUs had richer environments, including opportunities for more resident autonomy, de-

cision-making, and more varied community living options.

- MDUs at seven of the eight facilities were clean, well-maintained and free of safety hazards. Residents at these facilities were appropriately dressed and well-groomed. In the six OMRDD MDUs visited, residents received generally good care, with day programs and leisure time activities, little need for physical interventions to control behavior, and documented informed consents for the use of psychoactive medication, which was administered consistent with established behavior plans. Serious deficiencies were found at the Manhattan Psychiatric Center MDU where common areas were dirty, furnishings were soiled and worn, and residents' personal hygiene was poor.

In contrast to the findings of nearly 15 years earlier, the 1994 study found substantially improved conditions and far more opportunity to live and participate in the community for the residents.

- Treatment planning was superior in the OMRDD facilities with specific behavior plans, including a component teaching positive behaviors; in contrast, OMH treatment plans relied heavily on the use of medication and group or individual therapy.
- In 90% of the serious incidents reviewed, the facility had protected its residents by completing a competent and comprehensive review of the incidents; however, in the remaining 10% the Commission found serious deficiencies with problems ranging from failure to notify law enforcement authorities to investigative practices which jeopardized the integrity of the investigation. As noted in previous Commission reports, the Commission also found that such deficiencies were not always detected by the facilities' Incident Review Committees.
- No excessive use of restraint, seclusion or other physical interventions were found in the MDUs by the Commission.

The Commission recognized that care and treatment provided by OMRDD facilities most appropriately met the total range of needs of individuals with both mental illness and developmental disabilities, and recommended that OMRDD and OMH continue the transfer of psychiatrically stable OMH MDU residents to OMRDD MDUs. Over 2000 such individuals have been transferred to OMRDD MDUs since 1978. Notwithstanding, the Commission's study revealed that each Office had something to offer the other about the treatment of persons with multiple disabilities: OMRDD needs to provide opportunities for residents to participate in individual or group counseling where appropriate, and OMH needs to design and implement behavior plans which give staff clear directions in how to respond to residents' maladaptive behaviors.

Other Commission recommendations included the need to improve the incident reporting and review process including a revision of OMH regulations to define a complete investigation and expand the type of incidents to be reported to outside bodies such as the Commission. The Commission also recommended specific corrective actions for the deficiencies found in the care and treatment at the Staten Island and Manhattan PC MDUs.

Restraint and Seclusion Practices in Psychiatric Facilities

The use of restraint and seclusion in state psychiatric centers has doubled over the past decade (1984-1993) and has been associated with over 100 patients deaths during that period. Issuing a series of reports on restraint and seclusion, in the first report, *Restraint and Seclusion Practices in New York Psychiatric Facilities*, the Commission found wide variations in the frequency with which these interventions were used by psychiatric facilities in New York. This study found that a patient's odds of being restrained or secluded varied from less than one in one hundred to more than one in ten, depending on the psychiatric center or public hospital (Article 28) psychiatric unit.

The Commission concluded that, rather than facility demographics or patient characteristics, it is the treatment preferences and practices of administrators and clinical staff which predicted low rates of restraint and seclusion. Typically "low-user" facilities shared a strong patient-centered treatment orientation, and administrators believed strongly in minimal use of restraint and seclusion. These facilities have instituted policies and practices to keep usage low by assuring greater personal liberties for patients (e.g., more off-unit privileges, telephone and visiting privacy, and freedom to take unscheduled showers). The study also found that at these facilities patients received more therapeutic activities, and had better living conditions.

A second Commission report on the use of restraint and seclusion, *Voices From the Front Line: Patient's Perspectives of Restraint and Seclusion Use*, contains the results of the largest survey of former psychiatric patients reported in the literature. The survey found that many patients who were restrained or secluded during their inpatient stays reported these interventions were used illegally and that they were often poorly

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Restraints responsible in patients' deaths

The Saratogian
September 23, 1994

By JAY GALLAGHER
Gannett News Service

ALBANY – Incidents of forcibly restraining patients or isolating them in bare rooms in state psychiatric centers almost doubled between 1984 and 1992 and has played a role in 111 deaths, according to a new report from a state watchdog agency.

The agency, the Commission on the Quality of Care for the Mentally Disabled, also found that half of former psychiatric patients who responded to a survey said they had been restrained or secluded while hospitalized.

"The commission concluded that, despite Mental Hygiene Law and regulatory restrictions, there is a risk that restraints and seclusion are being used as punishment or for staff convenience at some facilities," the report says.

"This is shocking and unacceptable," said Harvey Rosenthal of the state Association of Psychiatric Rehabilitation Services. "These reports provide substantial evidence that serious physical and psychological harm is occurring daily in psychiatric and general hospitals in everypart of the state."

The study shows there were no such incidents at Saratoga Hospital. However, there were many at the Capital District Psychiatric Center.

Restraint involves using a straitjacket, sheets to tie a patient to a bed or other means to prevent the free use of arms and legs. Seclusion means placing a patient alone in a locked room with only a mattress.

By law, they can be used only with a written order from a doctor.

The commission, set up in the wake of the Willowbrook scandal 20 years ago to monitor the care of the mentally ill and retarded, was directed by the state Legislature to look at the issue in reaction to stories about the deaths of patients while restrained or secluded.

The report found that 1,391 orders of restraint or seclusion on adults were issued in 1992, compare to 1,409 in 1984, despite a drop in the number of patients from 23,596 to 13,133.

For children, the use of restraints and seclusion jumped from 72 10 years ago to 342 in 1992 – even though the number of child patients dropped from 620 to 483.

treated, abused or injured when restrained or secluded.* Almost one-third of the 1,040 respondents stated that, while inpatients, they were concerned for their safety and well-being, and that their basic dignity and privacy were violated.

Based on study findings, the Commission concluded that, despite Mental Hygiene Law and regulatory restrictions, there is a risk that restraint and seclusion are being used as punishment, or for staff convenience at some facilities. The Commission believes there is a need to re-examine the laws, regulations and policies which have allowed facilities such broad discretion in the use of restraint and seclusion and will issue a third report (Spring 1995) which will evaluate the adequacy of existing protections governing use of these interventions and recommend appropriate changes.

Isolated Predictors of Restraint and Seclusion Use by Psychiatric Services of General Hospitals

(N = 103)

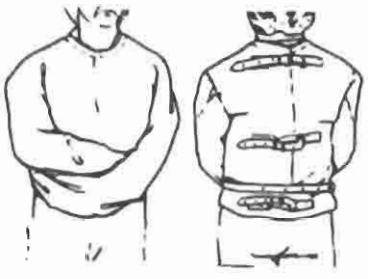
Patient Characteristics		*Facility Characteristics*	
More indigent patients	⇨ ***Higher*** % patients secluded	***More*** patients average daily census	⇨ ***Higher*** % patients secluded
More Caucasian, Non-Hispanic patients	⇨ ***Lower*** % patients secluded	Urban location	⇨ ***Higher*** % patients secluded
More recently admitted acute patients	⇨ ***Lower*** % patients secluded ***Lower*** % patients restrained	Downstate location	⇨ ***Higher*** % patients secluded ***Higher*** % patients restrained
		Medical school affiliation	⇨ ***Higher*** % patients secluded ***Higher*** seclusion orders rate

* Two recipient advocacy groups, the New York Association of Psychiatric Rehabilitation Services and the Recipient Empowerment Project of the NYS Mental Health Association helped design and distribute the survey to former patients of psychiatric facilities.

Commonly Used Mechanical Restraints

Full Restraint Sheet

Waist/Vest Restraint



Camisole

Four-Point Restraint

Chair Restraint

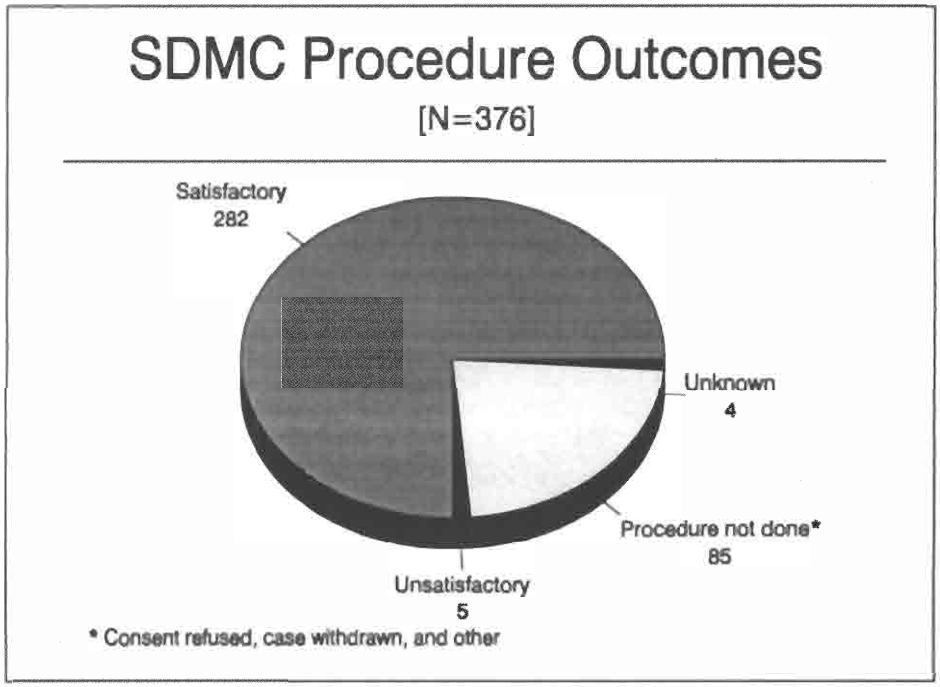
The SDMC Program: A model program for fostering choice, maintaining responsibility

The Surrogate Decision-Making Committee Program (SDMC) was established as an alternative approach to the court system for obtaining an informed choice about major medical treatment for individuals with mental disabilities residing in facilities licensed by state offices of the Department of Mental Hygiene. Prior to the SDMC program, treatment often was delayed for weeks or months because of legal difficulties in obtaining informed consent for patients and residents deemed incompetent to give consent. The program provides less expensive, more accessible, and more personalized decisions than the judicial process, while assuring protection of patient/resident rights and best interests.

Surrogate Decision-Making Committees operate through four-person volunteer panels, composed of a health care professional, a lawyer, a former patient or relative, and an advocate [The complete list of the current 273 volunteer panel members is listed in the back of this report on p. 79]. The first task of these panels is to determine whether an individual is capable of making an informed choice and giving consent. If the patient/resident is deemed mentally incapable, the panel is authorized to provide substitute consent, or refuse the proposed treatment, upon consideration of the best interests of the individual. The panels always meet with the patient before making any decision. The "best interest" test includes relative risks and benefits, alternative treatments, quality of life with or without the treatment, and the previously-expressed values and beliefs of the individual.

The SDMC program currently operates in a 20-county area. The program is administered by the Commission, with the assistance of local community dispute resolution centers in three areas of the state.

During the reporting period the SDMC program reviewed 376 cases in which 282 individuals were given consents to receive major medical treatment which had positive effects. From the program's inception in 1986, through July 31, 1994, 3,154 cases have been heard at SMDC hearings. During the past year, Commission SDMC staff have conducted new panel member training sessions in the Dutchess, Upstate, and NYC regions. As a result of these trainings 43 new volunteer panel members were added to the program. Commission staff also conducted training sessions for providers in the Dutchess and Rockland regions. These training sessions were designed to assist providers in their understanding of the SDMC program and its requirements, enabling the providers to send complete information in a timely manner which expedites the process and eventual major medical treatment, if deemed necessary and in the best interests of the persons with disabilities.



Promoting Responsibility by the Investigation of Deaths

In answer to that ageless question, yes we are our brother's keeper. Those involved in the care and treatment of disabled individuals are charged with the responsibility of enabling their fellow brothers and sister to be, as the Army puts it, all that they can be. As fallible individuals, care providers also have the responsibility to learn from their mistakes, the times they fell short of the mission with which they were entrusted. And, as part of a larger community, they also share in a responsibility to spread the news of the lessons they learned so that fellow care providers can grow in their service to others.

During the report period, the Commission acted on its responsibility to spread the news through the publication of a continuing series of case studies entitled: *Could This Happen In Your Program?*

The series presents problematic situations brought to the Commission's attention and the remedial actions taken by facilities. Challenging the reader to question, "Could this happen in my program?" the case studies are intended to engage program staff and administrators in reflection and discussion of existing policies and practices, staff training issues, clinical matters and the need to institute additional actions to better protect the individuals they've been entrusted to serve. The series of studies is designed to challenge staff at all levels of a program's operation with the task of being all that they can be in the service of others.

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- Swimming safety tips are discussed in the case of Matthew Sweet* who drowned while on a summer outing with staff and fellow consumers of his community residence. Unable to swim, Mr. Sweet was allowed to enter the water at a public beach. While staff's attention was momentarily diverted to other clients' care needs, Mr. Sweet disappeared. When staff noticed he was missing, they searched the crowded beach area and the nearby picnic area, but didn't notify lifeguards - who would have immediately conducted a coordinated, professional water search. Mr. Sweet's lifeless body was found by a bather in nine feet of water, at the bottom. His case study presents the lessons learned by his service agency through tragedy concerning buddy systems, assessing individuals' water safety skills, supervision during swimming activities, and working with professional lifeguards.
- The cases of Mildred Thomas* and Jacob Fine* respectively discuss lessons learned by agency staff who failed to notice signs and symptoms of illness and complications following surgery or who neglected to alert supervisory or medical staff of changes in consumers' status which would have triggered alarm.
- When Noah Paul* was admitted to a general hospital for a relatively minor problem, his caretaker informed hospital staff that he needed "supervision" while eating (as he had a tendency to eat too fast). Hospital staff, however, interpreted the caretaker's report as indicating that Mr. Paul needed "assistance" with eating (i.e., his food needed to be cut up). Left alone to eat his carefully cut luncheon meal, Mr. Paul aspirated. His case study illustrates ways in which service agencies can more explicitly communicate to other pro-

*Pseudonyms

viders the special needs of their charges and monitor them.

- Interagency communication, and its vital importance in today's service delivery system which is becoming increasingly fragmented, is discussed in the case studies of Julian Webber* and Frieda Fleischman* - whose deaths by suicide were precipitated by signs of decompensation, obvious to staff of their residential programs, but not communicated to staff of their clinical programs.

To date, the Commission has published 13 case studies in its continuing series: *Could This Happen In Your Program?* Available free of charge to any interested party, the studies are used as inservice training tools in New York State programs and by facilities in more than 35 states. Libraries and colleges have also requested copies of the case studies, some of which have been reprinted in national publications.

Commission BBS

The Commission on Quality of Care Communication and Assistance Network [CQCCAN] is the Commission's electronic bulletin board system [BBS] which makes available, to the growing number of people who have computers and modems, Commission published materials or abstracts. The BBS also offers users an overview of the Commission and its purpose, "Whom-to-Call" on CQC staff, and E-mail and forum contexts for user-to-user and user-to-all communication possibilities.

518-486-7711

Recommended Settings: 8 data bits, no parity, 1 stop bit, full duplex, no software flow control – XON/XOFF=off, auto line feed off. Freeware "CQC.EXE" can be downloaded which creates full graphics software capability.

Enforcing the ADA: Court Accessibility

When President George Bush signed the historic Americans with Disabilities Act (ADA) in July 1990, it did not immediately end discrimination against persons with disabilities in the United States. What it did in fact do, was provide an enlightened national policy of offering persons with disabilities an equal opportunity to share in the many benefits of American citizenship. The ADA, in recognizing that discrimination would not be removed by fiat, provided reasonable mechanisms for the enforcement of its laudable provisions.

During the past several years, the Commission and its network of regional advocacy offices and services have assisted others in the development and implementation of many statewide and local training initiatives on the ADA and its federally-related statutes. The Protection and Advocacy for Individual Rights (PAIR) program, in particular, has been dealing with special cases relating to the implementation of the ADA [see the section on the PAIR program later in this report].

During this reporting period the Commission released the report, *Access to NYS Courts for Individuals with Disabilities*. The report was based on a survey conducted by the Commission in conjunction with the New York State Bar Association's Committee on Mental and Physical Disability, the Independent Living Centers throughout the state, with support from the Office of Court Administration.

The report describes the results of surveying the accessibility of 275 courts in 40 counties in New York State. Among the findings:

- only 8% of the courtrooms in New York State are fully accessible to people with disabilities;
- over three-fourths of the courts surveyed lacked adequate signs to indicate accessible routes;
- seventy percent of court rest rooms surveyed were inaccessible, 52% of elevators were inaccessible, and 65% of the courthouses did not have parking

spaces with access aisles permitting wheelchair entry and exit of vans;

- over 80% of the of the courts surveyed had no assistive listening systems or Telecommunication Device for the Deaf (TDD) for hearing-impaired individuals;
- most courts surveyed lacked plans or even knowledge about how to assist persons with mental illness or mental retardation; courthouse staff who are trained or knowledgeable can provide tailored assistance to accommodate the needs of persons with mental disabilities--such as making courthouse schedules flexible, providing a quiet area free of excessive stimulation, and consulting with local mental health and mental retardation agencies and crisis services.

To promote greater accessibility throughout the state's court system, the report recommended that:

- The Office of Court Administration (OCA) standardize court forms, such as small claims applications and other regularly-requested forms, in braille or large print.
- OCA and the State Association of Magistrates provide disability awareness training, including issues related to mental disabilities, at court personnel conferences. In July 1993, ADA training for judges was provided at the judicial seminars and a videotape was made of the training.

The study determined that personnel in courts of all types across the state have taken good faith steps to make many courts accessible, but significant barriers remain in providing full access by persons with less recognizable disabilities. Little difference was found among levels of courts, although town and village courts had the greatest availability.

"We are strongly committed to assuring that our courts are accessible to all individuals, including individuals with disabilities. To achieve this goal, we have implemented a comprehensive plan to be certain that the programs and services conducted by the courts are in full compliance with the ADA. The efforts of all of those who participated in this Survey will further highlight the importance of meaningful access to the courts, and we are grateful to them for this contribution."

— Chief Judge Judith S. Kaye

- Each court designate a staffer as "accessibility ombudsperson" to assist individuals with disabilities on their accommodation needs, utilizing judicial district ADA coordinators as a resource.
- Counties establish "accessibility task forces" made up of court personnel, county officials, local disability service agencies, and individuals with disabilities, to develop creative methods to ensure ADA compliance. OCA reports TDD communication with all courts is now available through the telephone relay system, and assistive listening devices are reportedly available in every court and sign interpreters are available upon request.

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Chief Judge Judith Kaye commented: "We are strongly committed to assuring that our courts are accessible to all individuals, including individuals with disabilities. To achieve this goal, we have implemented a comprehensive plan to be certain that the programs and services conducted by the courts are in full compliance with the ADA. The efforts of all of those who participated in this Survey will further highlight the importance of meaningful access to the courts, and we are grateful to them for this contribution."

Moving Towards Full Inclusion and Least Restrictive Environment

Full inclusion refers to educating children with disabilities, no matter how severe the disability, in regular classrooms with their age and grade peers, rather than in segregated environments. Full inclusion implies using support services for the children rather than moving them to segregated environments for these services. This approach guarantees a free and appropriate education in the least restrictive environment for children with disabilities, as required by the Individuals with Disabilities Education Act of 1990.

Full inclusion does work and, in many instances has worked remarkably well. There are several important keys to making it work, including a desire and commitment by all involved, proper and adequate training for all staff members, and advocacy on the part of family members and dedicated advocates.

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The Protection and Advocacy for Persons with Developmental Disabilities (PADD) program administered by the Commission has special education services as a high priority for children served by the program. Two significant court cases involving PADD office attorneys resulted in full inclusion for the students in question, while in another case a federal court order had to be invoked to implement required services. *Mavis v. Sobol and South Lewis Central School District* was a landmark case brought by the PADD office in Syracuse, Legal Services of Central New York. In the decision, Judge Mc'Curn cited extensively from recent *Oberti v. Board of Education* and *Daniel R.R. v. State Board of Education* federal court decisions. *Oberti* is described as the seminal "inclusion" case in which the

court interprets the federal Individuals with Disabilities Education Act (IDEA) concept of least restrictive environment with what the educational advocates have defined as full inclusion of special education students into the regular education classroom. Judge Mc'Curn not only stated that South Lewis must provide for an individualized education plan (IEP) which will develop a least restrictive environment, but, in addition, such a placement was owed to the child and other individuals with disabilities who have been disenfranchised from the "mainstream."

The *Mavis, Oberti* and *Daniel RR* cases set the stage for another precedent setting settlement with the City of New York Board of Education. *Somoza v. NYC Board of Education* was an Impartial Hearing in which a *pro bono* law firm affiliated with the PADD legal support unit, New York Lawyers for the Public Interest, sought full inclusion for twin girls with severe cerebral palsy. The case gained national recognition when one of the twins asked President Clinton in a public forum for school children why her sister couldn't attend class with her. The President responded that her sister should be given a chance to attend the same class. The New York City Board of Education responded favorably and moved significantly farther from what had been a dismal history of segregated special education programming. An Office of Inclusion was instituted to monitor the Somoza settlement and to provide future training for staff on inclusion techniques. The twins will be provided with motorized wheelchairs and additional services to make their classroom experience as rewarding as possible.

However, the Carmel Central School District was not as cooperative as New York City. *O'Brien v. Carmel Central School District* had to be filed because the district failed to abide by the final decision of the State Review Officer who ordered that a new IEP be developed for the plaintiff to provide for support services in a reading and math class. The Review Officer ruled that the district had erred in attempting to change the plaintiff from a full inclusion program, which she had attended from kindergarten through fifth grade, to one which would remove her from regular math and reading. The regional PADD office, Westchester/Putnam Legal Services, will go to court asking that this child, who has been in full inclusion since kindergarten, be allowed to continue in Middle School.

[These cases are more fully elaborated in the Legal Interventions section of this report below.]

Living Conditions II: Manhattan PC and Bernard Fineson DC

Approximately ten years ago, the Commission conducted systemic reviews of living conditions in New York State psychiatric and developmental centers (*A Review of Living Conditions in Nine new York State Psychiatric Centers,* May 1984; *Review of Living Conditions in New York State Developmental Centers,* May 1988). During the past year, Commission staff made unannounced visits to Manhattan PC and Bernard Fineson DC, comparing conditions to those ten years ago.

Review of Patient Living Conditions at Manhattan Psychiatric Center

In January 1994, Commission staff conducted an unannounced inspection of patient living conditions at Manhattan Psychiatric Center. Over a three day period, four Commission staff visited 14 wards. In addition to a review of environmental conditions and attention to patients' personal needs, Commission staff

Approximately ten years ago, the Commission conducted systemic reviews of living conditions in New York State psychiatric and developmental centers. During the past year, Commission staff made unannounced visits to Manhattan PC and Bernard Fineson DC, comparing conditions to those ten years ago.

reviewed the provision of programming/activities on each of the sample wards.

This fourth Commission review of patient living conditions at MPC over the past ten years found continued progress in improving some aspects of the quality of patients' lives. Most notable among the areas of improvement were:

- the availability of emergency medical equipment to all wards visited within a five minute period;
- the development of a system for issuing each patient personal clothing in a timely manner and the elimination of communal clothing;
- the provision of personal hygiene supplies and kits to almost all patients;
- ample supplies of bed linens, towels, washcloths, and bathroom supplies; and,
- improved safeguards for secure storage of patients' personal belongings.

At the same time, however, deficient conditions were found in a number of areas. Of particular concern was:

- overcrowding on the majority of wards visited, especially the Mentally Ill Chemical Abuse (MICA) Unit, which negatively impacted on the quality of life for all patients;
- widespread cockroach infestation;
- multiple plumbing problems, including problems in the supply of hot water;
- a need to provide more individualized attention to patients who demonstrated a need for additional assistance in managing their hygiene and personal clothing; and,
- a need to improve the on-ward programming for patients to counter patient inactivity.

By far the most significant negative finding was overcrowding which, with few exceptions, occurred mostly on the Intermediate Treatment Units. This problem negatively impacted on environmental conditions, attention to patients' personal needs, and the success of programs and activities. Not surprisingly, almost all Treatment Team Leaders and Chiefs of Service Commission staff spoke to during the review identified overcrowding as the most problematic issue in developing effective treatment plans for their patients. This problem was particularly problematic on the unit which houses the majority of MICA patients at MPC.

In response to these findings, MPC redirected their management efforts to deal with all the issues cited. To address overcrowding, actions taken included assigning specific staff and committees to facilitate discharges of patients ready for release and to review and revise treatment plans for patients who were about to age-in to long term care. Further, MPC recognized the particular problems within the MICA Unit and they implemented a plan to reconfigure the unit from one ward to a four ward unit to assist patients in advancing through different stages of treatment individualized to meet specific needs.

BFDC Environmental Review

On February 23-24, 1994 Commission staff conducted an unannounced site visit to Bernard Fineson Developmental Center to review environmental conditions. During the visit, Commission staff toured six units in Buildings 1, 10, and 11.

The environmental review revealed many positive findings for which staff deserve recognition:

- With few exceptions, individuals were neatly groomed, dressed appropriately in clean, properly fitted clothes, and appeared to be receiving sufficient help in personal hygiene tasks.
- Most individuals had ADL kits which were stocked with a comb, brush, deodorant, toothpaste and toothbrush, etc.
- Individuals' privacy rights appeared to be respected as indicated by the provision of privacy screens during personal hygiene routines. Client Rights' posters informed individuals of their rights and identified persons to contact if they felt the need.
- The meal routine observed in the largest dining room was well organized and satisfactorily met individuals' needs for assistance and implementation of goal plans. Dining rooms throughout the complex generally had goal plans posted to remind staff of individuals' programs. Meal menus

seemed nutritionally well-balanced, and special diets were provided as ordered. A plan provided for an alternate entree to accommodate individual food preferences.

- All individuals participate in day programs, and schedules indicated ample recreational and leisure time activities during evenings and weekends. Recreation and leisure supplies were available and accessible.
- Each unit was equipped with emergency equipment which had been properly inspected and appeared to be in good condition.
- Basic supplies of linens and towels were plentiful; no evidence of shortages was apparent.

Notwithstanding these very positive observations, there were a number of problems. Issues which were more serious or widespread are described below:

- Fire alarms on units housing individuals who are deaf or severely hearing impaired had not been adapted to accommodate their disability.
- Storage of emergency medical equipment and discontinued controlled substances in Building 10 was unsatisfactory. Emergency equipment had been stored well out of easy reach with items spread around the room rather than on a mobile cart easily transportable to an emergency scene. Also, the medication cart contained a substantial quantity of controlled substances which had been discontinued and should have been discarded.
- Individuals' personal clothing was stored in a locked clothing room rather than appropriately placed in the individuals' dressers and wardrobes. This practice appeared to be the norm for nearly all individuals in Building 11 and for most in Wing B of Building 1.
- The number and nature of environmental problems in Building 1 suggested a need for more careful monitoring of conditions. In particular, Commission staff were concerned by the condition of bathrooms, evidence of vermin and roach infestations and the presence of smears of blood permitted to remain on walls in the day room and a resident's bedroom.
- Commission staff found ADL kits on several units which either lacked any toothbrush or contained a badly worn toothbrush needing replacement.

Many of the deficiencies were corrected at the time of the visit. The Commission received a plan of correction and the remaining problems were addressed within one month. BFDC plans on closing Building #1 in the near future and relocating individuals to newly renovated units on the campus.

Insisting on Accountability in the Community: Following the Money, Following the Clients

There are specific institutional arrangements in New York State to facilitate program formulation and execution and to ensure, or attempt to ensure, accountability for the receipt and expenditure of public funds for services to its mentally disabled citizens. Needless to say, there are very great differences in the nature of these systems but all are intended to make certain that programs serve their public purpose and are administered legally and in conformity with executive and legislative intent. Thus, accountability, or the obligation to measure or assess one's acts, carries with it a duty to ensure that public monies have been spent for public purposes.

During 1993-94, the Commission has assessed the custodianship of monies and assets by various providers as well as the systems that should control the direction a program should take. By looking at problematic agencies, the Commission has been able to determine how well they have been monitored and, if not, how and why the oversight systems have failed. In those instances where problems did not appear to be isolated in nature, the Commission expanded its reviews and recommendations to include the systemic issues.

At the same time, the Commission has in place a quality assurance system to assist individuals and families on a case by case basis. Calls for assistance are addressed, and when it is determined that serious problems or deficiencies may be present, in-depth investigations are conducted.

The Commission routinely receives reports of alleged adult abuse from mental hygiene institutions and community settings. During the reporting period, 4,714 such instances were reported. Some typical cases are illustrated in the narratives below.

The Case of Community Living Alternative, Inc.: "Take the Money and Run" in Group Home Operation

Group Home Operator Takes the Money and Runs

The Commission report (*Missing Accountability: The Case of Community Living Alternative, Inc.*, June 1994) describes how funds were misappropriated through numerous withdrawals by checks payable to "cash," much of it allegedly to cover costs in areas where Community Living Alternative, Inc. (CLA) was most deficient in providing for its residents. It also describes how, despite monthly visits by a case manager for the BDSO – the local service office for OMRDD in the New York City area – and yearly certification inspections, the agency was permitted to operate a program which endangered the welfare of the residents.

The Commission investigation of CLA began after complaints by family members and staff about chronic deficiencies in food, household supplies, recreation activities and facility maintenance were validated. Later findings included consistent insufficient staffing, inadequate treatment planning, fraudulent documentation, failure to meet some residents' medical and dental needs, and a generally oppressive atmosphere in the home. CLA's executive director attributed the problems to insufficient public funding, despite reimbursement of $53,000/year per resident. Commission requests to review financial records initially were rebuffed and, on the November 6, 1992 return date of the Commission subpoenas, the executive director padlocked the doors and fled to North Carolina, leaving the 10 clients stranded at their day programs.

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Fiscal Irregularities

The Commission investigation determined that the CLA executive director, who had a criminal record, was using a false name and social security number to conceal his criminal record, and to conceal the fact that the President of the CLA "Board of Directors" was his wife. The Commission found that the board was a sham, and that this husband and wife team diverted approximately $510,000 in public funds and leased several luxury automobiles. A certified public accountant (CPA) retained by CLA to perform an independent audit filed false and misleading audit reports to the State and committed other professional misconduct.

Although OMRDD had maintained a considerable history of monitoring and regulatory presence at CLA, its efforts were neither integrated nor coordinated in a manner which would ensure detection and correction of the fraud. A 1981 audit of CLA detected the practice of checks written to "cash." Although the agency agreed to terminate the practice, there was no follow-up. From 1988 to 1992, this practice increased more than five-fold.

In 1992, CLA succeeded in a rate appeal to OMRDD for additional funds to hire more staff, although it failed to give OMRDD financial data to support the appeal. OMRDD violated its appeal processing protocol and granted the rate increase anyway, as well as a retroactive payment of $138,798 for the cost of additional staff CLA had never hired. The windfall payment of Medicaid funds subsequently was misappropriated mostly through cash payments to the former executive director. A Commission study of the rate appeals process was subsequently undertaken to determine whether the flaws which surfaced in the CLA investigation were symptoms of systemic problems in OMRDD safeguarding of public funds.

Regulatory and Monitoring Failures

OMRDD maintained both a monitoring presence in the residence by the monthly visits of the case manager from the BDSO and conducted yearly certification inspections. The case manager's failure to alert the BDSO to the significant problems in the quality of life of the residents at CLA was attributable to his poor performance and to the minimal expectations placed upon him by the BDSO. He admitted that his visits were always announced and usually coincided with a resident's quarterly review. Having missed all the environmental problems; the lack of attention to residents' personal care, medical, dental and dietary needs; the absence of activities; and the inadequate staffing, the case manager completed a checklist indicating the residence's compliance with basic care standards. In fact, over a two-year period, replies to questions on each resident's reporting form generally indicated no problem. (In the few instances where there was a problem noted, the case manager explained that he had mistakenly checked the wrong box.) Each of these checksheet reports was signed by the case manager's supervisor who also never made a visit or asked any questions.

Certification activities at CLA began to reveal significant problems in the provision of care and treatment to residents in 1989. At that point, serious programmatic deficiencies were cited repeatedly over the next several years and should have signalled that the program was in trouble. Married to the repeat deficiencies were plans of correction that promised year after year that improvements would be made, often naming the very same people that had failed to make the corrections the previous year. Reading the plans in sequence, one is struck by the minimal effort that CLA put into the plans and the apparent absence of careful consideration of the OMRDD staff member giving approval.

In addition to yearly certification visits and monthly visits by the BDSO case manager, three OMRDD employees worked second jobs at CLA. Two of these individuals admitted that they saw the lack of food and the roaches in residents' beds, but failed to report them. One individual admitted to signing attendance sheets for meetings she never attended and to not correcting

Report: State home operator skims funds

Rochester Times-Union
July 7, 1994

Leased luxury cars while clients ate canned stew

The Associated Press

ALBANY – A watchdog agency's report on a group home for the mentally retarded, where operators allegedly skimmed $510,000 in state funds, depicts state regulators as asleep at the switch.

The Commission on Quality of Care for the Mentally Disabled yesterday criticized the state Office of Mental Retardation and Developmental Disabilities for failing to spot trouble at the group home.

The operators of the Queens home, Community Living Alternative, leased luxury cars for themselves while their clients ate canned stew nightly for dinner, the report said.

"It's a scary thought that in a highly regulated system that something like this could slip through," said Clarence Sundram, commission chairman.

A spokesman for the state OMRDD called the case "extraordinarily unusual" and said steps have been taken to prevent similar situations.

Federal law enforcement authorities are looking into the case, Sundram said. Most of the state money is unaccounted for, he said.

The residence for severely retarded adults was operated by Leslie Wright, who used the alias Les White to conceal from state regulators that the chairwoman of Community Living Alternative's board of directors was his wife, Kay Wright, the commission said.

Tipped by the sister of a group home resident, the watchdog agency began an investigation in 1992 and found shoddy facilities. Toilets were leaking, and the washer, dryer and air conditioners were broken, the report said.

Frequently, one person was on duty to care for the 10 retarded residents for shifts as long as 24 hours, the commission said.

A check of food bills during a February 1992 inspection found it had been months since fresh fruit or vegetables were bought.

Auditors found that large withdrawals of state funding, payable to cash, were made ostensibly to buy food and supplies.

The Wrights repeatedly appealed to the state for more funding, even though it received $53,000 each year per resident. The state granted $138,000 in retroactive funding in 1992, despite getting no evidence the money was needed, the commission said.

Although unable to account for *much of the money*, the commission was able to tell from motor vehicle records that the Wright and his wife leased two late-model Lexus automobiles.

The Wrights fled to North Carolina with financial records on the day a commission subpoena was to take effect – padlocked the doors of the group home and leaving its residents stranded at their day programs, the commission said.

case record information she knew was inaccurate. The third staff member who held joint employment with the OMRDD and CLA (a professional hired at CLA responsible for program planning) reportedly saw no quality of life issues, but admitted to signing program plans without ensuring their accuracy or checking to be sure that they reflected needs identified in the individual's functional assessment.

Thus, it was not only the poor performance of any one of these monitoring functions (fiscal and programmatic) that allowed the egregious conditions at CLA to occur, it was also the failure of the staff performing various functions to communicate effectively and share important information.

Recommendations and Corrective Actions

The Commission report on CLA recommends statutory or regulatory changes to permit state agencies to obtain key background and criminal history information on program operators, to make CPA's liable for negligence in auditing mental hygiene facilities, and to authorize revocation of an operator's license when a program is not operated in a fiscally responsible manner.

After CLA was abruptly closed, OMRDD acted swiftly to obtain a court-ordered receivership, to locate another agency to operate the program, and to place some residents elsewhere. The Commission has made referrals to various state and federal law enforcement agencies for possible crimes, including misappropriation of medical assistance funds, use of false social security numbers, tax law violations, and possible violations of public accountancy regulations.

The OMRDD agreed to take the following corrective actions:

- improve communication and coordination between OMRDD fiscal regulatory staff and its program regulatory staff;
- tighten oversight of the rate appeal and auditing processes;
- improve the review of the character and competence of executive directors and members of boards of directors;
- improve the review of plans of correction submitted by agencies in response to OMRDD inspection deficiencies and require verification that the corrective measures have been implemented;
- define more clearly the obligations of OMRDD employees who hold a second job in an agency doing business with the OMRDD; and,
- implement improved training for case managers.

Consolidated Fiscal Report Revised

Commission investigations which found significant fiscal manipulations, misappropriation and outright thefts, invariably also found misleading or intentionally misstated certified financial reports, either in the general purpose financial statements or in the Consolidated Fiscal Report (CFR) which are submitted to the mental hygiene agencies. Due to legal technicalities and the fact that the certified public accountant (CPA) is hired by the facility itself, the CPA is not legally liable to the State for filing negligently or carelessly inaccurate reports.

Accordingly, the Commission proposed legislation which would permit the state to hold auditors liable to it for negligent acts, in the same way they would be liable to the facility that hired them. Experience has shown there has been little or no deterrent to such malpractice in accountancy and often the facility officers directly benefited from or were in complicity with the accountant, and, therefore, there would not be any incentive to seek damages from the accountant. In some cases, the facility might also have been victimized by its officers and accountants and could not be expected to make up the lost funds.

The legislation was not passed due to objection by the New York Society of Certified Public Accountants (NYSSCPA), but a task force was assembled to study the problem and to proposed solutions, including to streamline the CFR. This revised CFR will make CPA's more aware of the state's interests and the possibility that the CPA may nevertheless be held liable for inaccuracies that rise above ordinary negligence, e.g., gross negligence or intentional misstatement.

Crossing the Line from Empowerment to Neglect: The Case of Project L.I.F.E.

Failure to Obtain Offsets for Advance Payments

During the Commission's review of Project L.I.F.E., a not-for-profit agency which operated 60 co-op apartments for individuals with mental disabilities in Manhattan and the Bronx (*Crossing the Line from Empowerment to Neglect: The Case of Project L.I.F.E.*, July 1994), Commission fiscal investigators noted two practices involving duplicative funding for agency activities that warranted further study and follow up. Both of the practices allowed the agency to receive and retain funds collected from third party sources even though the State was already paying for the services through regular payments to community residence providers.

Duplicative Payments for Client Living Expenses

In the first case, Commission staff noted that OMRDD was not recovering advance payments to Project L.I.F.E. to cover client living expenses pending their receipt of supplemental security income (SSI) and other benefits. Because residents receive payments retroactive to the date of their application for benefits, the failure by OMRDD to recoup these monies resulted in windfall payments over a several year period of $300,000 for 37 of Project L.I.F.E.'s residents. In the absence of any directive from OMRDD, agency officials concluded that these monies had to be made available to residents to spend as they like or conserved in a "luxury fund." Thus, even though the State had paid for the residents' living expenses pending receipt of their checks, residents were encouraged to "spend down" these funds within six months – often on vacations and luxury items – in order to meet the resource levels required to remain on SSI.

Because this problem existed statewide and since there was no legal or regulatory barrier to prevent the State from recouping its advances, the Commission worked

A Case of Neglect?

New York Newsday
July 13, 1994

By Michael Moss
STAFF WRITER

A group that cares for the mentally disabled in 60 apartments in Manhattan and the Bronx is facing possible decertification because of impending official reports of neglect and failure to control aggressive clients.

The group, Project LIFE, has subjected its residents to summary evictions, inadequate health care and neglect even when they pose a danger to themselves and to neighbors, a watchdog state commission has found. A separate probe raises concerns about management.

The allegations are staunchly denied by Project LIFE in extensive documents and testimonials from clients' parents and board members presented to state officials. But they are likely to fuel the battle over replacing large state hospitals and shelters with group homes.

With the number of group home residents statewide increasing by 1,300 each year, nowhere is the battle more heated than on the Upper West Side, where Project LIFE has clients on Riverside Drive and 96th and 97th Street apartments.

Favorable news accounts of the group contrast sharply with the findings of the watchdog state Commission on Quality of Care for the Mentally Disabled, whose report, "Crossing the Line from Empowerment to Neglect," was obtained by New York Newsday in advance of its expected release next week.

The report alleges that one resident routinely carried a razor, another brandished a knife, and others in the various apartments exhibited acts of aggression that Project LIFE should have reported to law enforcement authorities.

Project LIFE executive director Anita Schwartz denies many of the commission findings, and says others were skewed to reflect a philosophy the group does not share.

"Our people for the most part are productive members of the community," Schwartz said yesterday. "They are minimally different from you or I. There's risk involved when you push people toward independence. But it's not neglect. It's a granting them the dignity of self-determination."

Project LIFE is also under investigation by the Quality Assurance arm of the state Office of Mental Retardation and Developmental Disabilities.

Schwartz said agency officials indicated they would seek to revoke the group's certification. "Nothing justifies this," he said.

with OMRDD on a policy which was disseminated in October 1994 that requires retroactive payments to be considered as resident income and available for the residents' living expenses for the months applicable to the retroactive payments. Implementation of this policy is expected to save the State $1 million annually.

Duplicative Case Management Payments

While at Project L.I.F.E., the Commission's fiscal investigators also found that the agency was placing one-half of all of the Medicaid receipts it received from Comprehensive Medicaid Case Management (CMCM) services into a liability account to avoid duplicating payments already provided by OMRDD for case management through the agency's community residence rate. The CMCM program which was initiated in 1989, in part to receive Medicaid reimbursement for some services to residents of OMRDD residential programs, has grown to $18.6 million by 1994. Even though a State regulation (in effect until February 28, 1993 when community residences became partially Medicaid funded) required providers to "offset" these Medicaid funds against their community residence payments, OMRDD was neither recouping these funds nor has there been any directive issued to the agency clarifying the State's plan to recoup these monies. Concerned that other providers might also have monies that should have been recouped by the State, the Commission has undertaken a study to take a closer look at the statewide implementation of the CMCM program and the related offset [see below, "Looking Ahead," p. 71].

Adult Home Initiatives and Reforms

Adult Home Reforms

During the 1994 Legislative Session several major bills were enacted to promote reforms within the adult homes industry. Many of these reforms were based on recommendations the Commission made in its previous studies of adult homes serving a predominately mentally-ill population (*Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services, and Regulation,* October 1990; *Exploiting the Vulnerable: The Case of HI-LI Manor Home for the Aged and Regulation by the NYS Department of Social Services,* May 1992). The reform initiatives addressed such issues as character and competence reviews, more responsible financial reporting requirements, required Department of Social Services audit and inspection reviews, a quality improvement program with financial incentives, establishment of an adult home oversight team within the Commission, and provision for advocacy services for residents of adult homes which serve predominantly mentally ill individuals informing and assisting them in their rights.

However, because of the State's current fiscal crisis, some of the provisions of these reform bills have not been implemented, including the establishment of an oversight team within the Commission and the protection and advocacy program for residents of adult homes.

Quality Assurance in Individual Cases of Care and Treatment

Care and Treatment Cases

The Commission's Quality Assurance Bureau (QAB) has developed a system for empowering individuals with disabilities requesting assistance. If at all possible, requestors are given advice on how to proceed with their own complaint and are then asked to try to reach some sort of resolution on their own. Commission staff were able to assist more than three-quarters of the 2,000 people who called during the reporting period in this way.

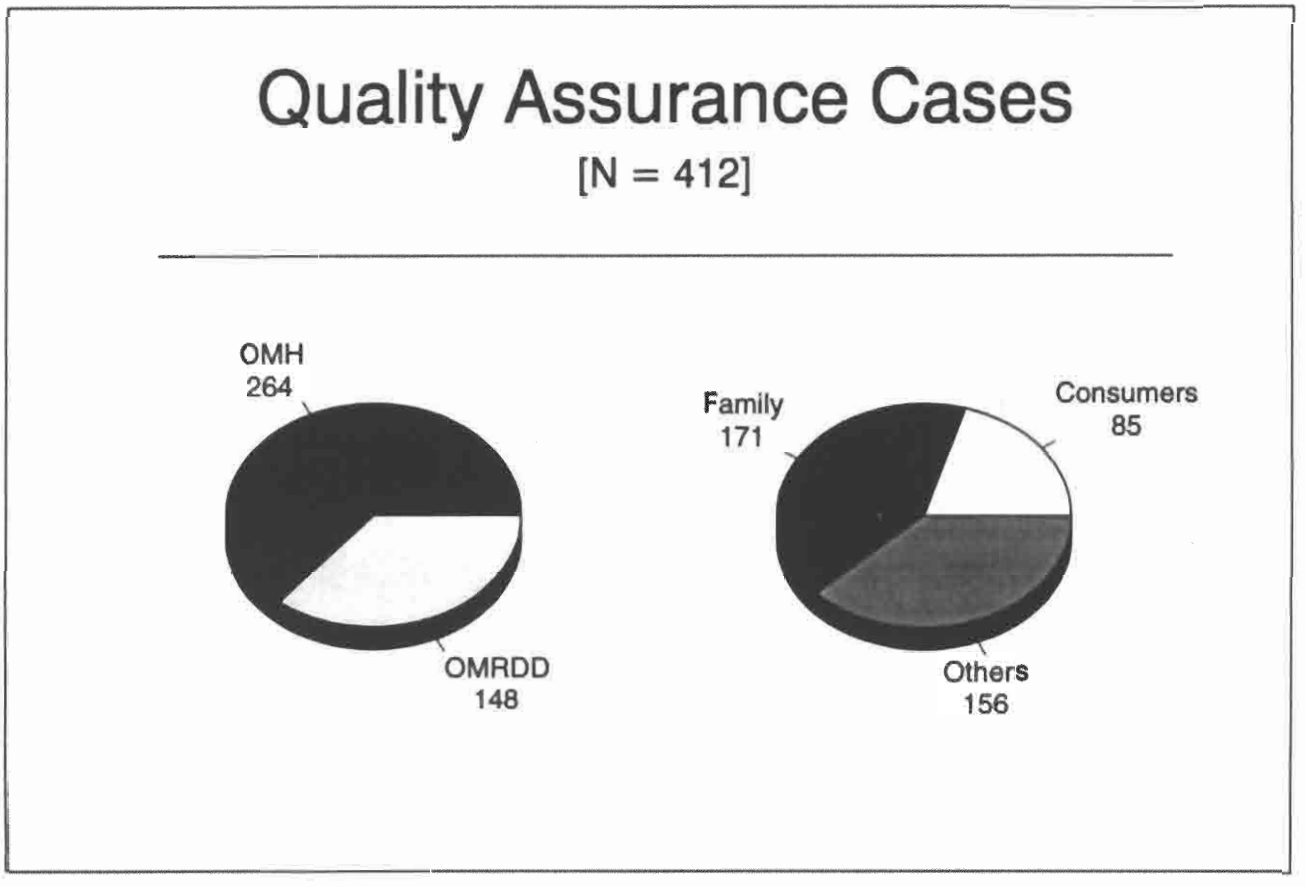
However, for a significant number of people, additional assistance from QAB staff was needed. Thus, staff opened cases for more than 400 of those calling for help. As in years past, investigations were conducted into care rendered by Office of Mental Health certified programs twice as often as in those programs certified by the Office of Mental Retardation and Developmental Disabilities. Most often the complainants were family members.

In about one-third of these cases, only advocacy on the part of QAB staff was needed. However, in-depth investigations were conducted in over 250 cases. Serious deficiencies were found in almost half of these investigations. As has been noted throughout this annual report, these deficiencies often reflect not merely isolated problems, but also systemic ones.

Living Conditions

Significant problems in living conditions were noted in several cases, and in most instances, poor living conditions were also indicative of other serious issues:

- An unannounced site visit to a Western New York OMRDD certified community residence revealed that food supplies had dwindled to a one day supply, and there was no system in place for meal planning or food purchase. Personal hygiene kits were not available and no laundry hampers had been purchased. The Commission visit also found that this residential program had developed no individual service plans, nor had they established an appropriate incident review system. Following the visit, the agency agreed to establish a system for meal planning, purchase hygiene kits, train staff in incident reporting, revise their incident reporting procedures, review staff hiring practices, and develop a Quality Assurance Committee.
- An anonymous complaint about a state-operated Individualized Residential Alternative in the Hudson Valley triggered another unannounced visit. This visit revealed a long-standing problem with hot water which at times forced staff to retrieve hot water from the washing machine to enable individuals to complete their hygiene activities. Although none of the residents used tobacco, smoke permeated the residence due to staff smoking. Finally Commission staff discovered that one individual was not allowed to attend weekly church services due to a lack of staff. At Commission staff request, the hot water problem was corrected, staff are no longer allowed to smoke in the residence, and staffing patterns were changed to enable this individual to attend church on a weekly basis.



- An unannounced visit to an OMH certified community residence in Queens revealed significant environmental difficulties. Despite the cold winter winds there was no heat, and windows were improperly installed, making them impossible to lock. The gas stove functioned improperly, creating a significant safety problem. The floor in one of the bedrooms was rough and unpolished, and its occupant frequently received slivers. In addition, there was not enough hot water for all residents to shower. Following the Commission staff visit, the agency promised to make corrections. A follow-up visit several months later revealed that the agency had corrected all of the problems.

Medical Care

Medical care was a frequent problem:

- The parents of a young man at a New York City psychiatric center complained that their son had gone blind in his left eye due to a lack of timely treatment for glaucoma. Commission investigation revealed that there had been a three month delay in obtaining an initial eye exam after a physical exam detected poor vision in his left eye. Although this exam revealed the glaucoma, there was an additional three month delay before he was seen in a specialty clinic. While this man's blindness may not have been preventable, Commission staff learned that, although his psychiatrist was aware of his condition following the initial clinic visit, he informed neither the family nor the treatment team that the patient was blind in his left eye, and in fact, falsified records shortly before the Commission visit. Following both the Commission investigation as well as that of the facility, the facility implemented plans to test a broader range of patients for glaucoma, inservice training was provided to nursing staff, an audit of medical/nursing care was conducted on this unit, and the psychiatrist, medical specialist, and nursing staff (who failed to document) were disciplined.

- The mother of a Hudson Valley developmental center resident called the Commission to complain about poor dental care for her daughter. Staff had informed the mother that her daughter had a swollen jaw and that she was being treated with antibiotics. Several weeks later, staff requested that the mother provide permission for the use of a jump suit since her daughter was stripping and scratching her face. Convinced that the cause of this misbehavior was tooth pain, the mother enlisted Commission help.

The investigation revealed that once her facial swelling was noticed, the young woman had been treated with antibiotics. However, because she was uncooperative, no dental exam was completed. In fact, her refusal to be examined was a long-standing problem. However, Commission staff also noted that no x-rays had been taken for over *seven* years! It was Commission staff finding that had the facility been more aggressive in pursuing appropriate dental care for this young woman, her eventual need for multiple extractions under general anesthesia may have been avoided.

- In response to an anonymous request, the Commission conducted an investigation into an incident in which a mid-state psychiatric center patient reportedly attempted to strangle a female therapy aide. The patient had to be physically removed from the employee and restrained and most likely suffered a fracture and dislocation of his right pelvis as well as a severe fracture of the right acetabulum (hip bone) as a result of this intervention. The complainant was concerned that this individual did not receive medical treatment until twelve days later.

It was the Commission's overall finding that, although the patient was not abused by staff, the supervision provided to him immediately prior to the assault was inadequate as was the medical care rendered him after the injury. As a result of the Commission review, several systemic changes were implemented. The physician responsible for his medial care resigned, a system designed to improve communication between nurses and physicians has been implemented, and the agency has begun to work with the local medical center to ensure more appropriate services for the psychiatric center's patients who use their emergency services.

Discharge Planning

Cases in which inappropriate discharge planning was the primary problem were also numerous during the reporting period:

- A former patient of a Western New York voluntary hospital's psychiatric unit complained that she was discharged from the hospital without medication or prescriptions, despite the fact that she had been taking several medications during her hospitalization, including the benzodiazepine, Xanax. The discharging physician did in fact discharge this woman without prescriptions or a referral to an outpatient psychiatrist. In fact, this woman was rehospitalized just four days later in acute benzodiazepine withdrawal. At the Commission's request, the hospital reviewed this psychiatrist's discharges for a six month period to ensure that this was not a routine problem.

- A father complained that his daughter was inappropriately discharged from a New York City psychiatry clinic. Historical material indicated that this woman had a history of multiple psychiatric hospitalizations, suicide attempts, an eating disorder, abuse of prescription medications, and self-injurious behaviors. Despite evidence that she was decompensating and might accidentally kill herself through drug overuse, she was abruptly terminated without appropriate referrals to alternative clinics and without the benefit of a psychiatric evaluation because she had missed six consecutive appointments over a 13-day period. In response to Commission intervention, the clinic agreed to continue to provide her services until she was accepted in another clinic. During one of these clinic visits, she was deemed to be in need of hospitalization and was admitted involuntarily to the hospital. Following Commission investigation, the clinic's discharge policy has been updated and revised to comply with Mental Hygiene Regulations.

- The daughter of a 76 year-old patient in a New York City municipal hospital called to complain that after three months of hospitalization, her father was discharged to Hawaii without proper discharge planning. Upon arrival in Hawaii, her dad was assaulted and robbed, lived on the streets, and subsequently was housed in a homeless shelter. Commission review determined that the man had resisted the treatment team's efforts to transfer him to a state hospital, refer him to a nursing home, or involve his daughter in treatment planning. He was adamant about returning to Hawaii, although all community supports previously provided to him were no longer in place. After three hearings, the court ordered him discharged and gave the hospital four days to make arrangements. However, the social work department, believing that the court order relieved them of all further responsibility, took no action to plan for his discharge, i.e. did not attempt to link him with residential outpatient services.

It was the Commission's finding that the court-ordered release of this gentleman did not relieve them of their responsibility to execute a reasonable discharge plan and that their failure to do so was in violation of both Mental Hygiene regulation and a recent Appellate Court decision (*Heard v. Cuomo*). In response to the findings, the Commission was assured that in the future all judicial discharges will be reviewed by Social Work Administration to determine the options for discharge, within the constraints, if any, imposed by the courts.

Restraint

The Commission's findings in cases involving complaints of the improper use of restraint found many violations of Mental Hygiene Law:

- A 62 year-old resident of a New York City ICF was brought to the psychiatric unit of a voluntary hospital after she psychiatrically decompensated at the residence. She presented at the hospital withdrawn and apparently suffering from auditory hallucinations. Because of her unsteady gait, the hospital restrained her almost continuously for two weeks following her admission. This woman's sister complained that since her hospitalization, her sister had become incontinent and was having much greater difficulty walking, most likely due to her prolonged inactivity. Commission staff helped work out an arrangement whereby the ICF would provide staffing for this woman while she was hospitalized, obviating the need for restraint. Additionally, the Commission review revealed that hospital staff repeatedly ignored both hospital policy and Mental Hygiene Law for the proper use of restraint. In response, several physicians and nurses were disciplined, all psychiatric department doctors were reinstructed in hospital procedures

for restraint, and a quality assurance audit was conducted.

- The parents of a 14 year-old patient on an adult psychiatric ward of a New York City voluntary hospital called to complain that, as a result of a fight with another patient, their son was restricted to his room for 23.5 hours a day with a guard at the door. Commission investigation revealed that the hospital had instituted a room restriction with one-to-one staffing for this boy, reportedly due to his aggressive and threatening behavior toward other patients. Initially, he was only allowed out of his room for three 15-minute periods a day. His behavior was reviewed every three days, and appropriate behavior was rewarded with an additional 15 minutes of "freedom." However, the behaviors which would precipitate the boy's return to his room appeared to be very minor infractions which did not appear to warrant long term restriction--laughing or talking loudly, flexing his muscles, swearing, and arguing over television stations. Additionally, Commission staff discovered the hospital had no policy to define the parameters on the use of room restrictions. At the Commission's request, the hospital has developed and implemented a policy on room restriction.

- The mother of an 18 year-old dually diagnosed young man (mental retardation and mental illness) complained about the care he received at a New York City municipal hospital. Commission review found that, upon his arrival on the psychiatric unit, this young man was restrained continuously for the first sixty hours of his hospitalization. Over the first fifteen days of his hospitalization, he was in restraint 70 percent of the time. He was often not released at two hour intervals as required by law, and physician documentation of the need for further restraint was at times quite vague. When out of restraint, this young man was commonly restricted to his room. Commission staff helped facilitate a consultation by a psychiatrist from a Developmental Disabilities Clinic which led to changes in both programming and medication. This young man's restraint was subsequently decreased by over 90%.

Cases Involving Crimes

The Commission was involved in a number of investigations in which a mentally disabled individual ran afoul of the law:

- The Commission received a report on a man who had become seriously mentally ill and, in his psychotic state, stabbed his mother several times. The police responded and took the man to a NYC municipal hospital Comprehensive Psychiatric Emergency Program (CPEP) where he was eventually admitted. This CPEP made arrangements for another forensic unit to accept this man after his arraignment. However, when the individual was released to the police, no information relative to his severe mental illness or his plan for admission to a forensic unit accompanied him to his initial court appearance. The judge ordered that the man be released in his own recognizance. The family hid his endangered mother and called the Commission for help.

  Commission staff immediately contacted the hospital and learned of a long-standing procedure which prohibited the hospital from sending any clinical information about an evaluated patient in police custody to the court. Accordingly, the hospital felt they had done nothing wrong. The Commission found this response unacceptable and impressed upon the hospital the need to take responsible action in this matter. After considerable effort by Commission staff in coordinating family and clergy contacts, the man was located on the street and voluntarily presented himself for admission.

  In response to this episode, the hospital reviewed its procedures in handling pre-arraigned individuals and is developing a plan that would allow them to send a judge a simple form letter that informs the court that the individual has been evaluated and needs hospitalization, outpatient services, or no services.

- The Commission initiated a review of the stabbing of a toddler in the head with a pen by a homeless man who had a history of mental illness and was living in a shelter in NYC. The media reported the man had eloped two months earlier from a

state hospital and had been treated and released from a psychiatric emergency room a month prior to the attack.

A review of the man's record at the state hospital revealed that he had been admitted to a municipal hospital after kicking a seven year-old girl in the genital area, expressed homicidal ideation while hospitalized, and was transferred to the state hospital because he was considered dangerous. While in the hospital he remained psychotic and received no more than limited escorted privileges. Despite his clear lack of improvement, after his escape, he was determined by hospital staff not to be dangerous, and the police were not contacted. When shelter staff contacted the hospital a month later, they were not informed that this man was potentially dangerous, nor were they asked to return him to the hospital.

The state hospital has agreed to classify any patient who leaves the hospital and does not have unescorted access to the grounds to be either a current danger or unable to care for him or herself and thus placed on escape status. This status creates a heightened obligation to search for and return the patient to the facility.

This man was brought to the psychiatric emergency room about one month prior to the attack, as he had requested voluntary admission. While in the ER, he withdrew his request for admission and asked to be released. The psychiatrist determined that he was not dangerous and so released him. When the psychiatrist did call the state hospital in an attempt to confirm the man's statement that he was LWOC from there, she was erroneously informed he was not their patient. It was the Commission's finding that the emergency room staff should have attempted to contact the shelter staff for additional historical information.

Monitoring Adult Abuse

By statute, incidents of alleged abuse of adults are routinely reported to the Commission. During the reporting period, 4,714 instances of alleged abuse were reported. Some typical cases and Commission responses are listed below.

Sexual Activity Among Individuals – Capacity to Consent

The Commission identified a series of incidents involving sexual activity among participants of an OMRDD-certified voluntary agency's day treatment program and became concerned over the agency's inadequate response to these incidents. The agency maintained a position that, absent an individual's objection to sexual activity, the activity is considered consensual, regardless of the severity one person's retardation. Additionally, the agency relied on assessments conducted by another agency in determining capacity, despite acknowledging that their opinion differed from that agency's determination. The Commission addressed these issues with the agency and received written assurance that the agency will now be implementing sexual capacity assessments which will be reviewed by the Interdisciplinary Team and update sexuality training for both participants and staff at the facility.

By statute, incidents of alleged abuse of adults are routinely reported to the Commission. During the reporting period, 4,714 instances of alleged abuse were reported.

Supervision – Staff Neglect

The Commission received a report from a state-operated ICF in the Hudson Valley Region stating that a 75 year-old, severely mentally retarded and diabetic man had been found wandering along a road near the residence, attempting to flag down passing cars. The individual was brought by ambulance to the local hospital and it was at that time staff became aware he was missing.

The facility learned through their investigation that the two staff on duty planned an outing with all eight residents and that at some point while boarding the van this individual wandered away unnoticed and was left behind. A record review revealed the possibility staff had falsified records in an attempt to obstruct the investigation. The facility recommended disciplinary action in the form of fines against the two staff persons.

Commission staff believed that the details of this case demonstrated a lack of reliability on the part of these two staff persons which warranted increased supervision of the employees – a recommendation made to the facility. The Commission also recommended that the facility consider re-assigning and splitting up these individuals as an additional safeguard for the residents of this ICF. The facility responded to the concerns and indicated that unannounced site visits by the team leader have been increased and that the schedule of the residence manager has been changed to ensure evening hours supervision of the staff. The facility also agreed with the Commission recommendation to separate the two employees and indicated they will no longer work together.

Improper Restraint

The Commission was informed of an incident at a developmental center where an individual sustained a fracture of the right humerus following a restraint episode. During an interview with the staff person who administered the restraint, he described an inappropriate technique and stated that it had been taught to him when he was first hired in 1984. Although the facility concluded that the employee had used an improper restraint, the facility found that there had been no intent to harm and so imposed a two week suspension as a penalty. The Commission's review noted that the employee had not received SCIP training since his initial hiring and recommended the facility review their records to verify that SCIP training and refresher courses have been completed by all direct care staff. The facility responded positively and noted that all employees of the cottage where the incident occurred were informed that the technique used was improper and that only currently approved techniques are to be used in the future.

Sexual Assault – ICF Resident on Home Visit

The Commission received a report from a privately operated day treatment program in New York City regarding an individual who resides in an ICF and who complained of vaginal pain upon her arrival to program. Staff of the day treatment program took her to the emergency room and called the police. An investigation by the OMRDD Office of Internal Affairs revealed that this young woman had returned from a weekend home visit to the ICF and had complained of vaginal pain, but staff did not have her medically examined. Based on a lack of evidence, the specific allegation of rape could not be substantiated.

The Incident Review Committee review included a recommendation for this young woman to be interviewed, using a list of questions prepared with the assistance of a sexuality consultant, upon her return from home visits, with specific instructions about how to proceed should any concerns arise. The Commission's review noted that the IRC failed to address the problems with the medical management of this client upon her return from the home visit. Commission staff also learned that both the developmental center and the hospital had had previous concerns regarding the inappropriate sexual attention this young woman received from her father. She was not receiving any sexuality training. The Commission made an additional recommendation that the treatment team be more aggressive in providing sexuality education and training and requested that the facility review Commission concerns regarding the delay in medical attention. The Commission also responded directly to the Office of Internal Affairs with concerns over the investigative process. Specific attention was called to the previous concerns regarding possible sexual abuse and questioned why certain pivotal interviews with members of this individual's family were not pursued.

The Commission received a surprising response from the DDSO informing us that not only would our concerns not be addressed, the treatment team had decided not to implement the recommendations of the IRC. The Commission responded by requesting that this matter be re-opened by the Special Incident Re-

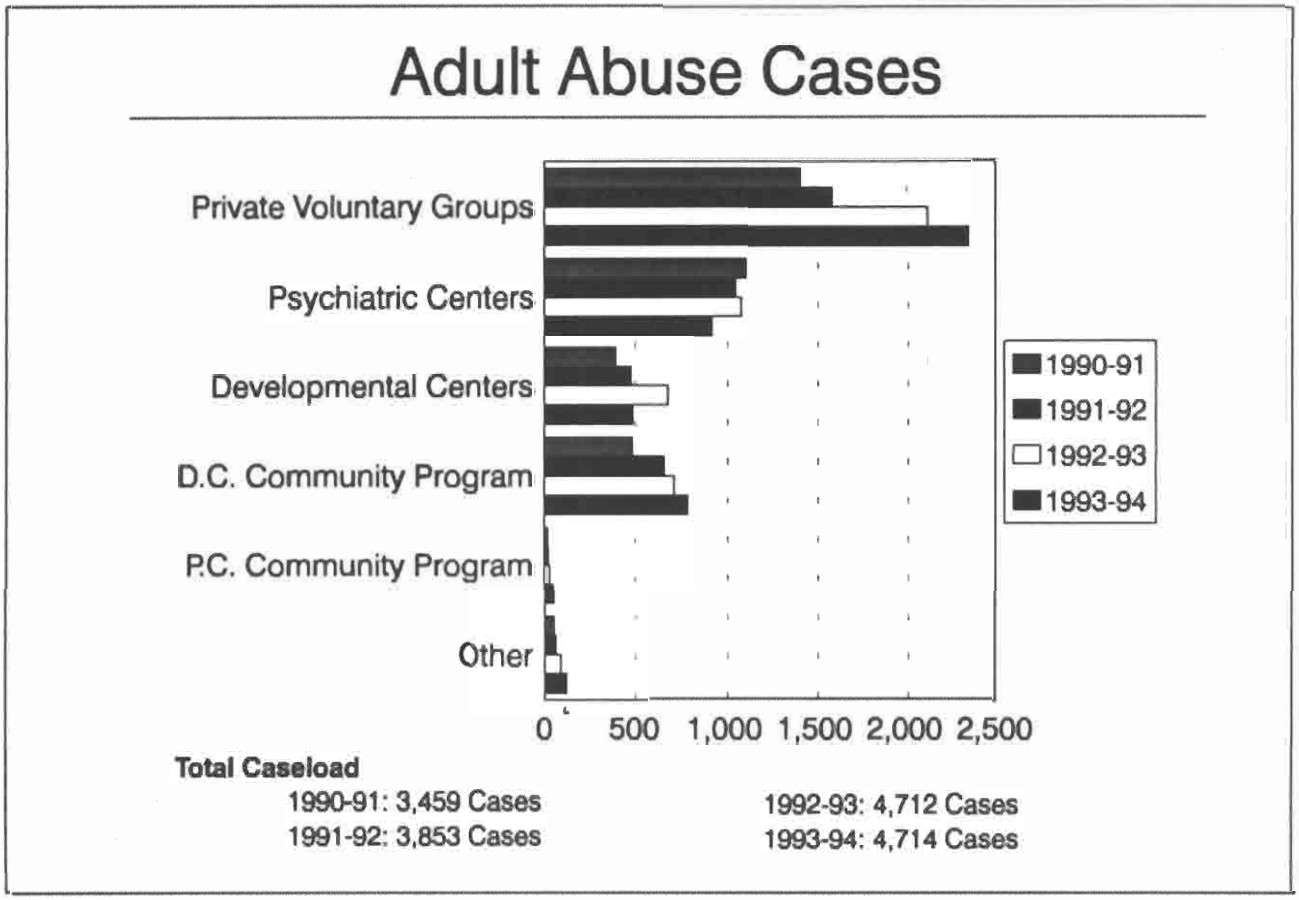
view Committee and this was done. The Commission was informed that its comments and suggestions were reconsidered and incorporated into the deliberations of this case. The Committee reviewed their recommendations with the ICF and administrative staff and formulated an action plan which implemented the IRC's recommendations. Additionally, a new policy and procedure was developed for securing medical care, with particular attention to nights, weekends and holidays.

Escape

The Commission received a report from a downstate psychiatric center that a male patient was discovered on the grounds with a broken leg, apparently caused when he attempted to escape by jumping from a second story window. During the review of this incident, the Commission discovered that this same patient had been named as the perpetrator in a sexual assault allegation filed by another patient. Although that allegation could not be substantiated, a review of this patient's clinical record revealed that he had an extensive history of sexually inappropriate behavior, including an incestuous relationship with his father, and pedophilia, which resulted in an arrest and conviction for child molestation. The Commission also learned that there had been frequent prior escapes by this patient.

The sexuality issues, particularly with respect to the frequent escapes, alerted the Commission that there may be serious problems with the care and treatment this patient was receiving. The Commission learned that the treatment team was working on returning this patient home with his father and questioned the appropriateness of this discharge. A case conference was held and recommendations were made including medication changes, attendance in a pre-vocational group, and remaining on a locked unit with all levels and passes being reviewed by the Special Release Committee.

During the follow-up, however, the Commission learned that, despite these recommendations the patient was not participating in a pre-vocational group and all levels and passes were not being reviewed by the Special Release Committee. The Commission also noted he was not receiving treatment as a sex offender



and his father was continuing to visit regularly and clinicians were continuing to hold discussions with him about the patient returning home. The Commission related the concerns to the facility and, as a result, all of the previous recommendations were implemented. Additionally, the facility secured specialized sex offender training for the patient.

Physical Abuse

The Commission received several allegations of abuse, one wherein a woman victim was noted to have multiple bruises over her body which looked like whip marks. The patient identified two employees, stating one had inflicted the marks and the other had attempted to intervene. The facility investigation substantiated the abuse and recommended discipline for the two involved employees and the patient was transferred to the Secure Care Unit of the hospital.

Following the transfer, it was noted that although she had not experienced any further abuse by staff, the patient had been the victim of a number of assaults by other patients due to her intrusive and attention seeking behavior. These serious problems were not being addressed by staff of the Secure Care Unit. There had been no amendment to her treatment plan, nor was there a behavior plan or any other interventions in place for this patient other than the increased use of seclusion and PRN medications. The treatment plan that was in place was inadequate and lacked measurable goals. The plan failed to address several chronic health problems, such as her underweight status, seizure disorder and unsteady gait. Also, despite her clinical record showing that she had been sexually and physically abused since age four, no treatment was offered in this critical area.

The Commission requested that her treatment plan be revised, and that attention be given to her extensive history of sexual abuse. The Commission received her revised plan which established measurable goals and addressed her specific clinical needs. Additionally, the patient agreed to a new course of medication and was experiencing success with it. After several months her treating psychiatrist noted she had shown significant clinical improvement, was involved in a work plan on the ward, and had gained some weight.

The Need for Vigilant Monitoring in Family Care Homes: the Case of Joan Stalker

Today, over 4,000 individuals reside in OMRDD-certified family care homes across the state, an increase of more than 20 percent during the last four years. As reductions in the populations at state institutions increase, the need grows for placements in the community which, with some support services, can approximate the everyday life of non-disabled persons. In exchange for a modest fee to the home operators, family care residents participate in family and community life and share in household responsibilities. Family care is intended to provide stable, surrogate-family living arrangements for such children and adults who are unable to live independently, but who don't need more structured care and services, and who would benefit from supervision and training in a family setting to increase their abilities and independent living skills.

The death of a 50 year-old mentally retarded woman, who lived in a Suffolk County family care home, underscores the need for proper monitoring and support from agencies which sponsor and certify individuals who undertake to serve mentally disabled persons. A Commission investigation resulted in the home's closure, and cited state and local agencies for ineffective monitoring of the home and failure to safeguard its residents while abuse allegations were under investigation. State agencies also were cited in the report for not detecting an overcrowded and illegal family care home in Suffolk County, where the deceased previously lived, and for inappropriate discharges from state psychiatric centers to the home.

Investigation Findings

The Commission, and its Mental Hygiene Medical Review Board released the report on the May 1992 death, entitled *In the Matter of Joan Stalker: A Study on the Need for Vigilant Monitoring of Family Care Homes*. The Commission investigation determined:

- autopsy findings revealed severe bruising and a raging bladder infection, suggesting abuse and neglect by the operator of the family care home where the woman died.
- despite earlier warnings of possible abuse at the home, the local sponsoring agency failed to ensure the safety of its four residents.
- state psychiatric centers improperly discharged patients to a family care home where the deceased previously lived, which was only certified for mentally retarded individuals. That home's eventual closure resulted in the deceased's move to a second home where she died. And
- the state agency responsible for oversight of Long Island family care homes allowed the first family care home to operate without detecting the grossly overcrowded conditions.

The Commission's investigation resulted in closure of this family care home by OMRDD, and OMRDD and the State Office of Mental Health (OMH) have agreed to use the report as a training vehicle for family care home-sponsoring agencies throughout the state to prevent similar tragedies. OMRDD also agreed to review its family care program operations on Long Island. The report recommended to OMH that Commission findings concerning improper discharge practices by State Psychiatric Centers to uncertified facilities be addressed, as the Commission has recommended in previous reports [*In the Matter of the Jacob Home: An Uncertified Adult Home Serving Residents with Mental Illness*, August 1991; *Life and Death at New Queen Esther Home for Adults*, June 1993; *Falling Through the Safety Net: "Community Living" in Adult Homes For Patients Discharged From Psychiatric Hospitals*, August 1993]. A recent OMH directive reminded psychiatric centers in the New York City area of their responsibility to determine that family care homes to which patients are discharged are properly licensed and in compliance with regulations, and directs them to conduct unannounced visits to ensure compliance.

The Commission report further recommended OMRDD ensure that its sponsoring agencies:

- swiftly and thoroughly investigate abuse allegations, while maintaining contact to protect home clients.

Agency Reports Abuses

The Daily Gazette
December 14, 1993

By David Bauder
The Associated Press

ALBANY – A watchdog agency's probe into the 1992 death of a 50-year-old mentally retarded woman in Suffolk County revealed Monday a series of breakdowns by agencies responsible for her care.

The woman, identified by the pseudonym Joan Stalker by the state Commission on Quality of Care for the Mentally Disabled, collapsed and died on the way to a podiatry appointment that May.

An autopsy found she had a severe bladder infection at the time of her death. There were also bruises all over her body, suggesting abuse and neglect by operators of the family care home sponsored by the Little Flower Children's Services, the commission said.

"The tragedy in tis case is not just the death. The agencies involved abdicated their responsibilities," said Gary Masline, spokesman for the watchdog agency.

Stalker was transferred out of a Long Island developmental center in 1972 and lived for several years in a family care home licensed for four mentally retarded people. The Wyandanch, N.Y. home was operated by the Evers family.

But in the mid-1990s, operators of that home began taking in psychiatric patients, the report said. Even though the home was not licensed to care for the mentally ill, 12 women were placed in the home.

"Some slept in the basement, and others in cramped, very hot bedrooms," the report said.

The commission said this situation went undetected by state officials for at least six years, despite requirements that the home be inspected. The home was shut down by the state Office of Mental Retardation and Developmental Disabilities after they were tipped off to the conditions.

Stalker was then transferred to a newly-certified family care home in Suffolk County. Seven months after the transfer, one of the mentally retarded residents reported that the home operator had slapped and pushed her to the floor, the report said.

Little Flower requested a probe by state officials of the incident, and it took four months to conclude that the home operator had injured the resident, the report said. During the interim, Stalker died.

The commission's investigation into Stalker's death was inconclusive about the cause. But it noted that the home operator gave conflicting statements about the origins of Stalker's bruises and said her explanation for not following up on Stalker's bleeding bladder "defied belief."

This second home is also no longer operating, said Ronald Byrne, spokesman for OMRDD.

- ensure regular, unannounced and comprehensive visits to homes.
- require visits to ensure that clients who are absent from their day program due to prolonged illness have their needs met. And
- advise sponsoring agencies to discuss discipline at homes with the clients.

Community Volunteer Advocacy in Group Homes: Evaluation of the Westchester County Ombudsman Program

In Chapter 50 of the Laws of 1993, the Legislature requested that the Commission conduct an evaluation of the Westchester County Ombudsman Program. The Legislature specifically asked the Commission to assess the effectiveness of the program and to comment on the desirability of its replication in other counties of the state.

The Westchester Ombudsman Program is a volunteer advocacy program for individuals with developmental disabilities living in community residences and community-based intermediate care facilities (ICF-MRs) in Westchester County. The program had been operating since June 1991 when the first group of volunteer ombudsman were trained and, as of June 1, 1994, 37 active volunteer ombudsmen were visiting 34 of the community residences and community-based ICF-MRs located in Westchester County.

The evaluation sought the opinions of the many parties involved with the Westchester program, including agency administrators and group home managers and staff, individuals residing in group homes and their families, and ombudsmen themselves. Uniformly, the different groups praised the program as valuable in promoting friendships between individual residents and ombudsmen and in bringing "fresh eyes and viewpoints" to the group homes and their services.

The evaluation found more mixed opinion of the program's usefulness in identifying quality of care problems, investigating complaints, and more generally, in asserting a "watchdog" posture, as contemplated in the program's authorizing statute (Mental Hygiene Law, Section 41.13). Group home managers and ombudsmen both remarked that ombudsmen rarely engaged in these activities, noting that ombudsmen were more likely to drop in for an informal visit, bring small gifts for birthdays, and serve as "informal" advisors for individuals who have no involved family. Ombudsmen, themselves, were quick to point out that their role was not always an easy one, but that it was a very rewarding one. Most noted that being a good ombudsmen required some time, patience, and special consideration for the feelings of group home staff who sometimes fear that the ombudsmen may be unfair critics of their daily work. Based on the comments from the agency administrators, group home staff, and individuals residing in group homes, it appeared that most ombudsmen had overcome this challenge.

What is clear is that all counties should strive to develop realistic and manageable strategies to capitalize on the wealth of volunteer resources in their communities who can contribute to their community programs in many ways, but most importantly, as community friends for individuals they serve.

The Commission concluded that there was much merit to the Westchester Ombudsman Program, but it was cautious in advocating for its replication in other counties. What is clear is that all counties should strive to develop realistic and manageable strategies to capitalize on the wealth of volunteer resources in their communities who can contribute to their community programs in many ways, but most importantly, as community friends for individuals they serve.

Watching Over the Children

The Commission continues its special role in monitoring services to children in the mental hygiene system. During the past year, this role included a study on the practices surrounding the use of psychotropic medications in the treatment of children; an analysis of children's deaths reported to the Commission during the period 1989-1993; fulfillment of its statutory role according to the Child Abuse Prevention Act of 1985, as revised in 1992, to investigate allegations of child abuse/neglect received by the State Central Register (SCR) on behalf of children in residential programs operated or certified by the Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities; a systematic review of the care and treatment of children during their acute hospitalization and discharge from psychiatric hospitalization at general hospitals; and, continuing assistance to families of infants and toddlers (from birth to age three) with disabilities in a special early intervention program.

Informed Consent: Psychotropic Meds and Minors

A fundamental protection that must be afforded every child in an inpatient psychiatric facility is the careful prescription, administration and monitoring of psychotropic medications. Conformance to prescribing standards and vigilant monitoring must be undergirded by a commitment to ensuring that children's parents are truly informed of, and consent to, the treatment to be provided to their son or daughter, especially when powerful medications are to be prescribed.

Effective October 18, 1994, an amendment to Mental Hygiene Law requires clinicians to secure the consent of a parent or guardian or the authorization of a court for the non-emergency administration of psychotropic medication to minors in public and private hospitals certified by the OMH.

A Commission study of medication practices in the treatment of children (*The Role of Psychotropic Medication in the Treatment of Children in NYS Mental Health Inpatient Settings,* November 1992) found that Office of Mental Health policy failed to provide for this important safeguard in treating children. This policy failure left the prescription of psychotropic medications without even the most rudimentary measure of accountability commonly used in hospital settings for discharge plans, reports of incidents, or monitoring of persons in restraint or seclusion.

In response to the Commission's findings, the OMH agreed to require *written informed consent* from parents/guardians for the administration of psychotropic medications to minor children in department operated facilities. This was a commendable first step, but it offered no safeguards to the children in private psychiatric hospitals, on the children's mental health units of general hospitals, or to youths in residential treatment centers. These modalities treat substantially more children each year than department facilities. While department facilities serve approximately 2,900 children and youths each year, public and private hospitals serve approximately 4,000 youngsters and residential treatment facilities serve approximately 650 children and youths. Because the children in public and private psychiatric hospitals/units are being treated for acute psychiatric symptoms and out-of-control behavior, they are particularly likely to be medicated both with standing doses and PRN/STAT administrations of medication. Clearly, *all children* in inpatient psychiatric treatment required and deserved the same protections extended to children in departmental facilities.

The Legislature agreed with the Commission's perspective and, effective October 18, 1994, an amendment to Mental Hygiene Law requires clinicians to secure the consent of a parent or guardian or the authorization of a court for the non-emergency administration of psychotropic medication to minors in public and private hospitals certified by the OMH.

The new law also accommodates those situations where seeking informed consent from the parent of a youth 16 or older would have a detrimental effect on the minor or where the parent is not reasonably available. When a parent or guardian of a youth 16 or older has refused to consent and the treating physician and a second physician who specializes in psychiatry and is not an employee of the hospital have determined that the youth has capacity and the administration of psychotropic medications is in the youth's best interest, the youth may consent on his/her own behalf.

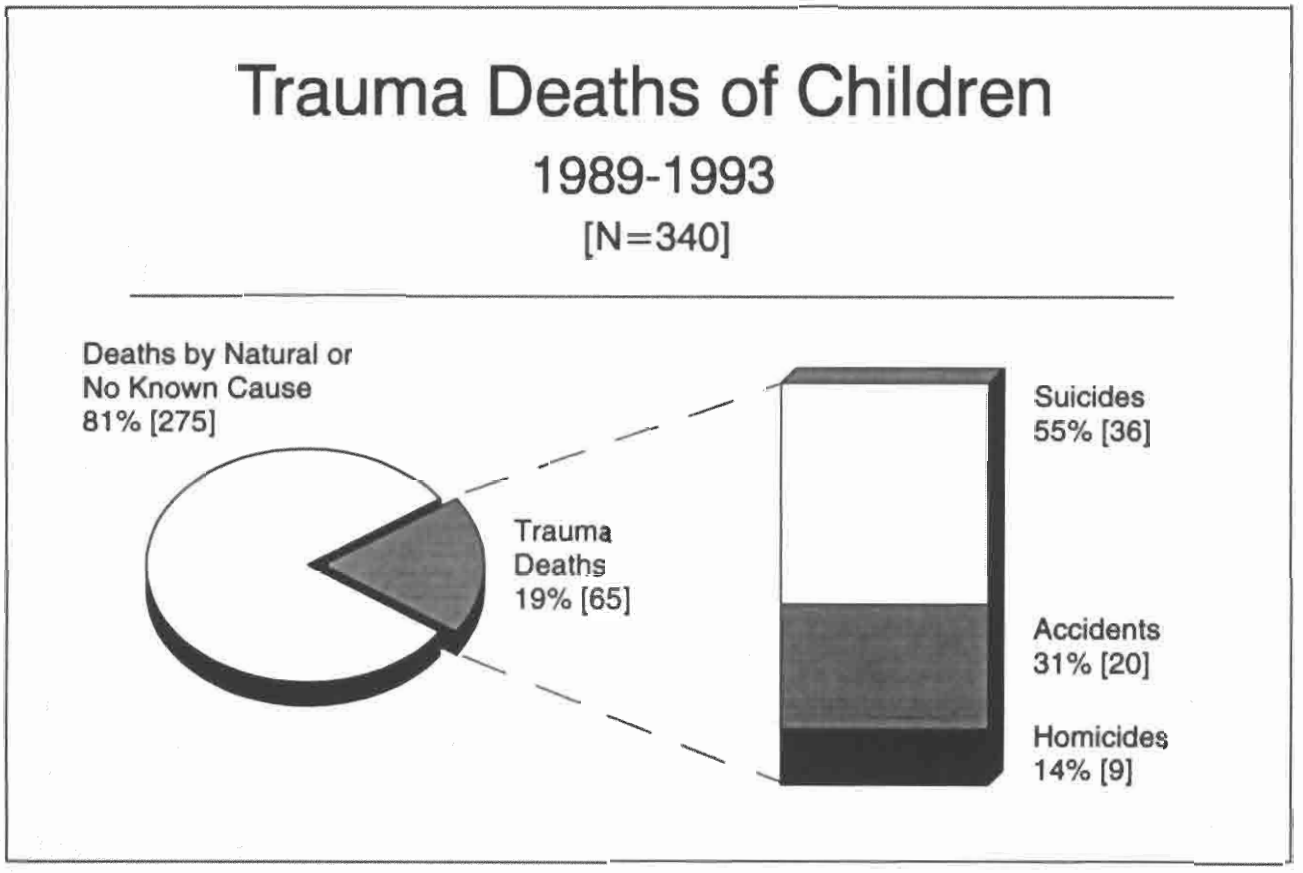
Analysis of Children's Deaths

As children grow, their ability to navigate safely through childhood depends in large part on the presence of informal and formal support systems. Children with special needs, such as children with mental disabilities, are particularly vulnerable to health risks, inadequate education, economic disadvantages, and wearied families. Besides the Commission's role of investigating allegations of child abuse and neglect emanating from residential facilities and providing significant oversight presence for children with disabilities, the Commission has a statutory obligation to investigate the unusual or unnatural deaths of children who receive services from the mental hygiene system.

In an effort to further the Commission's child protection role on behalf of children with mental disabilities, the Commission conducted an analysis of the 340 reported children's deaths that occurred during 1989-1993.

The Commission's study compared the deaths of children in mental retardation programs to those of children in mental health programs. The children in the mental retardation programs were much more likely to be young children (between the ages of one and ten), medically frail, living in an inpatient/supervised residential setting, attributed to a "natural" cause, and never the result of either suicide or homicide. However, almost one of every three deaths of children in mental health programs was attributed to either suicide or homicide.

The "trauma deaths" of children led to the further finding that one of every five children's deaths reported to the Commission during 1989-1993 were deaths as a result of accidents, suicides, and homicides.



This finding prompted the Commission to look more closely at the "trauma deaths" of children, and led to the further finding that one of every five children's deaths reported to the Commission during 1989-1993 were deaths as a result of accidents, suicides, and homicides. These children were typically adolescents (between the ages of 15 and 20), white, male, and outpatients of mental health programs.

From the investigations of children's deaths, the Commission found that often both mental retardation and mental health program staff were quick to identify "what went wrong," but the Commission has continued to stress the importance of "learning from mistakes" and establishing policies, procedures, and professional standards which empower and guide staff in their mission to protect vulnerable children. The Commission issued the following challenges to provide children safe, supportive, nurturing environments:

- **Identify Patterns and Describe the Problem**

  Many mental hygiene programs and facilities document and tabulate information about the children they serve. Thoughtful analyses of these data often reveal associations between the demographic characteristics of the children served and their clinical characteristics with various outcome measures. The ability of mental hygiene programs and facilities to identify children who are at risk of death, especially trauma-related deaths, is an important first step towards reducing this untoward outcome.

- **Recognize and Respond to Medical Emergencies**

  Children's deaths in mental retardation facilities were more frequently attributed to natural causes than children's deaths in mental health facilities. When problems were identified, however, it was most often in the area of failure to carry out treatment orders, or failure to recognize and respond to medical emergencies promptly and appropriately. Underscoring the extreme dependence and vulnerability of these children with complex health problems, these concerns reinforce the need for well-trained and ever vigilant staff carrying out their treatment regimes.

- **Reduce Trauma Deaths**

  Although all children are at risk of accidental deaths, the higher risk of children in the mental hygiene system for trauma-related deaths, especially suicide, warrants special attention. For a child whose judgment is impaired, life is in turmoil, and support systems are weak, assessments of suicide risk potential and environmental or social circumstances which may facilitate suicide may be life-saving tools.

- **Strengthen and Support Families**

  Help prepare, equip, and support families who may already be stretched to their limits, in raising children with mental disabilities.

Monitoring Children's Care/Abuse

The Child Abuse Prevention Act of 1985, revised in 1992, invested the Commission with the responsibility to investigate allegations of child abuse/neglect received by the State Central Register (SCR) on behalf of children in residential programs (except family care) operated or certified by the Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities.

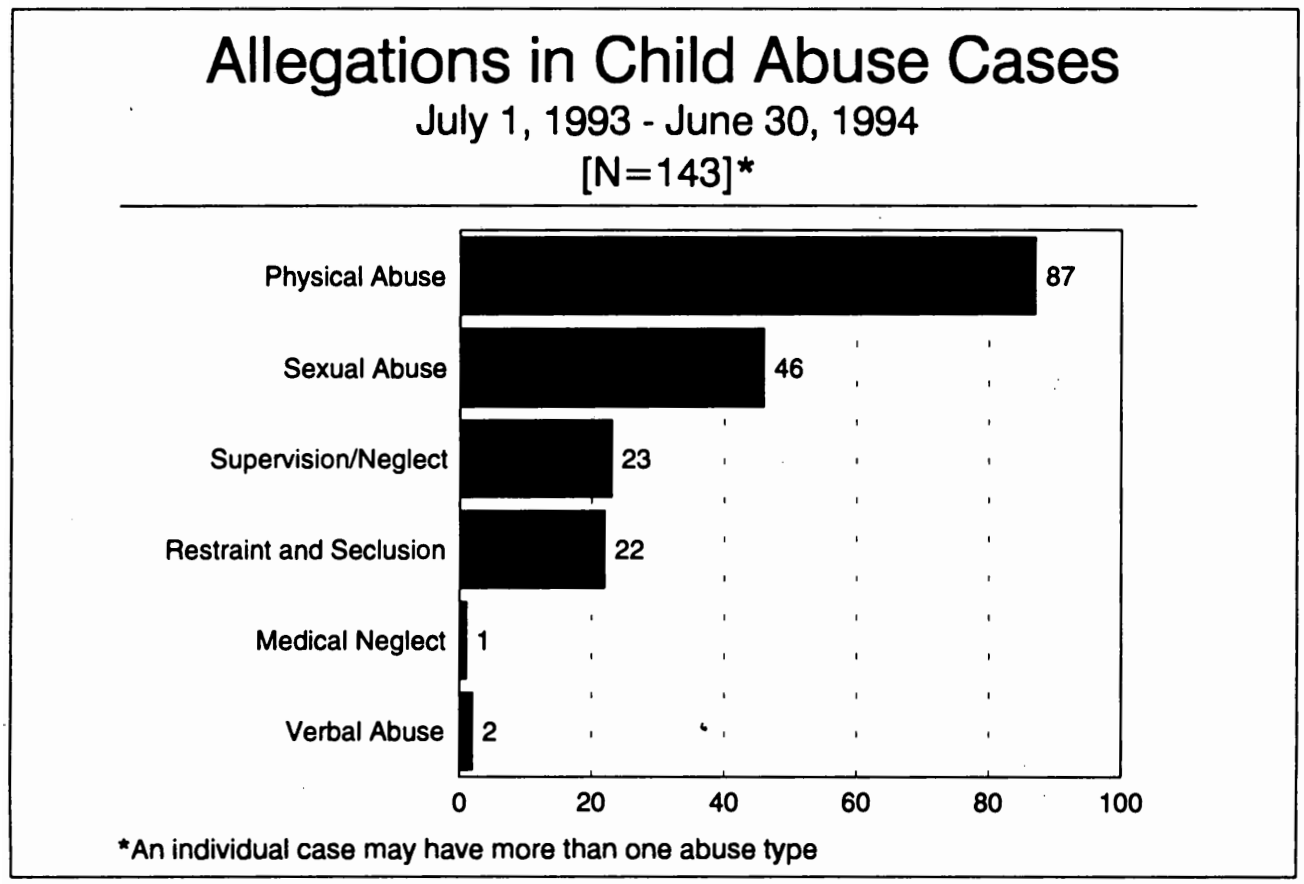
After a thorough investigation, the Commission must advise the Department of Social Services whether the cases should be indicated or unfounded. An indicated case is one where there is some credible evidence that the child has been abused or neglected (as defined in Social Services Law) by the named subject. The subject's name is placed in the State Central Register, pending due process procedures. In a case for which the Commission recommends unfounding, Commission investigation has found insufficient credible evidence that the child was abused or neglected or the abuse or neglect did not fall within the statutory definition. The Commission indicated 12% of the 128 cases it closed during the report period.

The Commission received these 143 SCR cases, most from programs operated by OMH, particularly children's psychiatric centers and residential treatment facilities. Reports from OMRDD facilities accounted for one-quarter of the cases forwarded to the Commission. Sixty percent of the total cases included an

allegation of physical abuse. In investigating these cases, Commission staff found that many were associated with physical interventions used with children allegedly displaying threatening or aggressive behavior. Thirty percent of the allegations forwarded to the Commission alleged that a staff member engaged in some kind of sexual activity with a child in care. In some of these cases, the victim clearly recognized the staff member's wrongdoing and his/her own victimization. In other instances, the child believed herself "in love" with the perpetrator or saw the activity as at least consensual and had yet to recognize the exploitation.

These cases, and many of the cases with other kinds of allegations, illustrate the multiple considerations these cases raise. The Commission makes a recommendation to the Department of Social Services (DSS) to indicate or unfound the case, but Commission staff also work with facilities to ensure that the care and treatment needs (such as sex abuse counseling) of the children are met. In addition, Commission staff use this opportunity to ensure that policies and procedures are clear and promote the safety of the children and that incidents, including the specific allegation under investigation, are properly reported, investigated and reviewed. Acting in this broad capacity, the Commission made recommendations for change in one-third (48) of the SCR cases. The case examples presented below illustrate both the kinds of allegations the Commission investigated as well as the variety of recommendations made.

- It was alleged a staff member in a children's psychiatric center left a child unsupervised and the child was later found engaged in sexual activity with another child. Both of the children were supposed to be checked every 15 minutes (they were at risk for escaping and for their sexual behaviors), and it was reported the assigned staff member did not complete these checks. The Commission investigation learned the morning incident occurred while the two staff members were left with the responsibility to supervise the 12 children because two assigned staff arrived late to work and a third called in sick. In addition, a cottage practice allowing children to sleep late and miss breakfast complicated effective supervision, as some children were in their bedrooms when others were in the dining area and bathrooms.



The Commission noted the absence of a coordinated transfer of responsibilities from specific night shift staff to day shift staff. In addition Commission staff questioned the adequacy of 15 minute observation checks to prevent the escape and involvement in sexual activity in this "unfounded" case.

In response, the facility developed a new level of supervision which requires continuous eyesight supervision but not necessarily within arms length. The facility also addressed the systemic problem of staff tardiness by initiating special audits which identify staff who are frequently late and/or absent. The facility also revised the overtime approval process to identify the name of the tardy staff member for whom coverage is needed.

- A 15 year-old patient in a private psychiatric hospital initially denied she had engaged in a sexual relationship with a mental health worker as alleged. When law enforcement authorities informed the Commission they were closing the case because of the lack of evidence and cooperation, the Commission re-entered the case and interviewed the alleged victim at the time she was beginning to realize she had been exploited. She shared information regarding the worker's residence, meetings with the worker outside the hospital, and she identified persons who could corroborate her story. The Commission investigated further and found the information was accurate and "indicated" the case. Sharing this information with the local district attorney, the case was reopened and eventually the allegation was confirmed, and the worker was arrested and charged with 3rd degree rape. He pleaded guilty and was sentenced to five years of probation.

- A 15 year-old female patient of a private psychiatric hospital alleged that a male staff member offered to allow her to leave the hospital in exchange for sex. The Commission investigation developed sufficient credible evidence to support her claim and "indicated" the case. The Commission learned that staff had failed to report prior allegations of the subject's improper fraternization and physical contact with other patients. As a result of this investigation, the hospital staff members were re-educated about their incident reporting responsibilities. Also during the investigation children in the hospital told Commission staff they were afraid to report allegations. The hospital accepted and implemented the recommendation that the patients also be trained and counseled to help them feel safe about reporting incidents.

- It was observed during an exam in a local hospital that a 16 year-old resident of a developmental center had bite marks and scratches on his back, raising questions about the adequacy of the supervision he was receiving. When the Commission's review of records and interviews of staff failed to uncover details of the injuries, dates, and responsible party, Commission staff shared extreme concern with the developmental center that severe injuries of this nature could go untreated and undocumented for an extended period of time. Commission staff found the facility policy for shift-to-shift body checks was not being implemented. Facility staff's indifferent attitude to the injuries and their failure to request medical treatment constituted neglect.

  Commission staff also found that the facility staff had failed to conduct a requested three day food intake study as the child's weight had dropped 35 pounds in two months time. Commission review also located five other residents who were losing weight and were well below their ideal weight range.

  In seeking to determine which residents had biting behaviors Commission staff learned that several identified "biters" did not have a behavior program to address their aggressive conduct.

  The Commission's investigation also uncovered significant staffing problems on the night shift where usually only two staff were covering the needs of the residents – of whom 19 of 20 receive psychotropic medication for behavioral problems. Similar serious staffing shortages were determined to occur on the weekends. The facility addressed all these concerns with a plan of corrective action but disputed our findings about the staffing levels citing their OMRDD funding level prevented placing additional staff on the units. This case was "unfounded" because the Commission could not determine when the injuries occurred, whether they were caused by staff or other residents, and which staff had failed to report them.

- As a result of multiple investigations of inappropriate physical restraints at a children's psychiatric center, the Commission found that staff were not receiving adequate retraining in physical intervention techniques and thereby "unfounded" the case. The Commission questioned the frequent practice of physically carrying children during physical escorts. Of equal concern were the comments of the children who reported they didn't feel safe when they were restrained because staff didn't care if they got hurt.

  In response to the concerns raised by the Commission, the facility acknowledged the need to substantially reduce the use of seclusion and physical restraint in the hospital. The hospital committed itself to revising its current program and developing a hospital-wide behavior modification program. In addition, the facility was planning the implementation of the"psycho-educational model," a program being implemented in some children's psychiatric centers across the state. The hospital also targeted 13 staff from the Secure Unit for extra training in restraint techniques.

- While investigating a report that child care workers at an RTF locked a child in a closed corridor and failed to remove him for an unknown period of time, the Commission investigator found the facility's policies and procedures regarding children's supervision were inadequate. The current procedures did not have specific staff assigned to observe youngsters identified as requiring special observation, nor were observation sheets required to document the supervision. Also, at shift change there was no formal transfer of responsibility for a child's supervision. In the absence of these policies, the case was "unfounded." In response, the facility revised its policies and created a new category of supervision to address the needs of children requiring special observation.

- The Commission's investigation of an inappropriate physical escort and restraint of a child on a psychiatric admitting unit in a county hospital revealed flaws in the hospital incident reporting system as an obvious abuse allegation was not reported to the State Central Register. Commission review also revealed that the hospital had *no* policy or standardized curriculum for teaching staff members proper physical intervention techniques. Finally, the Commission learned that the facility investigation effort was carelessly done and allowed the three staff involved in the restraint to collaborate on their written statements for the investigation.

  The Commission recommended that the hospital establish incident review and investigation guidelines that would establish a credible process. In response, the hospital developed policies and procedures for managing crisis situations, obtained the services of a certified instructor and scheduled a 12-hour training course for employees. In addition guidelines and procedures were established for future investigations. As in other cases, the absence of policies and inadequate staff training formed the basis for "unfounding" this case.

- The Commission investigator of an allegation of physical abuse in an RTF program observed and shared with the facility that staff were improperly implementing a behavior plan to reduce a child's 1:1 supervision. In addition, among other concerns, the Commission learned that the facility was not providing medical exams for all children injured in incidents, including instances of restraints.

  The investigation revealed that reasonable supervision was being provided and the child's injuries were sustained while playing with peers.

  The RTF responded that it instituted a policy following the Commission investigation providing for an exam of every child requiring restraint. The facility also reported that after review and revision of his program, the child in question showed a significant decrease in his incidents and he no longer required 1:1 supervision.

- The Commission investigated an allegation of neglect wherein a profoundly retarded child in an ICF for the multiply disabled sustained a second degree burn on his foot during bathing. The tub had a leaking hot water faucet, a condition known by some staff before the incident. Commission investigation learned that the facility maintenance staff had failed to correct a leak in a valve and the facility's supervisors failed to modify bathing procedures when the problem was identified. Commission staff also noted that the procedures used to address facility maintenance needs lacked ac-

countability. In sharing this case with the OMRDD, the licensing and certifying agency, the Commission noted that this serious environmental problem of having hot water lines feed directly to the bathing areas had resulted in burns to several children over the years. As a result of this "unfounded" case (lack of employee culpability), the local DDSO awarded a grant to the agency to install new plumbing to correct the problem.

- It was alleged staff left residents of a community residence unsupervised and a 17 year-old mentally retarded resident was physically and sexually abused by an adult resident. This was determined to be untrue and the case was "unfounded." The investigator identified numerous deficiencies in the quality of care and treatment provided the residents. The Commission informed the agency that a resident's treatment plans had failed to properly identify and address his extensive history of familial sexual abuse and another's significant substance abuse history. The Commission also noted that the residence staff had not followed the policies regarding search procedures when the child eloped, and the police were not notified.

  As a result of the Commission review, the local DDSO expanded the membership of the treatment teams and established a written log to insure staff concerns were addressed by the team. Special committees were established to examine the agency's service to children and human sexuality policies. Also, staff received training on incident reporting and client sexuality and plans were developed to hire more women to address gender specific issues of care and treatment.

Acute Psychiatric Hospitalization of Children with Developmental Disabilities

In another effort to monitor services to children in the mental hygiene system during the past year, the Commission looked systemically at the care and treatment, and discharge of children with developmental disabilities during their acute psychiatric hospitalization at general hospitals. Overall, the Commission found that general hospitals had a difficult time in meeting the special needs of these children, especially in managing their behavior while on the unit, and in arranging appropriate placements and services upon discharge. Hospital staff also indicated to Commission reviewers that their psychiatric units are sometimes inappropriately used as the placement of last resort for children with mental retardation.

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During the Commission's review of 10 children's and adolescents' psychiatric units at general hospitals, 14 children, out of a sample of 62 children, were identified as having mental retardation or a developmental disability. Many differences between the MR/DD children and the other children in the sample were identified. For example, the MR/DD children tended to be younger and were much more likely to have had at least one other out-of-home placement prior to their current admission (72% vs. 46%).

While the MR/DD children were less likely than the other children to have been admitted to the hospital due to behaviors related to a conduct disorder (57% vs. 77%), the MR/DD children were more likely to have been admitted for psychotic symptoms (36% vs. 19%). Nevertheless, once admitted to the hospital MR/DD children were likely to demonstrate more serious behavioral problems than other children, and less likely to evidence psychotic symptoms or suicidal behavior. For example, the MR/DD children were more likely than the other children to have currently displayed aggressive behavior (86% vs. 71%), assaultive behavior (79% vs. 60%) and inappropriate school behavior (50% vs. 39%).

As a consequence of the MR/DD children's tendency to assault or hit another child or staff member during their hospitalization, these children also tended to receive more PRN/STAT administrations of psychotropic medication, and to be restrained. Specifically, MR/DD children were more likely than the other children to receive more than 10 actual administrations of PRN/STAT psychotropic medications (57% vs. 27%) during the 30 days prior to the Commission's review. Staff more often choose to restrain MR/DD children (43% vs. 21%), while secluding the other children (0% vs. 21%). Although MR/DD children tended to be the aggressors, these children also were significantly more likely to have sustained an injury requiring first aid (36% vs. 17%).

In addition to staff heavily relying on chemical and mechanical restraints to manage the MR/DD children's behavior, review of the children's records also indicated that staff were not adept at utilizing treatment planning to address aggressive and assaultive behaviors of the MR/DD youngsters or to protect them from harm. Although most children's records of the Commission's sample contained current comprehensive assessments and referenced each child's strengths and needs, the records of the MR/DD children were significantly more likely than the other children's records in the sample, to have unreasonable or inappropriate treatment plans that did not address certain behaviors or problems, or plans that did not describe what interventions would be used to address the behaviors (50% vs. 21%). Hospital staff also had difficulty with setting up appropriate discharge placements and services for the MR/DD children in the Commission's sample. Record reviews revealed that the MR/DD children were not as likely as the other children to have a discharge plan in place (71% vs 94%), and that where there was a discharge plan, it was unreasonable given the circumstances the child and/or the child's family was in, and the lack of offered alternate choices for placement.

Hospital staff reported to Commission reviewers that children with special needs often presented for hospital admission with problems that threatened their current placements, and that hospitals often accepted these children with no viable placement options. Nevertheless, many of the children's cases studied by the Commission showed that general hospital staff did not view their role as involving active placement outreach, rather they viewed their role as managing the acute psychiatric symptoms of MR/DD children.

The lack of effectiveness of the general hospitals' placement outreach is best reflected in the fact that the MR/DD children had longer lengths of stay than the other children in the Commission's sample. Whereas more than three quarters (78%) of the children with MR/DD had been in the hospital for more than six weeks, less that half (46%) of all the other children had lengths of stay of more than six weeks.

Early Intervention for Infants and Toddlers with Disabilities

As a result of legislation passed in 1992, New York State has begun to develop and implement a statewide system to assist families of infants and toddlers (from birth to age three) with disabilities in obtaining appropriate services to enhance the development of their children and support the efforts of families in meeting the special needs of their infants and toddlers. The Commission has assisted the New York State Department of Health, which serves as the lead agency for the program, in the development of a statewide

Early Intervention Program by promoting the active involvement of families in this program. One of the initiatives undertaken by the Commission has been the production of a Family Rights booklet developed in cooperation with parents, service providers, the State's Early Intervention Coordinating Council, and the Department of Health. Under the Department of Health's regulations governing this program, each county and New York City are required to provide a copy of this booklet to families free of charge. The Commission, additionally, has taken the lead role in providing copies of this handbook in braille, upon request, and in collaboration with the Department of Health, the booklet has been translated into Spanish. This handbook is designed to help guide parents through the process and ensure that they are aware of their rights under the program.

New York State affords parents the opportunity to resolve problems through a mediation program designed to provide parents with a non-adversarial complaint process.

Although the Early Intervention Family Rights Manual is an important resource to parents, the Commission also has reached out to families to provide training sessions throughout the State to further promote the active participation of families in the Early Intervention Program. One such effort undertaken in cooperation with the American Indian Health Program of the Department of Health, is an outreach initiative developed by the Commission to provide early intervention advocacy training to Native Americans.

Under the federal law which authorizes the establishment of the Early Intervention Program, parents are to be provided with a formal impartial hearing system in order to resolve complaints. Unlike the federal law, New York State also affords parents the opportunity to resolve problems through a mediation program designed to provide parents with a non-adversarial complaint process. In order to ensure that such services are available, the Department of Health requested the Commission, in collaboration with NYS Association of Community Dispute Resolution Centers, to conduct a training program for mediators for the Early Intervention Program. The Commission was given primary responsibility for the development and conduct of the training sessions with logistical support services provided by the NYS Association of Community Dispute Resolution Centers. The training included panel members representing parents, county, early intervention officials, and early intervention service providers. Three training sessions were held in New York City, Albany and Rochester and resulted in a total of 67 mediators completing the training. In order to ensure the availability of mediation on a statewide basis, additional training sessions have been scheduled to be conducted by the Commission on Long Island and Central New York.

Protection and Advocacy in a Diverse System of Rights and Responsibilities

In 1980, Governor Hugh Carey designated the Commission on Quality of Care, which had an already established reputation as an independent "watchdog" agency over the mental hygiene system, as New York's Protection & Advocacy agency under federal law. Today, the Commission's Advocacy Services Bureau is responsible for the administration of several federal advocacy programs, each of which serves a special population of individuals with disabilities.

When Congress passed the various Protection and Advocacy programs, it was mindful that individuals with disabilities are often vulnerable to abuse and neglect and are often denied their basic civil rights. Congress did not create any new rights for individuals with mental illness, but acted to ensure that the rights of all individuals as specified in the United States Constitution, as well as each state's constitution and related laws, would be protected.

Administering a network of regional offices, the Commission has a proven history of protection and advocacy by assisting individuals with disabilities in many ways, including individual case assistance, technical assistance, and legal representation through a network of non-profit advocacy agencies.

The reports below summarize accomplishments of the programs over the past year.

Protection and Advocacy for Persons with Developmental Disabilities

More than 23,000 New York State citizens with developmental disabilities were served by the New York State Protection and Advocacy for Persons with Developmental Disabilities (PADD) program this past year. The PADD program, administered from the Commission's central office in Albany, operates through contracts with private, non-profit legal services and advocacy agencies (listed in the appendices).

The services provided by the PADD program include legal assistance and nonlegal individual advocacy and encompass a variety of educational and training programs and special efforts fostering community integration of persons with disabilities. Among these services provided during the past year were: case advocacy services to 2,026 individuals, training for 8,203 individuals, class action litigation representing approximately 3,000 persons, abuse and neglect reviews of 4,002 cases, and responses to requests for information, materials, referrals, and technical assistance services for 3,876 requests.

The following cases provide some examples of the type of activity and successes achieved in the PADD program.

Employment and Educational Assistance

The Commission's PADD legal support unit in New York City, New York Lawyers for the Public Interest (NYLPI) was able to assist a group of municipal employees without having to involve the courts. There were two problems facing a group of paraprofessionals (teacher aides) who were employed by the New York City Board of Education. First, there was no career ladder available to these individuals because their IEP (individualized education plan) special education diplomas precluded them from taking college level courses which are required by the Board of Education for employment advancement. Further, the United Federation of Teachers union was planning to lobby the Board for the creation of a separate job title with lower pay for paraprofessionals with IEP diplomas.

Combining a blend of investigation, preparation for litigation, negotiation and group organizing, the NYLPI attorney was able to convince the Board of Education to discontinue the idea for a separate job title. Then the Board offered funding to the City University of New York to set up a program of remediation to prepare the IEP graduates for college credit courses. It was clear throughout the negotiation that the requirements of the Americans with Disabilities Act (ADA) helped persuade the Board in making accommodations for individuals, who by virtue of excellent references from teachers, were "otherwise qualified" for the position.

Reasonable Accommodation for a Blind Employee

The Commission's Protection and Advocacy Program for Persons with Developmental Disabilities legal support unit for New York City, New York Lawyers for the Public Interest (NYLPI) was successful in resolving a case on behalf of a blind employee of the NYC Human Resources Administration (HRA). The young woman needed a magnifying device to read and when the HRA did not purchase it for her, she bought her own device. Subsequently, the magnifying device was broken and the young woman again asked for HRA's assistance in purchasing a new one. HRA failed to recognize that the device was a reasonable accommodation to the woman's disability under the Americans with Disabilities Act (ADA) and NYLPI had to intervene on her behalf. Through the *pro bono* assistance of a NYLPI member law firm, a settlement was reached with HRA. A $6,000 settlement was agreed upon to cover the cost of the client's out of pocket expenses and lost wages.

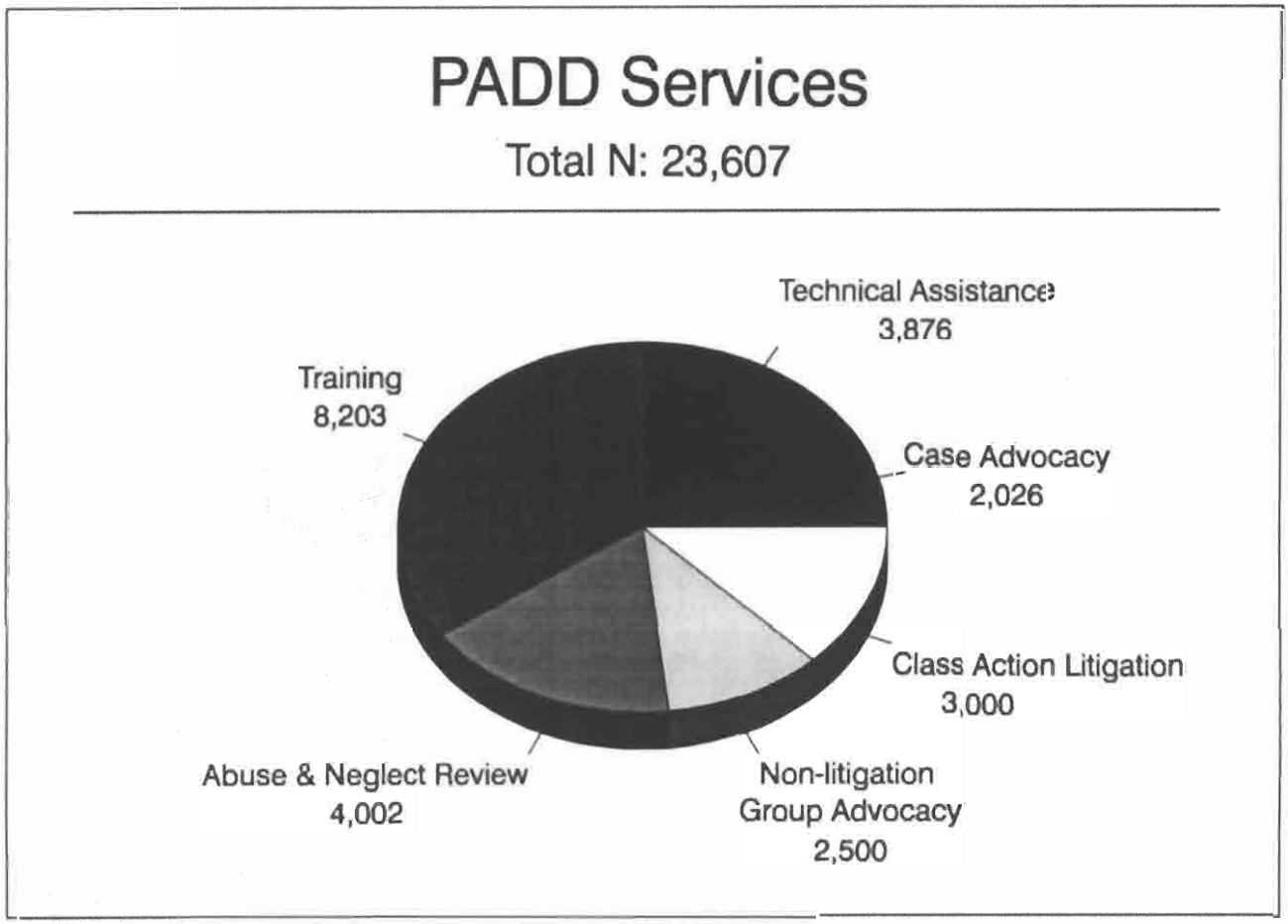
Assistance in Parochial School Setting

The Commission's new PADD contract office in White Plains, Westchester/Putnam Legal Services (WPLS) avoided a possible Church /State issue for a special

avoided a possible Church /State issue for a special education student who attends a parochial school in Port Chester, New York. At issue was a parent's claim that the Port Chester School District was providing no services to her child who is designated by the District as having special education needs. The District contended that the parent chose the parochial school of her own volition and because of the separation of Church and State under the Establishment Clause of the U.S. Constitution, the District could not provide any services onsite at the parochial school. The mother counterclaimed that her daughter could not travel, because of her disability, to either a neutral site or to the Port Chester public school building. A recent federal court decision in *Zobrest* ruled that a public school could send a sign language interpreter to the parochial school and that the individual could be in the classroom the entire day as long as the interpreter was not "signing" religious instruction. Citing *Zobrest*, the WPLS attorney entered into negotiations with the Port Chester School District attorney and together they agreed that an indirect *consultant teacher* would be assigned to the child and that this consultant would assist the parochial school teacher in preparing appropriate plans of instruction for her. As a gesture of real concern for the education of one of its students, the parochial school provided a teacher aide at the parochial school's expense. No such obligation for parochial schools exists under either state or federal law.

Housing Assistance

The Commission's Protection and Advocacy Program for Persons with Developmental Disabilities Outreach Office in Manhattan assisted the family of a child with multiple disabilities to move to adequate housing. The family was living in an apartment with no heat or plumbing and the New York City agencies responsible for finding new housing indicated that the waiting lists were very long. The family was encouraged to move in with friends or relatives which would add a further urgency to the case and hopefully would move the family up the list. However, it wasn't until the NYC Protection and Advocacy Program (NYCPADD) became involved that the family found a new home. The P&A staff brought into the case, Sinergia, a generic service



the agency administered housing complex. Then Sinergia, through case management services, assisted the family in gaining all the appropriate social services, thus assuring a healthy environment for the child.

Assisting a Homeless Ex-Offender with Developmental Disabilities

In another homeless situation, the NYCPADD helped a young man with developmental disabilities who was recently released from prison. Although his prison record indicated an IQ of 42, the State Office of Mental Retardation and Developmental Disabilities (OMRDD) was reluctant to serve him. Further, the OMRDD appeared impervious to the fact that he was living in an abandoned car because his family would not accept him home upon his release from prison. After calls to the NYC and Albany offices of the OMRDD, a place was found for the young man at the Brooklyn Developmental Center. Additionally, the man was assigned to a specially trained parole officer who has had experience in serving parolees with developmental disabilities. This case highlights a very serious problem involving the release of individuals with developmental disabilities from prison. These individuals are leaving in ever increasing numbers with no housing, employment or roots in the community. The Commission has commenced an initiative with OMRDD, the Division of Parole, and the Developmental Disabilities Planning Council to address their special needs.

Special Education Residency Issue

The Commission's Protection and Advocacy Program for Persons with Developmental Disabilities legal support unit in Buffalo, Neighborhood Legal Services (NLS) quickly resolved a special education residency issue which might have caused the discontinuance of a private residential school program for an adolescent with a dual diagnosis of mental retardation and mental illness. The case came on referral from the Council on Children and Families and at issue was the legal residence of the child's mother who was transient and homeless. The child had been a resident of the Western New York Children's Psychiatric Center and the staff had sought a more appropriate setting to deal with the child's severe self-abusive and assaultive behavior. A placement was found at the Chamberlain School in Massachusetts and tuition payment came via the North Tonawanda School District which had agreed with the recommended placement. The parent was living somewhere in the environs of North Tonawanda and although she had no fixed address, residency was accepted. However, the mother moved to somewhere within the Kenmore School District and when North Tonawanda became aware of the situation, it notified Chamberlain that North Tonawanda would no longer pay the $100,000 tuition. The NLS staff immediately contacted the Buffalo Law School which had a class action against North Tonawanda on another issue. This case was incorporated into the lawsuit and as part of the negotiations, North Tonawanda agreed to continued payment.

Right to Privacy

The Commission's Protection and Advocacy Program for Persons with Developmental Disabilities in Binghamton, Broome Legal Assistance Corporation (BLAC) resolved an interesting right to privacy case. A young adult had called into her sheltered workshop and stated that she would not be going to work that day. Instead, the woman went out shopping, where she was observed by a workshop employee. The employee followed the young woman home and then proceeded to enter the house and "inspected" every room including the refrigerator. The young woman's parents reported the incident to the BLAC attorney who researched the authority of a private agency to enter a private home. The attorney wrote a letter to the employee's supervisor and the agency's executive director indicating that the only agency having authority to investigate any suspicions of neglect or abuse was the Adult Protective Services of the Department of Social Services. The executive director apologized to the family.

Move of Special Education Students Thwarted

The Commission's Protection and Advocacy Program for Persons with Developmental Disabilities in

Plattsburg, North Country Legal Services (NCLS) thwarted a wholesale move of special education students from their Board of Cooperative Education Services (BOCES) program in Malone to the Salmon River School District. At issue was the fact that many students were going to be moved from their home school and there was no consideration for each student's individual education plan (IEP). The NCLS attorney notified the committee on special education (CSE) chairperson of the potential violation of state and federal laws. The parents were very concerned about the uprooting of their children from familiar surroundings and by the fact that the move allegedly was necessary because of a population influx in the Malone school. The special education students had to be relocated to make room for their typical education peers. To the parents and their attorney, such treatment was discriminatory and in possible violation of the Americans with Disabilities Act (ADA). As a result of PADD intervention, the students were not relocated.

Community Placement

The Commission's Protection and Advocacy Program for Persons with Developmental Disabilities (PADD) legal support unit in New York City, New York Lawyers for the Public Interest (NYLPI) negotiated the community placement of an individual with developmental disability who has a severe behavior disorder. Working with the Committee on People with Behavioral Challenges of the Commissioner's Task Force on Willowbrook, the Institute for Basic Research and the Commissioner of the Office of Mental Retardation and Developmental Disabilities (OMRDD), the NYLPI attorney was able to secure a pilot program for his client which eventually may serve eighteen other individuals with a similar disorder. Like the individuals presently represented in *John S v. Cuomo* and in the *Benjamin B v. Webb* case, this client lived in a psychiatric hospital for years because no community residence could accommodate his behavior. Such a community facility would be a desired goal for many of those class members and everyone awaits the evaluation of the pilot.

Protection and Advocacy for Individuals with Mental Illness [PAIMI]

The Protection and Advocacy for Individuals with Mental Illness (PAIMI) program in New York State is a federally funded program which provides New York State with both expanded abilities within the Commission to investigate reports of abuse and neglect of individuals with mental illness and with the availability of a statewide network of regional offices which are equipped to provide eligible individuals with an array of legal and non-legal advocacy services. Additionally, outreach, education and training, and technical assistance--as well as information and referral services—are available both from the Commission and from regional offices within the PAIMI system.

Since its inception in 1987, the PAIMI program has served approximately 80,000 persons through a combination of individual advocacy services, class action lawsuits, systemic advocacy initiatives, and education/training/outreach projects. During the past year, the PAIMI program served over 8,000 individuals, including 1,800 individuals in case advocacy, 800 persons in non-legal group advocacy services, 1,566 individuals with information and referral services, and 4,700 individuals in education and training activities. Examples of case activities and outcomes are listed here.

Lack of Sign Interpreter Addressed

New York Lawyers for the Public Interest, Inc. represented a deaf woman who sought emergency psychiatric hospitalization in a New York City public hospital and who was provided with no sign interpreter for four days, at which time an interpreter was provided *only to secure her agreement to transfer to another hospital.* The first facility apparently made no effort to use its night and weekend procedure to secure an interpreter through the hotline provided by the New York Society for the Deaf.

A complaint had been prepared, but prior to filing, the PAIMI attorney reached a settlement with the New York City Health and Hospitals Corporation (HHC), which proposed to change its policy to add meaningful alternatives to its current procedures for securing interpreters when it is unable to meet the need during nights and weekends. Another part of the agreement is that HHC will provide broad-based staff training regarding this new policy, to assure that staff are informed of alternatives.

Discriminatory Inquiries in Application for NYS Bar Exam

The Mental Disability Law Clinic at Touro College was contacted by a third year law student to complain about a question on the Character and Fitness portion of the application for admission to the Bar in New York. The questionnaire required all applicants to state whether they had received any inpatient treatment for mental health or substance abuse conditions since the age of 18.

The Law Clinic together with New York Lawyers for the Public Interest, Inc. wrote a letter to the NYS Office of Court Administration stating that the inquiries violated the Americans with Disabilities Act. The letter also requested that OCA rewrite the questionnaire in order to avoid litigation.

The Office of Court Administration has agreed to revise the questionnaire to comply with the ADA.

Transition Programming Addressed for Young Woman

North Country Legal Services, Inc. continued its tireless and consistent advocacy on behalf of a young woman who turned 18 years old this year. NCLS has assisted this client previously when she was refused Clozaril by a state psychiatric center due to her young age even after it was recommended by her treating psychiatrist. In the years since that problem was solved, she improved and was able to move to a residential treatment facility outside of her home region.

New York State PAIMI Services

Individuals Served Since 1987

Service	*Individuals Served*
Individual Case Assistance	13,000
Training and Technical Assistance	28,000
Advocacy	30,000
Information and Referral	8,500

This year, NCLS was contacted again by the young woman's guardian regarding the need to develop a local special education program. Although local school programs agreed that it was time for her to come back to her community and continue her education, no transition plan had been developed with the facility where she resided, which was several hours away. After the PAIMI program's involvement, coordination and transition planning occurred in a more orderly way and the client is now receiving services in her home community.

A lingering issue yet to be addressed for the young woman is the lack of interest or unwillingness of many local psychiatrists who accept Medicaid to prescribe her Clozaril, which she still needs to maintain her level of functioning. At the end of this reporting period, she continued to receive her medication and psychiatric monitoring from the psychiatrist at her previous residential program, which is more than 200 miles from her home.

Hill-Burton Funds Obtained to Pay Hospital Bill

Disability Advocates, Inc. assisted an individual who was unable to pay a bill from a private psychiatric hospital in the amount of $18,000. The client stated that the hospital had assured her upon her admission that insurance would cover her bill. She was unable to pay this large sum out of a weekly salary of only $200.

DAI negotiated with both the hospital and their collection agency regarding this problem. The hospital initially refused to use Hill-Burton funds to pay the bill because it claimed that the client had not cooperated by applying for Medicaid. DAI discovered that the client had indeed made an application for Medicaid, but had been denied. The hospital ultimately agreed to DAI's request to suspend collection activities and will utilize Hill-Burton funds to cover this bill. The client has no responsibility for any payment.

Client Reimbursed for Lost Property

An individual was admitted to a local community hospital in Saratoga Springs and later transferred to the Capital District Psychiatric Center. In both of these facilities, her personal property was misplaced by staff and was no longer available to her. Disability Advocates, Inc. successfully negotiated settlements with both hospitals so that their client was reimbursed appropriately for all her losses.

Community Placement Achieved for Elderly Client

Neighborhood Legal Services, Inc. assisted an elderly resident in a psychiatric unit who contacted the PAIMI program because he both needed and wanted to be placed in a supportive community placement. In order to obtain such a placement, this client needed to get to funds available in his bank accounts, but due to the fact that he had a disinterested individual acting as his Power of Attorney, this had been a problem for him and his social worker.

PAIMI assisted the client in gaining access to his funds and he has since found a placement in an adult home, which was his goal when he contacted the program.

Youth Obtained Appropriate Educational Services

Neighborhood Legal Services, Inc. developed a successful advocacy initiative related to educational services from a home school district in *Matter of K.L.* This adolescent had a history of psychiatric hospitalizations and emotional problems and was released from residential placement last spring. Prior to the residential placement, the local school's Committee on Special Education had refused to classify the child and he had not done well in school.

NLS was successful in obtaining CSE classification for the 1994-95 school year as well as the placement that K.L. desired. He was placed in a classroom for emotionally disturbed children, with a resource room placement one period per day, and was also provided with counseling services.

Access to Peer Advocate Assisted

Legal Services of Central New York, Inc. assisted an individual who had been refused the presence of a peer advocate to be present at the individual's treatment

team meeting. The PAIMI attorney advised the facility about Mental Hygiene Law 33.02 (a)(11), which provides an individual with the right to have an advocate accompany a patient to such a meeting. After the facility had been informed, it allowed the advocate to attend the meeting, as requested by the client.

It is an interesting sidelight to this individual case that the section of Mental Hygiene Law referred to was added by the Legislature within the last two years and was suggested by the Commission as a result of a recommendation by the Advisory Council to the PAIMI program.

Client Assistance Program [CAP]

The Client Assistance Program (CAP) is a federal program administered by the Commission designed to help New Yorkers with disabilities secure the rights, benefits, and programs available to them under the Federal Rehabilitation Act. The Commission and its statewide network of participating CAP agencies assists individuals with disabilities secure quality vocational and other services related to employment, education, transitioning from school to work, and self-support.

Advocacy and support services for individuals receiving State-administered vocational and related services are fundamental to the CAP mission. Through these services individuals with disabilities are aided in negotiating an often intimidating service system to achieve meaningful employment and to promote independent living.

While the Commission continues to be proud of CAP efforts for system-wide reform, individual advocacy remains the most vital aspect of CAP activity. As a result of these services, consumers are aided in negotiating service systems and in pursuing individual goals and aspirations. The network of CAP offices tirelessly advance respect for individual rights through a comprehensive understanding of vocational service systems, mediation, and advocacy. Mediation and advocacy are the primary tools CAP uses to bridge the gap between consumers and the State's service delivery system, but in some extreme circumstances litigation is also used.

In the 1993-94 report period, 1,224 individuals asked for and received individualized advocacy case services. In these cases, CAP attorneys and advocates provided an array of services to resolve disputes between consumers and federally funded vocational and related service programs. Again, CAP has been highly successful in achieving resolution of issues for consumers of services, with 96% of the cases resulting in a decision to the consumer's satisfaction.

Listed below are typical CAP case examples.

VESID Access to Technology

Mr. V. is a thirty-five year-old VESID consumer who contacted CAP when he was informed by his VESID counselor that no vocational options were available to him as a result of his multiple sclerosis (MS). CAP has experienced a pattern of resistance in the Long Island region to VESID support for individuals who experience MS.

When Mr. V. contacted CAP, he was seeking assistance with the purchase of a computer system which would enhance his prospects for home-based employment. Mr. V. successfully utilized his contacts with several small businesses to secure offers of part time home-based employment providing accounting and bookkeeping services.

Mr. V. had extensive experience and training in accounting, bookkeeping, and income tax preparation. CAP supported Mr. V. in his contention that a computer system and supplies would dramatically enhance his marketability.

Following nearly a year of negotiations with the VESID counselor and supervising counselor, Mr. V. was able to obtain the computer system and supports. Mr. V. is currently performing well in his home-based employment.

VESID Consumer Choice in Training and Placement

Mr. F. is a twenty-one year-old VESID consumer who has cerebral palsy and a learning disability. He was uncomfortable with a segregated clerical training program recommended by VESID and contacted CAP for assistance. Mr. F. expressed serious reservations about participation in the training site recommended by VESID.

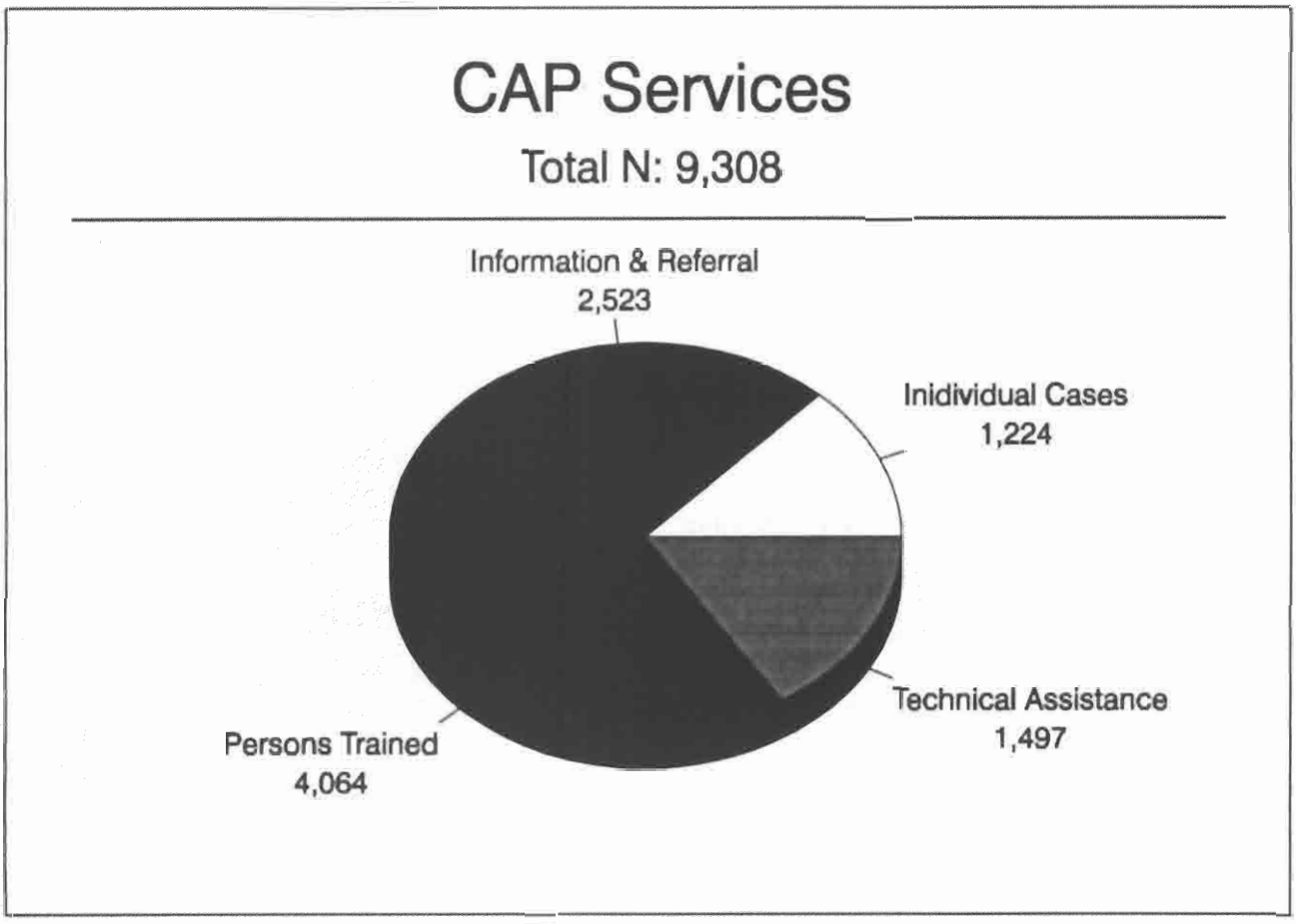
Through mediation and negotiation with the VESID counselor, CAP was successful in advancing Mr. F.'s placement in a supported employment setting. CAP was also instrumental in securing transportation services for Mr. F.

The supported employment setting was complemented with additional socialization training in the work environment. CAP also referred Mr. F. for recreational programming and assisted him in applying for the Office of Mental Retardation Developmental Disabilities Medicaid waiver program. Waiver eligibility will significantly enhance the availability of related services available to him. Mr. F. is currently on a waiting list for the Medicaid waiver program and is engaged in several ongoing recreational activities.

With support, Mr. F. pursued a Department of Labor job listing for an administrative services position at a major corporation. Mr. F. is currently employed as a clerk performing computerized mailing functions.

VESID Home-Based Employment Administrative Review

Ms. L. is a forty year-old VESID consumer who is highly skilled and has multiple sclerosis. Ms. L., who holds a Master's degree from Harvard University, was seeking CAP & VESID assistance with home-based self-employment as a psychologist and art dealer. VESID had approved a self-employment plan, but failed for some time to provide her with several services including home modifications, computer equipment, and



training. The delay and Ms. L.'s inability to engage in employment had placed the family in extreme financial difficulty.

CAP representation at an administrative review turned into a very constructive forum with VESID apologizing for the delay and attempting to assist with the family's immediate financial hardship.

The home modifications were completed, the computer purchased and, home-based computer training was arranged. Additionally, VESID immediately placed her in a civil service job as an investigator of social service cases to assist her in resolving an immediate financial crisis. CAP played a key role in initiating action, which resulted in this successful outcome.

VESID Small Business Assistance

Mr. B. is a VESID consumer who has severe asthma and initially contacted CAP for assistance in starting his own limousine business. He was told by VESID that he had to submit his plan to VESID and then to the Small Business Administration (SBA) to see if they would endorse his plan.

Mr. B. displayed a high level of frustration and anger indicating "everyone is giving him a run-around." Mr. B. indicated VESID had initially informed him that VESID self-employment funds could be utilized to defray costs associated with the purchase of a limousine. Upon further investigation VESID stated they are restricted by state law from contributing to the purchase of any vehicle. Mr. B. was so upset he would not deal with anyone in the local VESID office. He contacted the VESID district office and requested the manager serve as his counselor. A new VESID counselor was assigned and the district office manager committed to close supervision of the case.

CAP served as a mediator for Mr. B. during this period of time. Mr. B. turned to CAP with every development in his case and VESID interaction. Typically, Mr. B. was airing his ongoing dissatisfaction with VESID and related service providers.

Following nearly a year of negotiations, VESID ruled that self-employment sponsorship would be made available to Mr. B. to defray business expenses other that the vehicle purchase if he was approved for a Small Business Administration loan for which he had applied.

In that the VESID funding for self-employment is provided in the form of a state voucher, CAP was called upon to assist in negotiations between Mr. B and an insurance agent who was reluctant to accept the vouchers. Following much determination and CAP/VESID support Mr. B.'s limousine service is now thriving.

VESID Voice Recognition Computer Equipment

Mr. H. is a twenty-two year-old VESID consumer with cerebral palsy which significantly limits his fine motor coordination. Mr. H. contacted CAP for assistance in securing a voice-activated computer he contended would significantly enhance his ability to complete pre-law college studies. VESID had sponsored Mr. H. for a poorly administered technological evaluation. The evaluation was conducted in 10 minutes and utilized antiquated computer equipment. The findings of the evaluation indicated Mr. H. was not a candidate for the voice-activated technology.

CAP exposed the flaws in the administration of the original evaluation by securing a university-based speech therapist to critique and document the shortcomings of the evaluation. VESID agreed to a second technology assessment which was properly administered utilizing state of the art technology and lasting approximately two hours. Mr. H. was found to be an excellent candidate for voice-activated equipment and VESID purchased the Dragon Dictate voice recognition system. Mr. H. is presently receiving training in the use of his computer technology and is continuing with his studies.

VESID Transition from School to Adult Life

Family members originally called CAP to assist in Mr. D.'s transition from high school to adult life. Since Mr. D. is very limited physically as a result of cerebral palsy and has below average intelligence, the family feared he would be placed in day treatment and forgotten.

Mr. D. was interested in pursuing supported employment, was highly motivated, and had consistently demonstrated a positive attitude.

CAP was instrumental in assisting the family in negotiations with VESID, and they expressed concern that little progress would have been achieved without CAP's ongoing assistance.

As a result of CAP's intervention, Mr. D. and his family were connected with an array of services, including a comprehensive neuropsychological exam initially resisted by VESID, and an appropriate diagnostic vocational evaluation. Mr. D. also underwent a driving evaluation which unfortunately concluded that he is incapable of driving. A technology evaluation was undertaken and VESID committed to supplying a voice-activated computer if indicated for a job placement.

Following direct meetings with CAP, the VESID counselor, and family members, the VESID counselor ultimately listed Mr. D.'s vocational goal as supported employment, instead of sheltered employment.

CAP referred Mr. D's family to the local United Cerebral Palsy (UCP) which administers a Medicaid Waiver Program supporting a range of related services including family respite. With supported employment as a goal and as a participant in the Medicaid Waiver Program, Mr. D. has been involved in a habilitation day program at the UCP facility. Up to two or three times per week, he is also involved with specialized training, both in a separate area of the facility and in the community. Presently, he has chosen to complete his GED and enhance his independent living skills. He thinks he would like a job as a receptionist with the assistance of a voice-activated computer or to go on to college. At the moment, he is very satisfied that progress is being made and feels quite hopeful that he will reach his vocational goal.

Mr. D's services have been further complemented with his participation in self-advocacy training, summer camping, and wheelchair sports. The family is also active on the local Family Support Consumer Council.

Mr. D. and his family are confident that prospects for the future are considerably brighter then when they embarked on the transition process and know CAP remains available to assist them.

VESID Eligibility Denial Administrative Review

Mr. C. is a VESID consumer who has diabetes and is recovering from alcohol and substance abuse. He contacted CAP following a notification from VESID that he was ineligible for VESID services. Mr.C. was employed part-time and VESID had interpreted this activity as a demonstration that "no impediment to employment" exists in his case.

Mr. C was engaged in marginal employment which was inappropriate given the nature of his disabilities. He was working the midnight shift in a residence where the consumers were actively abusing drugs and alcohol. The work hours also prevented him from attending Alcoholics Anonymous meetings, which was the only form of treatment he could afford.

Mr. C. was seeking support for further schooling leading to a career as an accredited alcoholism counselor (CAC), and was anxious to leave his current working environment.

Repeated attempts on the part of CAP to negotiate a resolution to the case were met with considerable resistance on the part of the VESID personnel involved. Mr. C choose to pursue an administrative review with CAP representation and he was determined eligible for services.

In a subsequent meeting with his VESID counselor, Mr. C. was again told he was ineligible for services despite the administrative review decision. Once CAP affirmed his eligibility status, VESID questioned the appropriateness of Mr. C.'s vocational goal.

Following an extensive effort on the part of CAP and Mr. C., the VESID counselor was satisfied that Mr. C. was a viable candidate for employment in the field. Mr. C. was ultimately provided with a choice between

CAC training or college sponsorship leading to a degree in as a clinical social worker.

CBVH Access to Technology

Ms. P is a Commission for the Blind and Visually Handicapped (CBVH) consumer who stated that her extensive experiences with CBVH had been negative. Ms. P. is intent on working in the rehabilitation field and was completing a paid internship in rehabilitation teaching when she contacted CAP.

Ms. P was seeking CBVH support for adaptive technology and college sponsorship to complete her final year of undergraduate studies. Ms. P's ultimate goal is to complete a Master's degree in rehabilitation. There was disagreement over whether Ms. P's employer or CBVH was responsible for the purchase of the computer technology required for her continued studies, and she also stated that her counselor was not responsive to her needs.

Ms. P's last job was in a sheltered workshop and CAP served to assist her in demonstrating her likelihood for successful employment in rehabilitation. Negotiations with Ms. P.'s counselor resulted in a commitment that CBVH will purchase appropriate rehabilitation technology and Ms. P will be able to complete her final year of undergraduate school at Empire College in the Fall of 1994. The CBVH counselor also remains open to fuller graduate studies and sponsorship depending upon Ms. P.'s undergraduate performance in Empire college.

VESID Consumer Choice in Vocational Goal

This consumer presented with numerous issues, however, the focus of her complaint was around her VESID counselor and her evaluating physician. She felt they were forcing her into a career path she had no interest in. The consumer has a B.S. degree in electrical engineering and knows sign language. The consumer's disability however prevents her from processing verbal communication well, though she is very intelligent and does well in the math and sciences. She stated that VESID was forcing her toward a career in education: teaching the hearing impaired. The consumer stated that she pursued the engineering degree because, "she could do nothing else." She wanted to become a master gardener, has a NYS landscaping license, and works as a volunteer in a nursery.

She stated that both her VESID counselor and her physician told her that her career goals were a step backward, insisting that they knew what was good for her. The consumer also refused to follow through with mental health counseling for depression and acceptance of her disabilities.

CAP met with the consumer and the VESID counselor to discuss the issues. The consumer stated that she had difficulty expressing herself verbally, and wanted CAP support to assure that she got her point across. The consumer agreed to mental health counseling, and had her primary physician make a referral. The VESID counselor agreed to support the consumer's goal and will provide a job coach, and employment placement services when she completes her training.

The PAIR Program

The Protection and Advocacy for Individual Rights (PAIR) program is a federally-funded legal and nonlegal advocacy program supported through the Rehabilitation Act of 1992. Eligible individuals for the PAIR program are persons with disabilities not eligible for services from the Protection and Advocacy for Persons with Developmental Disabilities, the Protection and Advocacy for Persons with Mental Illness and the Client Assistance programs. Typically persons with head injuries, persons with mental illness living independently, and persons with learning disabilities are eligible for PAIR services. In New York State, this program currently serves the New York City region through a contractual arrangement with the New York Lawyers for the Public Interest and the Western New York region through a contractual arrangement with Neighborhood Legal Services.

During the past year, the New York State PAIR program served over 1,400 persons with disabilities, their families and advocates. Two hundred and seventeen

persons were provided with legal representation or intensive case advocacy services. Another 108 persons were given technical assistance in pursuing their rights while 105 persons were provided with information or an appropriate referral. Lastly, over 1,000 additional persons were trained at 33 educational sessions. Of the persons receiving intensive case advocacy services, 29 persons were ultimately provided with legal representation.

The following are examples of the legal and advocacy cases handled by PAIR staff during the past year.

Empire State Building

In an Americans with Disabilities Act (ADA) complaint case which received national attention, Helmsley-Spear (the Empire State Building's management company) and the Department of Justice reached a settlement of a complaint filed by New York Lawyers for the Public Interest, Inc.'s (NYLPI), PAIR program in January 1992. As a result of the settlement, the Empire State Building will be made accessible to people with mobility impairments. Under the terms of the settlement, Helmsley-Spear agreed to correct the problems identified in the NYLPI's complaint and to make numerous other modifications. Among the changes will be: automatic doors and curb cuts in front of the building to provide wheelchair access; elevator buttons, water fountains, and ticket counters will all be lowered; and lower periscopes will be installed on one of the observation decks.

Housing for Persons with Mobility Impairments

NYLPI's PAIR program together with the South Brooklyn Legal Services, the Legal Aid Society and the Eastern Paralyzed Veterans Association filed a class action lawsuit in federal court on behalf of public housing tenants with mobility impairments. In *Rivera v. New York City Housing* (94 Civ 4366, S.D.N.Y.) plaintiffs are challenging the failure of the New York City Housing Authority to provide enough housing accessible to people with mobility impairments and to make reasonable accommodations for people with mobility impairments already living in public housing.

Many of the plaintiffs live in inaccessible buildings with steps leading up to the entrances and down to the common areas. The elevators are too small for their wheelchairs and often break down. Their kitchens and bathrooms are too narrow for them to use. Their bathtubs and toilets lack rails and grips, and their sinks and counters are too high. As a result, these tenants depend on others to get in and out of their apartments and to cook, bathe, and use the bathroom.

Section 504 of the Rehabilitation Act required the City to make five percent of its federal public housing accessible by July 1992. This represents at least 5,000 apartments in New York City. The Housing Authority failed not only to meet the deadline but even to develop a plan for doing so. To date, it has made only 1,200 apartments accessible. Advocates for people with disabilities have met with representatives from the Housing Authority for years to no avail.

Educational Placement

Neighborhood Legal Services represented a very bright learning disabled high school student who experienced severe attendance problems. His parent sought placement in a Board of Cooperative Educational Services (BOCES) program designed specifically for students with attendance problems. The BOCES program refused to consider him, stating they would not accept students with disabilities into this program. After PAIR's intervention, the BOCES program reversed its decision and the student is doing very well in the program.

Tuberculosis and Least Restrictive Alternative

NYLPI's PAIR program, in conjunction with several other advocacy organizations, filed an *amicus* brief for the defendant in *City of New York v. Mary Doe*. The defendant in this case was detained against her will in a City hospital because she had tuberculosis. Although she was not yet contagious the City sought an order of detention because hospital officials feared that she would not take her medicine if allowed to leave.

Although the Appellate Division affirmed the order of detention, it adopted the standard urged in the *amicus*

brief: that the City may detain a person with tuberculosis only if the Health Commissioner demonstrates by clear and convincing evidence that equally effective, less restrictive alternatives to detention are unavailable or inappropriate. This standard both protects the public health and safeguards individual rights.

Hospital Bed

Neighborhood Legal Services, Inc. represented a woman with an adult onset severe disability who required a power hospital bed. At a Medicaid fair hearing appealing Medicaid's refusal to fund the bed, the hearing officer ordered a remand and, on review, the bed was obtained for her.

Public Accommodation

NYLPI's PAIR program through a participating member firm, White and Case, is seeking a public apology and a monetary settlement from a Manhattan bar for violating the rights of persons who use wheelchairs and who also have visual impairments.

In January 1994, Flo F. and a friend went to the bar to see a comedian perform. Before arriving, she and he friend called separately to confirm that the bar was wheelchair accessible. Both were informed that it was not: one was told that the bar had steps, the other that the doors were too narrow. When a friend visited the bar, however, she found out that it did not have steps and that the doors were sufficiently wide for a wheelchair to pass.

When Ms. F. and her friend arrived for the show, they asked to be seated near the front of the room so Ms. F. could see; instead, they were seated near the back. Soon afterwards a man who identified himself as the owner angrily told Ms. F. that she was a fire hazard and that wheelchairs were not allowed in the bar. He returned to berate Ms. F. several more times until she threatened to make a scene. NYLPI has been told by other callers that the pub makes a practice of discouraging wheelchair users from going there.

Public Accommodation – The Palladium

NYLPI's PAIR program has filed an ADA complaint with the U.S. Department of Justice against a prominent dance club in Manhattan, the Palladium.

The club, with many public areas inaccessible to wheelchair users, has failed to make readily achievable modifications to make it fully accessible and has discriminated in other ways against visitors with mobility impairments.

NYLPI represents a wheelchair user who attended a concert at The Palladium in July 1994. The individual called the club before he bought tickets to the concert and was assured that the club was accessible and that he and another friend, who is also a wheelchair user, would be placed at the front of the mezzanine so that they could see the stage. When they arrived at the club, the staff refused to take them to the mezzanine and instead placed them at the back of the dance floor. Surrounded by other spectators who were standing up, the two were unable to see the stage. When they asked to leave the club, several club employees told them that the only accessible entrance was backstage. Since the performer did not allow anyone backstage during the concert, the visitors were forced to stay inside. They were also told that the only accessible bathroom was backstage and closed during the performance.

An attorney from NYLPI wrote to the management of The Palladium on the client's behalf. After hearing nothing from the club for a month, NYLPI filed an administrative charge. Afterwards, the club's management offered to give the client a refund for his ticket. It did not offer, however, to make any changes in the club's architecture or employees' policies, asserting instead that the entire club was already accessible. At the client's request, NYLPI asked the management to give a tour of the club and has not withdrawn the complaint.

Court Access

NYLPI's PAIR program has begun a major effort to improve access to New York City courts for people with disabilities. These efforts follow up on the Commission's study on court accessibility (see above). Through the Freedom of Information Law NYLPI obtained surveys from the Commission that were sent to a number of state and federal courts in New York City. Every courthouse in New York City surveyed by the Commission had inaccessible features. Many had courtrooms and jury boxes inaccessible to people with mobility impairments; inadequate signs; and too few sign language interpreters, auxiliary aides, and communication devices. In fact, most had all of these deficiencies.

NYLPI has written to the clerks or chief administrators of all New York City courts to learn what improvements in access they have made, if any, since the Commission's survey was conducted. NYLPI is also reviewing evaluations and transition plans developed by agencies under the ADA to determine whether New York City courts plan to make modifications to improve access.

In Western New York, Neighborhood Legal Services is representing an adult with a disability (leg amputation) who has been unable to attend court hearings in both the city and county courthouses in Batavia, NY because they are inaccessible. The officials have refused to move the hearings to an accessible location.

Legal Interventions

Litigation remains a tool of last resort in the federal protection and advocacy programs administered by the Commission. Federal statute provides the power to use legal interventions to protect and enforce constitutional rights. Some of the litigation may involve several years of persistence before a successful conclusion is reached. The following are examples of legal actions pursued by the protection and advocacy programs.

PADD Legal Actions

Power Wheelchairs

Czelusta, Hazel, et al. v. Dowling & Chassin

The Commission's Protection and Advocacy Program for Persons with Developmental Disabilities in Buffalo, Neighborhood Legal Services (NLS) filed suit in *Czelusta, Hazel, et al. v. Dowling & Chassin* in the United States District Court in Buffalo. The suit was on behalf of several children with physical disabilities who were seeking funding through Medicaid for power wheelchairs. In each case, Medicaid had denied the approval based on the availability of another person to push the wheelchair to the child's requested destination. NLS claimed that this policy is contrary to the federal Medicaid statute's requirement that assistance be given to maximize a person's independence. Additionally, NLS claimed that the policy violates Sec. 504 of the Rehabilitation Act and the Americans with Disabilities Act. Settlement was reached for all named plaintiffs shortly after the filing of the suit. Each person received the desired equipment but the case has no precedent value. A follow-up case *Taylor v. Dowling and Chassin* has been filed as a class action lawsuit with the hope of receiving a decision which would indicate that it is never appropriate to deny Medicaid funding on the grounds that a caretaker is available to push the chair.

Precedent Setting Inclusion Victory

Mavis v. Sobol and South Lewis Central School District

After several years of litigation, the Commission's Protection and Advocacy Program for Persons with Developmental Disabilities in Syracuse, Legal Services

of Central New York (LSCNY), was successful in having the Federal Court for the Northern District agree that the South Lewis School District did not meet it's burden to show why Emily Mavis could not be provided a free and appropriate education in a regular classroom environment. In his decision in *Mavis v. Sobol and South Lewis Central School District,* Judge Mc'Curn cited extensively from the recent *Oberti v.Board of Education,* 995 F.2d 1204, 1207(3rd Circuit) and *Daniel R.R. v. State Board of Education 874 F.2d 1036 (5th Circuit 1989)* Federal Court decisions. *Oberti* is described as the seminal "inclusion" case in which the court interprets the federal Individuals with Disabilities Education Act (IDEA) concept of "least restrictive environment" with what the educational advocates have defined as full inclusion of special education students into the regular education classroom. Judge Mc'Curn ordered the South Lewis School District's committee on special education (CSE) to develop an individualized education plan (IEP) which will address Emily's particular educational needs and which is consistent with the IDEA's mainstreaming requirements. Those requirements indicate that a special education student must be afforded a free appropriate education meeting the student's individual and unique needs which is in the least restrictive environment. The first consideration for a least restrictive environment must be integration into regular education with supplementary support services. *Mavis* sets precedent for New York State and has been and will continue to be cited by a growing number of "inclusion" advocates.

Slighted Mother and Child Receive Restitution

Ranalli v. Pantazis

After lodging complaints with the Civil Rights Commission, Housing and Urban Development (HUD) and the Department of Justice, the Commission's Protection and Advocacy Program for Persons with Developmental Disabilities (PADD) at the Albany Law School finally received relief for its housing discrimination complaint filed with the United States District Court for the Northern District. In *Ranalli v. Pantazis* a mother of a child with Down's syndrome alleged that she was barred from buying a mobile home by the rental agent and owner of the mobile park, Ms. Pantazis. Further, it was alleged that Ms. Pantazis, upon noticing that the child with a developmental disability was looking at himself in one of the mobile home mirrors, demanded that he and his mother leave the premises. The federal magistrate recommended a settlement and ruled that there was a likelihood that Albany Law School would prevail. A cash settlement has been offered by the defendants and the final details of a sealed agreement are in progress.

Request that Federal Judge Enforce State Review Officer's Decision

O'Brien v. Carmel Central School District (U.S. District Court for the Southern District)

Under state and federal laws the decision of a State Review Officer (SRO) is final and binding on all parties. The only way to annul such a decision is to seek an appeal in federal court. However, when faced by an adverse SRO's decision, the Carmel Central School District chose to ignore it and continue with the individual education plan (IEP) which the SRO invalidated. The only option left to the parents, when faced with the district's blatant disregard for administrative procedure, was to seek a permanent federal court injunction with the help of the Westchester/Putnam Legal Services Corporation (WPLS), the regional PADD for the Lower Hudson Valley.

At issue was the school district's desire to change Katie O'Brien' fully inclusive education program at the point of her change to Middle School. The committee on special education (CSE) determined that Katie needed to be in a self-contained math class and a resource room for reading. The parents objected to this change and asked for an impartial hearing and then a successful administrative review to the State Review Officer. The SRO invalidated the individualized education plan (IEP) on the grounds that it violated the "least restrictive environment" requirement. Further, the SRO indicated that the school district had seriously misunderstood the legal requirement for inclusion by not properly informing itself of Katie's needs prior to developing the IEP.

The WPLS attorney will go to federal court to argue that Katie will suffer irreparable harm if not included in a regular math and reading class. What is particu-

larly vexing to Katie's parents is that she has been fully included since kindergarten and now Middle School has magically become a time when Katie must be removed from her peers.

Final Victory in Tuition Reimbursement Case

L.A. v. Sobol

The Commission's Protection and Advocacy for Persons with Developmental Disabilities (PADD) legal support unit in Buffalo, Neighborhood Legal Services (NLS) won a re-filed lawsuit in *L.A. v. Sobol.* This lawsuit had been formerly *Antkowiak v. Ambach* which was instituted in 1985 under the Education for all Handicapped Children's Act, now the Individuals with Disabilities Education Act (IDEA). At issue was the placement of a school-aged child in a school outside of New York State which was not on the state approved list. The NLS attorney had lost his federal court appeal of the case and was denied *certiorari* by the Supreme Court, thus closing out any further education law considerations. However, Section 504 of the Rehabilitation Act claims remained open to allow re-filing.

What provided impetus for the new case was a 1993 Supreme Court decision in *Florence County School District Four v. Carter.* The Court held that a parent could make a unilateral placement to a school not on the state approved list if the school district's recommended public placement violated IDEA and the private placement was proper under the Act, e.g. followed the child's individualized education plan (IEP). *L.A. v. Sobol* followed the language of *Carter* and the NLS attorney, co-counseling with a private attorney, convinced the Federal Court for the Western District to grant out-of-pocket tuition expenses incurred by the client for a two-year period.

New York City Takes a Big Step Toward Full Inclusion

Somoza v. NYC Board of Education

This case brought President Clinton to tears when Anastasia Somoza asked the President during a nationally televised White House meeting with schoolchildren, why her sister Alba who is non-verbal and quadriplegic could not be in a regular classroom with her. The President indicated that she should be given a chance to show that she could be educated in a regular classroom.

Anastasia and Alba are twins who are seriously disabled with cerebral palsy. Girded by such a Presidential endorsement, the Somozas challenged the New York City Board of Education for "dumping" Alba in a regular classroom without training the school staff in inclusion techniques and without providing the necessary support services. In fact, the family alleged that both sisters could be included in the same classroom if given the proper supports. An impartial hearing was commenced and the family was represented by a *pro bono* member firm of New York Lawyers for the Public Interest, the PADD legal support unit for New York City.

After hearing testimony from experts on inclusion, by school officials, the twin's mother and the sisters themselves, the New York City Board of Education agreed to a settlement. The settlement is considered a landmark move by the City to come into compliance with the inclusion requirements of the Individuals with Disabilities Education Act (IDEA). The Board established an Office of Inclusion which will monitor the implementation of the agreement. The settlement includes:

- motorized wheelchairs must be provided for the twins during school sessions;
- substitute health aides are to be trained on the girls' particular health needs;
- the school's staff will be trained in inclusion techniques by representatives of the Board's District Office of Inclusion and by a representative of the New York State Partnership for Statewide Systems Change;
- Alba will be given at-home training in her technology equipment for six hours a week for a minimum period of six months; and
- the girls' progress will be evaluated periodically by representatives of the District and the New York Partnership for Statewide Systems Change.

"This agreement will change the lives of our daughters," said Mrs. Mary Somoza. So too will be changed the lives of the other special education students throughout the five county New York City area.

New York City Housing Authority Fails to Meet Obligations under Sec. 504 and ADA.

Rivera et al v. New York City Housing Authority (NYCHA) and Ruben Franco as Chairperson of NYCHA

This class action lawsuit is brought on behalf of individuals with mobility impairments who reside in or have applied for housing owned and operated by the New York City Housing Authority (NYCHA). The action alleges that NYCA failed to provide the plaintiffs with accessible housing in violation of their rights under Sec. 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act. Further, the plaintiffs allege that NYCHA failed and/or refused to provide accommodations to individuals with mobility impairments when they requested them; to make a sufficient number of apartments, common use areas, and other facilities accessible; to make alterations accessible to persons with disabilities; and to offer available accessible apartments to persons with mobility impairments who reside in or have applied for NYCHA housing.

Plaintiff Sanchez cannot enter his apartment without dismantling his wheelchair. Plaintiffs, Rivera, Puerto and nine others similarly situated cannot enter one or more rooms within their apartments unassisted or without risk of hurting themselves or damaging the apartment walls. Still other plaintiffs suffer daily indignities because they cannot enter bathrooms via wheelchairs and must eliminate bodily waste into chamber pots and on paper padding. Many of these same plaintiffs and others are unable to bathe themselves because of their inaccessible bathrooms and lack of grab bars. Last, one individual must be lifted precariously by her ailing father and one other adult into the bathtub because NYCHA failed to provide a wheelchair accessible shower.

The PADD legal support unit for New York City, New York Lawyers for the Public Interest is joined by the Brooklyn Legal Services Corporation, The Legal Aid Society, and the Eastern Paralyzed Veterans Association in this lawsuit. The public interest law firms await certification of the class and a trial sometime in the new year. In addition, PADD has urged the Secretary of HUD to deny the request by the Housing Authority for further continuation of time to comply with its legal obligations.

PAIMI Legal Actions

Mentally Ill Mother Gains Custody of Her Child

Disability Advocates, Inc. assisted a mother who has a diagnosis of mental illness and a history of psychiatric hospitalizations to regain custody of her daughter. *In the Matter of Jamie C.*, DAI entered the case to represent the mother in Family Court proceedings when a local Department of Social Services sought to extend the child's residential placement, using the mother's psychiatric history as a reason to deny custody. DAI, in association with the attorney for the child, successfully negotiated a plan for increased visitation and eventual return of the child to the mother's custody. The child now resides with her mother.

Appropriate Treatment Obtained for Two Dually Diagnosed Clients

Legal Services of Central New York, Inc. filed suit in federal court, *Steven D. and Lewis C. v. Cuomo, et. al.*, on behalf of two residents of Hutchings Psychiatric Center who are deemed both mentally ill and developmentally disabled. Both plaintiffs were deteriorating physically and mentally due to lack of services, because they had been refused services both by the NYS Office of Developmental Disabilities and Mental Retardation and by the local county.

Several months after the suit was filed, the legal guardians for both the plaintiffs approved the detailed placement plans for Individualized Residential Alternatives and support services which were offered by the state defendants as part of a settlement. Each placement also provides for appropriate vocational, case management, medical, dental, and psychiatric services as well as related therapies. The settlement also provides for monitoring by the counsel for the plaintiffs (PAIMI) for a period of sixteen months to assure compliance.

Damages Awarded for Erroneous Hospitalization

A tentative settlement which includes $35,000 in damages to the plaintiff has been "so ordered" by the Dis-

trict Court. In this case, *Arnold v. Dvoskin,* the Mental Disability Law Clinic at Touro College argued that their client had been improperly confined under the State's Criminal Procedure Law.

In a previous decision, *Ritter v. Surles,* the New York Supreme Court declared Section 730.40 of the Criminal Procedure Law to be unconstitutional. In this opinion, the court declared that a psychiatric facility must either release or civilly commit a person ordered confined pursuant to this section of Criminal Procedure law. However, the NYS Office of Mental Health (OMH) neither appealed nor implemented the court's decision.

As a result of the failure of the OMH to enforce the Ritter decision, the plaintiff in this current litigation was erroneously hospitalized. Within the past year, the court ruled that because state law requires the Office of Mental Health to treat all individuals similarly situated to the plaintiffs in *Ritter* in the same manner as those plaintiffs, the decision in *Ritter* constituted clearly established law.

A Homeless Individual Assisted

New York Lawyers for the Public Interest, Inc. handled the case of *Peter P.* The client, an individual with mental illness, became homeless following a default on his property taxes and related charges of $3,000 to clean his home after a serious accident. (His home was cleaned without his consent by Adult Protective Services and he was then billed for the service.)

NYLPI represented Mr. P. at a hearing before the New York City *In Rem* Board and sought an *In Rem* agreement which would require the City to return his property and allow him to pay the property taxes on an installment plan. As a result of PAIMI involvement, the Board agreed to release Mr. P.'s property to him. NYLPI continues to represent him in developing a new payment agreement.

Independent Living Assured for PAIMI Client

Neighborhood Legal Services, Inc. represented a client who is under jurisdiction of the court pursuant to New York's Criminal Procedure Law *In the Matter of F.F.* Their client had been psychiatrically hospitalized under the Criminal Procedure Law, and several years ago he had been released to a Residential Care Center for Adults (RCCA), pursuant to an Order of Conditions.

F.F. contacted the PAIMI program because he wanted to leave the RCCA and live in an independent apartment in the community. Because of his continuing involvement with the court through the Criminal Procedure Law, he was unable to do this, despite the agreement of his treating psychiatrist. PAIMI intervened and was successful in finalizing a new order for their client, which was agreed to by both the state and the local district attorney. F.F. has now been able to move into his own apartment.

Class Actions

During the past year, the PAIMI program successfully settled one class action lawsuit and continued to monitor the progress of settlements in two other lawsuits from previous years.

An Adult Home Agrees to Pay Damages to Residents

Disability Advocates, Inc. filed a class action lawsuit in 1992, *Trautz v. Weisman,* on behalf of residents of a severely substandard adult home which housed a majority of mentally ill individuals, Weisman's Rockland Manor. During the course of the lawsuit, expert witnesses were consulted regarding the necessary repairs to the building which houses the facility and negotiations regarding resident safety and appropriate living conditions were ongoing.

A very favorable settlement was reached this year, which included payment of damages to some adult home residents as well as agreement to repair deficiencies in the home as identified by the expert witnesses. In addition to the positive outcome for these specific individual residents, the case set important legal precedents, including the judgment that a PAIMI agency may obtain "class-wide" injunctive relief when the PAIMI is a party to the litigation, and has received national attention.

Accessible Community Residences

Another class action lawsuit, *Pruitt v. Surles,* was settled in March, 1993, and the settlement continues to be

monitored. At issue in this case was the fact that community residences which are either operated or licensed by the NYS Office of Mental Health were not available for persons with physical disabilities in all regions of the state.

As a result of the settlement agreement, at least 5% of community residential beds in each region of the state will be accessible to persons with disabilities at the completion of currently planned residential bed development. Additionally, the Office of Mental Health has adopted new regulations regarding renovation and construction of community residences, as well as admission of persons about whom there are fire/safety concerns. The availability of home health care services has been expanded and made available in residences serving both adults and children.

Access to Fresh Air and Exercise Accorded Patients

New York Lawyers for the Public Interest, Inc. continued to monitor the settlement of another important class action lawsuit, *Jean D. v. Cuomo*. Settled late in 1993, *Jean D.* provided for regular access (at least one hour daily) to the outdoors and exercise or recreational opportunities for patients at Manhattan and Pilgrim Psychiatric Centers. It also required that these facilities keep records documenting their compliance with this agreement.

During this year, New York Lawyers and Mental Hygiene Legal Services have monitored the settlement and the records being kept by the two named facilities. Strong evidence developed regarding the need to train staff at both hospitals about what kind of weather should cancel this outdoor access and relatedly the need to clearly describe such weather in hospital logs.

The ultimate goal is to have the NYS Office of Mental Health use the settlement agreement in this lawsuit as a basis for a statewide policy in all psychiatric centers which acknowledges an individual's right to fresh air and recreational opportunities and establishes clear guidelines and expectations for the provision of these opportunities.

CAP Legal Actions

Employment Consistent with an Individual's Abilities

Woodford v. Gloeckler

Woodford represents an important issue in vocational rehabilitation services, challenging the notion that VESID is only required to provide services leading to entry level employment, as opposed to services consistent with an individual's abilities and leading to a meaningful career.

Neighborhood Legal Services (NLS) continues to challenge VESID's denial of graduate school sponsorship for Ms. Woodford who is pursuing a career in social work. CAP proceeded to litigation after a fair hearing decision affirmed VESID's denial of support. CAP is arguing that VESID is obligated under the Rehabilitation Act to provide services which "maximize employability" and enable individuals to pursue "meaningful careers."

In *Woodford,* CAP will attempt to demonstrate that a Master's degree in social work is a requisite to pursuing a meaningful career in the field of mental health social work. NLS will rely heavily on of *Polkabla v. CBVH,* a similar case in which the CAP program was successful and the State Appellate Division relied on the "clear language" of the Federal Rehabilitation Act and its legislative history, mandating state vocational rehabilitation agencies to "maximize employability" and to support individuals in reaching their "highest level of achievement."

Individualized Consumer Service Options

Odom V. Gloeckler

Odom raises an important dilemma in a case where the availability of individualized consumer service options are in conflict with VESID's vendor approval practices. Ms. Odom has cerebral palsy and learning disabilities which necessitate highly individualized training services. She seeks to overturn the VESID decision to deny her sponsorship at the Vocational Independence Program of the New York Institute of Technology (VIP) which Odom contends is the only pro-

gram which will assist her in becoming employable. VESID refuses to sponsor Odom because VIP is not a VESID-approved facility. VESID's vendor approval process sanctions specific services options available to all consumers of service.

New York Lawyers for the Public Interest (NYLPI) successfully represented Ms. Odom at a fair hearing where the hearing officer ruled that VIP services best meet Odom's needs. The hearing decision, however, was overturned by the VESID Commissioner. NYLPI then filed an Article 78 proceeding in Albany County. Odom argues that VESID's decision violated the Rehabilitation Act, was an error of law, was arbitrary and capricious, and violated her right to equal protection and her civil rights.

Home Modification Services

Bridger v. Gloeckler

Legal Aid Society of Mid-New York filed an Article 78 complaint in State Supreme Court in the case of *Bridger v. Gloeckler*. Ms. Bridger is an eligible VESID consumer who is quadriplegic as a result of a spinal cord injury and was denied VESID support for required home modifications. CAP will attempt to demonstrate that corrective modifications are required for Ms. Bridger to pursue her vocational goal as a clerk typist/secretary. VESID sponsored modest home modifications which were constructed poorly and resulted in a safety hazard for Ms. Bridger. In addition to calling for changes to assure Ms. Bridger's safety, CAP will also argue that the home modifications approved, were not adequate to meet her individualized needs.

The *Bridger* case highlights a number of longstanding problems CAP has experienced with VESID policies and practices governing the provision of home modification services. The case is due to be argued in the Third Department.

Out of State Independent Living Skills Training

Singer v. Gloeckler

During her first two semesters at college, it became apparent that Ms. Singer lacked the independent living skills necessary to negotiate the campus environment. Fortunately a nearby adjunct program was available and uniquely equipped to improve Ms. Singer's ability to negotiate the campus and varied activities of daily living.

Ms. Singer is a woman with cerebral palsy who was attending a Pennsylvania-based college, and living away from home for the first time.

The case challenges VESID's limits on out-of-state sponsorship. Neighborhood Legal Services (NLS) filed an Article 78 complaint in *Singer* after the VESID Deputy Commissioner ruled to deny her sponsorship for an intensive independent living skills training program based in Pennsylvania.

At the hearing level, CAP demonstrated that Ms. Singer's individual needs would be definitively addressed at the Pennsylvania-based program, and that equivalent services were not available in New York. The hearing officer concurred and ruled that the individualized service requirements, or articulated in the Rehabilitation Act, allow for the out of state sponsorship. The VESID overruling of the hearing decision and service denial was prompted by a VESID policy which limits out of state sponsorship.

An uncharacteristic delay of six months ensued before the hearing officer rendered a decision. CAP claimed that Ms. Singer's right to services had been abridged by the delay in the hearing process despite the favorable hearing decision. The VESID Deputy Commissioner overruled the decision and remanded the case back to the local VESID office to seek commensurate services within New York. Neighborhood Legal Services will argue in State Supreme Court that Ms. Singer's unique needs are best met by the Pennsylvania-based program.

CAP Fair Hearings

A fair hearing is an administrative review before an impartial hearing officer available to applicants and/or consumers of vocational rehabilitation services. CAP consumer representation at fair hearings remained high during the reporting period. Prior to seeking a fair hearing, concerted efforts are undertaken to resolve

consumer complaints through mediation and negotiation. The following are examples of CAP fair hearing cases during this report period.

VESID Assistive Technology

Long Island CAP provided representation at a fair hearing for Ms. T., a 51 year-old VESID consumer seeking assistance with the purchase of a power wheelchair which she required for an array of homemaker tasks and medical requirements. Ms. T.'s access to this technology would enable her to pursue her homemaker goal without the ongoing need and cost of home health care/personal assistance services.

The Permobil is a state-of-the-art wheelchair with a number of features critical for Ms. T. to accomplish her daily activities, maintain stamina, and accommodate other medical requirements. A customized Permobil would allow Ms. T. to recline for rest for her compromised circulation. It also has the capacity to raise or lower, allowing Ms. T. to independently accomplish a range of tasks essential to her homemaker goal. VESID had determined that Ms. T. was unable to perform as a homemaker and deemed her ineligible for services. CAP found that VESID based its determination on an occupational therapy assessment which relied on a ten minute home visit with no observation of Ms. T's ability to function within her home. Ms. T was extremely frustrated with the assumptions and findings of the evaluation and the VESID determination.

A hearing was held seeking VESID participation in the cost of the prescribed wheelchair. At the hearing, CAP highlighted the failure of the occupational therapist to conduct a functional assessment. Ms. T presented a videotape of her ability to accomplish various tasks independently. A commitment on the part of Ms. T.'s private health insurance to cover nearly half the cost for the chair based on the clear medical necessity for several features of the chair was also introduced. The additional features, and additional cost, were necessary to enhance Ms. T's functional capacity to achieve her vocational goal. The hearing officer agreed and directed VESID to provide Ms. T. with the support necessary to secure the Permobil wheelchair.

The VESID Deputy Commissioner over-ruled the hearing decision however, and directed Ms. T. to undertake a comprehensive evaluation to determine which features and equipment would be most appropriate. The second evaluation ultimately supported the need for the Permobil, given Ms. T.'s unique circumstances. VESID assisted in the purchase of the wheelchair.

VESID also agreed to alterations in Ms. T.'s bathroom and van to accommodate the new wheelchair. This will allow her further independence as a homemaker and enable her to transport herself and family members to medical appointments.

VESID Reimbursement for College-Related Expenses

Manhattan CAP provided Ms. E. with representation at a fair hearing. Ms. E. is a student at Hunter College in the Education Department. As she embarked on her studies she purchased various incidentals, equipment, and services with her limited fixed income. Ms. E. was also in need of tutorial services, a note taker, and childcare services.

The equipment was purchased with the expectation that VESID would provide reimbursement and included a tape recorder, tapes and rental of a computer. When reimbursement was requested, many of the items were denied at the VESID senior counselor level.

CAP and Ms. E. successfully argued at the hearing that nearly all the items purchased were essential to Ms. E.'s successful completion of her studies. In addition, Ms. E. pointed out the need for childcare support and the use of her own computer system.

The hearing officer's decision granted reimbursement for most of the items purchased and also directed VESID to reimburse Ms. E. for a portion of her childcare expenses. The VESID Deputy Commissioner decided not to review the decision and the hearing recommendation was implemented.

VESID Choice in the Vocational Goal

Ms. E. is diagnosed as learning disabled, and was originally seeking VESID support to pursue a career as a paralegal. Following a diagnostic vocational evaluation (DVE), VESID indicated that paralegal studies would not be appropriate. This was VESID'S finding despite the fact that Ms. E held an undergraduate college degree.

VESID was extremely resistant to supporting advanced studies and would only commit to the goal of mailroom messenger. Reluctantly Ms. E. agreed to pursue mailroom messenger as a vocational goal and participated in messenger training. Upon completion of the training and active participation in various placement efforts, she found it extremely difficult to find employment in the field.

Eventually Ms. E. approached her VESID counselor about support for paralegal training. Ms. E. was informed that VESID would consider an evaluation for paralegal training provided Ms. E. established a record of volunteer work with a law firm under the supervision of a paralegal. Ms. E. made a concerted effort to comply with this request, managing to secure a volunteer clerical placement with the American Civil Liberties Union (ACLU).

Concurrently and independent of VESID support, Ms. E. completed two introductory para-legal courses and passed with excellent grades. In that VESID had expressed reservations about Ms. E.'s ability to manage paralegal writing requirements, she independently secured writing tutorial services from the International Center for the Disabled (ICD).

Armed with her grades from her initial semester of studies and a letter of support from the Learning Disabilities Unit at ICD, CAP represented Ms. E. at an Administrative Review before the VESID District Office Manager. While impressed with Ms. E.'s efforts, the District Office Manager concurred with the counselor's objections, citing Ms. E's. failure to secure a volunteer placement within an agreed upon time frame.

Following completion of her second semester of studies, and a second volunteer position with a legal services hot-line at a major radio station, CAP represented Ms. E. at a fair hearing. The hearing officer ruled that Ms. E. demonstrated she is an appropriate candidate for paralegal training. The fair hearing decision directed VESID to support Ms. E. in her paralegal studies provided she successfully achieves passing grades in her second semester of studies. It was also suggested Ms. E. continue to participate in writing remediation.

The VESID Deputy Commissioner decided not to review the decision and Ms. E. continues in pursuit of a paralegal career with VESID support.

VESID Residential Training Program Denied

CAP represented Ms. D. at a fair hearing challenging VESID's denial for sponsorship at the Para Educator Center (PEC), a comprehensive vocational rehabilitation program which combines living skills in a residential setting. Ms. D. is a thirty year-old woman who has a keen interest in securing employment as a child care worker. Her disabling conditions include a learning disability, borderline I.Q., epilepsy, and a personality disorder. As a result of Ms. D.'s limitations, she had encountered difficulty in maintaining employment.

At the fair hearing, CAP demonstrated that the PEC program offered a course of study in child care which is explicitly designed for consumers with Ms. D's various disabilities. CAP also noted that the PEC program is an approved VESID provider in good standing.

The findings of a VESID-sponsored evaluation to determine if the PEC program was appropriate for Ms. D's needs was a critical factor in the case. The evaluation found that the PEC program would meet her needs, and that she was capable of becoming a teacher's aid/child care worker.

As an alternative to the PEC program, VESID recommended on-the-job training which was more consistent with VESID policy which promotes a preference for community-based evaluation and training. VESID also indicated PEC had a low placement rate.

CAP refuted the VESID claim that PEC had a record of poor placement with a report from VESID's Pro-

gram Monitoring Unit which indicated that 21 of 26 VESID-sponsored PEC students were placed in employment. A follow-up study of the PEC program indicates that 76% of PEC graduates from 1969-1987 remained employed and reported a high degree of job satisfaction.

VESID provided no evidence at the hearing regarding how the provision for an increased emphasis on on-the-job-training should be applied to the client's case. Specifically, there is no evidence from the agency that Ms. D's vocational needs will be adequately addressed in a vocational plan that does not include a residential component.

Moreover, the PEC program has a substantial field work component which provides for training in actual work situations which is consistent with on-the-job-training policy for a client with the handicaps and work experience of the client in this case.

The hearing officer found that VESID had failed to demonstrate how participation in the PEC program conflicted with their community-based placement and assessment policy. The policy emphasizes "placement and evaluation activities in real work sites and in the most integrated setting *possible*."

The hearing officer ruled that the evidence in this case indicates that Ms. D. requires substantially more than vocational training to overcome her disabilities and social and functional deficits if she is to succeed in her vocational objective.

The hearing decision directed VESID to reverse Ms. D's denial of sponsorship for the PEC rehabilitation program.

Education and Training

Training, technical assistance, and outreach are essential components of the protection and advocacy systems. Knowledge and information – about specific rights within service systems, advocacy techniques, or simply how to find help with a problem when it's needed– are important tools for individuals with disabilities, their family members, as well as service providers to possess. These services are also an effective way of using limited resources to assist individuals who are experiencing problems to act on their own, or support other advocates in providing assistance, especially in areas where legal assistance is not necessarily the best or only solution.

A major training effort this past year was the national conference entitled "Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities," which was co-sponsored by the Commission and Disability Advocates, Inc. This conference drew almost 900 persons to Albany for three days in June, 1994. [See above, p. 6]

Other examples of training and outreach provided during the past year are listed below.

PADD Training and Outreach

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

- **Law Guardian Training**: The Albany Law School PADD program was asked by the Office of Court Administration to conduct a series of workshops for attorneys who serve as law guardians or representatives for children involved in family court matters. In particular, the law guardians needed to be briefed on the substantive rights of children under the Individuals with Disabilities Education Act (IDEA).
- **Future Planning**: Requests are made constantly of the PADD offices to conduct trainings on guardianship and estate planning. Although PADD attorneys do not engage in the petition for guardianship or wills and trust development, they have been able to explain the applicable laws particularly as they relate to public benefits. This helps the parents to be more informed consumers when

seeking out a private attorney to do such work. Recently, the State Office of Mental Retardation and Developmental Disabilities has asked to share the PADD training materials as part of an OMRDD initiative on future planning.

- **Educational Advocates:** Both the Mid-Hudson and Neighborhood Legal Services offices have trained a cadre of parents to assist other parents at committee on special education (CSE) meetings. The parent advocates receive follow-up consultation from the attorney trainers and they may pass on the case to the attorney (allowing it has merit) if it becomes too complex or an appeal is warranted.
- **Work Incentives:** The Neighborhood Legal Services and Western New York Advocates offices have developed an extensive training program and manual on ways to begin productive employment without jeopardizing needed benefits like Medicaid which is tied to Supplemental Security Income (SSI) eligibility. The training provides critical information on programs which exist to help transition persons with disabilities into employment without loosing these needed benefits.
- **Inclusion Training:** Each of the PADD offices has been asked to conduct training on inclusion techniques. The Syracuse office has conducted joint trainings with the Center on Human Policy of Syracuse University. Others have been asked to co-present with members of Schools are for Everyone (SAFE). The Western New York Advocates office has presented training on developing an individualized education plan (IEP) to attain full inclusion.
- **Expert Witness:** The Syracuse office has developed a training on finding and preparing expert witnesses for testimony in impartial hearings or federal and state court. This training by Susan Young and Paul Kelly has been delivered at the National Association of Protection and Advocacy Systems conference as well as training for PADD staff.
- **Minority Outreach:** Ms. Loretta Goff of the NYC office in the PADD Minority Outreach Coordinator and has conducted workshops in various settings including Bayview Correctional Facility on cultural diversity, a Safehouse for Battered Women on prevention of developmental disabilities, presentations to students in ethnically and culturally diverse NYC/Long Island high schools on services to people with developmental disabilities, and trainings for minority service providers. Neighborhood Legal Services, the Buffalo PADD office, conducts successful outreach to the Hispanic community, particularly in issues related to special education.
- **Educational Advocacy Program**: conducted by a coordinator who plans presentations throughout the state and then assisted by a representative of the local PADD to provide consistency and follow-up after the training. Parents are the primary target audience and they are given a basic review of their rights within the special education system with further training in negotiation at committee on special education meetings and later advanced training in doing an impartial hearing. Over five hundred individuals have been trained over the past year and many pursue their own self-advocacy without a need for PADD intervention.
- **Disabilities Awareness**: continues its success in sensitizing school children to the needs of their peers with disabilities. Commission volunteers go out to schools and first conduct a pre-test of the children's perception of individuals with disabilities. Then a presentation is given by the instructor utilizing visual aids and role play. At a later visit to the school, a post test is administered to evaluate any changes in attitude. The post tests have revealed a significant change in attitude and willingness to be more accepting of classmates with disabilities. The students are invited to participate in an essay or art contest in which they may characterize situations involving individuals with disabilities. In this past year the winners of the contest were treated to a visit to the Governor's Mansion and presented with certificates of appreciation.
- **Disability and the Law:** This project has been producing a series of videotapes relating to various topics within the field of Developmental Disabilities. This year, the topic was *Doing justice? The Criminal Justice System and Persons with*

Developmental Disabilities. Experts in the field and participants in an alternative to the court system were interviewed to discuss the characteristics of developmental disabilities and their effects on the alleged offender. Recommendations are made on how to serve justice when persons with developmental disabilities are accused and convicted of crime, The program has been sent to over one hundred (100) cable companies in New York State.

PAIMI Training and Technical Assistance

During this report period, the Commission and the PAIMI regional office system provided training opportunities for 4,700 persons. These events varied widely by topic and number of individuals trained. Examples:

- Several of the regional offices in the PAIMI system have provided training and developed written training material on substantive topics of interest to PAIMI clients, their families, and mental health service providers such as: New York State's health care proxy law, employment discrimination, Medicaid waiver programs, New York State's guardianship programs, confidentiality, sealing of mental health records, ADA protections for persons with mental illness, and Social Security work incentives.
- Peer advocacy training was provided both by several PAIMI regional offices and by the PAIMI program director for several groups around the State, including The Mental Patients' Liberation Alliance; PEOPLE, Inc.; Middletown Psychiatric Center peer advocates; and the Westchester/Rockland Advocacy Coalition.
- Presentations by the PAIMI program director which discussed the program's activities and accomplishments were given at conferences sponsored by the Mental Health Association in New York State, the Recipient Empowerment Organization of the Mental Health Association in NYS, Rockland Psychiatric Center, and the Harlem Alliance for the Mentally Ill, as well as for numerous smaller groups of recipients, family members, and service providers.
- An attorney from Disability Advocates, Inc. gave a presentation on mental health law issues at the Law Guardian Panel of the NYS Supreme Court, Appellate Division, Third Department. Two further such trainings are scheduled for next year.
- "Beyond the Right to Refuse Treatment," was a workshop presented by staff from two PAIMI offices, Disability Advocates, Inc. and Touro College, at the National Association of Rights Protection and Advocacy annual conference in the fall of 1993.
- "Alternative Dispute Resolution," "Community Services Litigation," and "Advocacy Issues Facing Persons in Jails and Prisons," were workshops presented by staff from New York Lawyers for the Public Interest, Inc. at the annual conference of the National Association of Protection and Advocacy Systems in June, 1994.

Looking Ahead

OMRDD Rate Appeals: Flawed Medicaid Payment System

A Commission examination of the procedures and process (rate appeals and settlements) used by OMRDD for supplementing the rates of reimbursement for services provided by intermediate care facilities (ICFs) and community residences (CRs) began after it was found that Community Living Alternatives, Inc. (CLA) received a retroactive payment of $138,798 to fund additional direct care staff that were never hired because OMRDD did not examine CLA expenditures to verify that the costs had been incurred.

The Commission is finalizing a report for release in early 1995 on the management of the rate appeals process by OMRDD, indicating that there are serious systemic weaknesses affecting the payment of significant sums of public funds to OMRDD providers. Rate appeals play a significant role in the financing of OMRDD programs not only because of the number of provider agencies that receive additional funding through appeals but also because, once granted, rate appeals have a continuing and long term effect upon expenditures.

CMCM Study

After problems were found at Project L.I.F.E. [see above, p. 23] concerning the implementation of the Comprehensive Medicaid Case Management (CMCM) program. The Commission undertook a statewide study to determine whether fiscal and programmatic objectives were in fact being realized. The Commission has thus far identified some $4 million in one-time "hard dollar" savings that can be obtained by recouping the duplicate payments that have been made to providers.

Outpatient Psychiatric Clinics

In its July 1989 study entitled *Outpatient Mental Health Services,* the Commission reported that "there are staggering variations in the actual per unit cost of providing services, with a range of 545 percent in continuing treatment programs, 1269 percent in clinics and over 2000 percent in day treatment programs." The Commission made a number of recommendations to improve the cost-effectiveness of this program and to increase the availability of third-party payments for the cost of services unnecessarily borne by state and local governments.

Significant changes have been made in the funding of outpatient mental health services since 1989, resulting in annual recurring savings to state and local governments of $42 million. However, there remain substantial differences in the cost of delivery of these services among different providers. In an attempt to understand the reasons for these cost variations and to identify efficient and effective management and clinical practices, the Commission is conducting a follow-up study of a sample of outpatient clinics.

Survey forms to collect data on clinic operations have been returned from 171 (89%) of the 192 voluntary and county clinic programs. Statistical and programmatic analysis of the survey forms are continuing, complementing analysis of clinic fiscal data. The upcoming report will profile clinic characteristics, identify key factors and common practices affecting cost, and make recommendations for improvement. A second phase of this study will examine practices in state-operated clinics as they affect variations in their costs.

Private Psychiatric Hospitals

Private psychiatric hospitals play an important role in the mental health system, operating approximately 1,300 beds. In 1993, they received revenues of $173 million. As the State's role in the direct provision of inpatient mental health care declines, especially in the care of children and youth, the role of private hospitals has been growing. With the advent of managed care and the increasing reluctance of insurers to pay for extended psychiatric inpatient care, all private hospitals have sought entry into the Medicaid program to service the indigent population. The role of Medicaid in financing the operations of these facilities has grown 167 percent over the past five years and now represents 20 percent of the industry's total revenue..

In mid-1994, the Commission commenced a programmatic and fiscal study of the private psychiatric hospitals to assess the quality of care they provide, the patient population served, and their revenue, cost and profitability patterns. Site visits were made to eight hospitals and fiscal data has been obtained from all hospitals. These data indicate that the cost of services varied from a low of $271/day to a high of $938/day in 1993. The Commission's study is examining the reasons for these variations in costs of services, as well as the increasing dependence on Medicaid as a revenue source.

Investigations of Security Issues at Kingsboro and Manhattan PCs

Following two separate apparent homicides involving patients who left state psychiatric centers without permission, which raised issues of the adequacy of safety and security of patients and of the public, the Commission began a probe at Kingsboro Psychiatric Center and at Manhattan Psychiatric Center after an escaped Manhattan Psychiatric Center patient reportedly pushed a woman under a subway train. These investigations will examine safety and security practices at these facilities.

1993-94 Publications

In the Matter of Joan Stalker: A Study of the Need for Vigilant Monitoring of Family Care Homes, December 1993

Survey of Access to New York State Courts for Individuals with Disabilities, February 1994

Watching Over the Children: A Review of 1993 Commission Activities on Behalf of Children with Mental Disabilities, March 1994

Missing Accountability: The Case of Community Living Alternative, Inc., June 1994

Crossing the Line from Empowerment to Neglect: The Case of Project L.I.F.E., July 1994

Community Volunteer Advocacy in Group Homes: An Evaluation of the Westchester County Ombudsman Program, August 1994

Care and Treatment for Persons with Multiple Disabilities: A Progress Report, August 1994

Brochures - *Could This Happen in Your Program?* Series:

In the Matter of Mary Rose: A Case of Unclear Standards and Expectations in a Small Group Home

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In the Matter of Jacob Fine: Complications Following Surgery Go Unresolved

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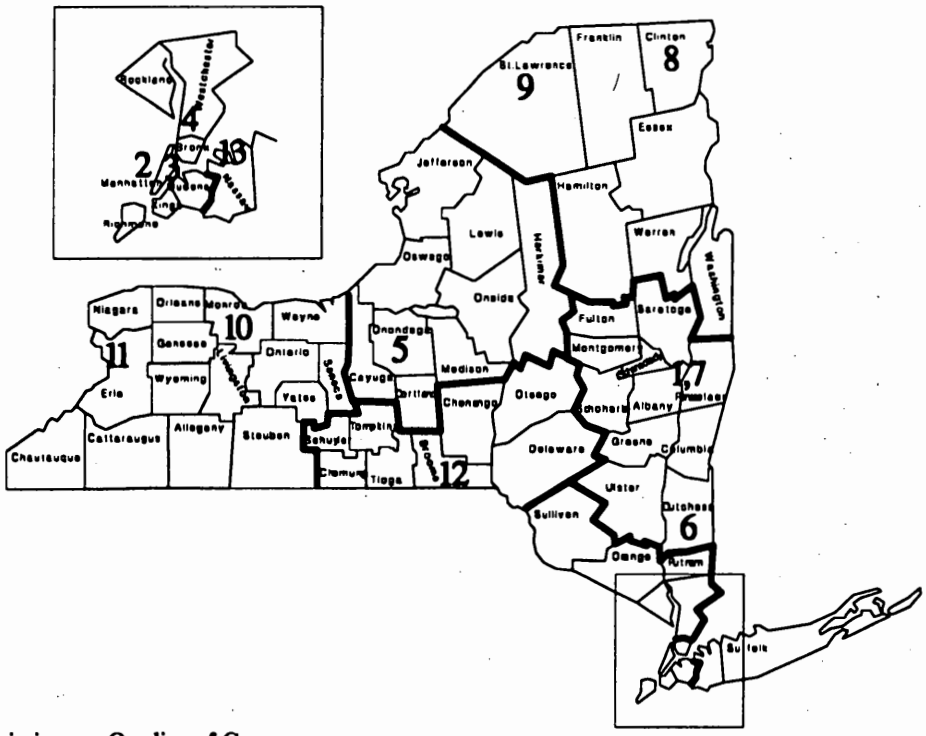
In the Matter of Julian Webber: Delayed Response to Decompensation Results in Tragedy

Protection and Advocacy for Developmentally Disabled Persons Regions and Offices



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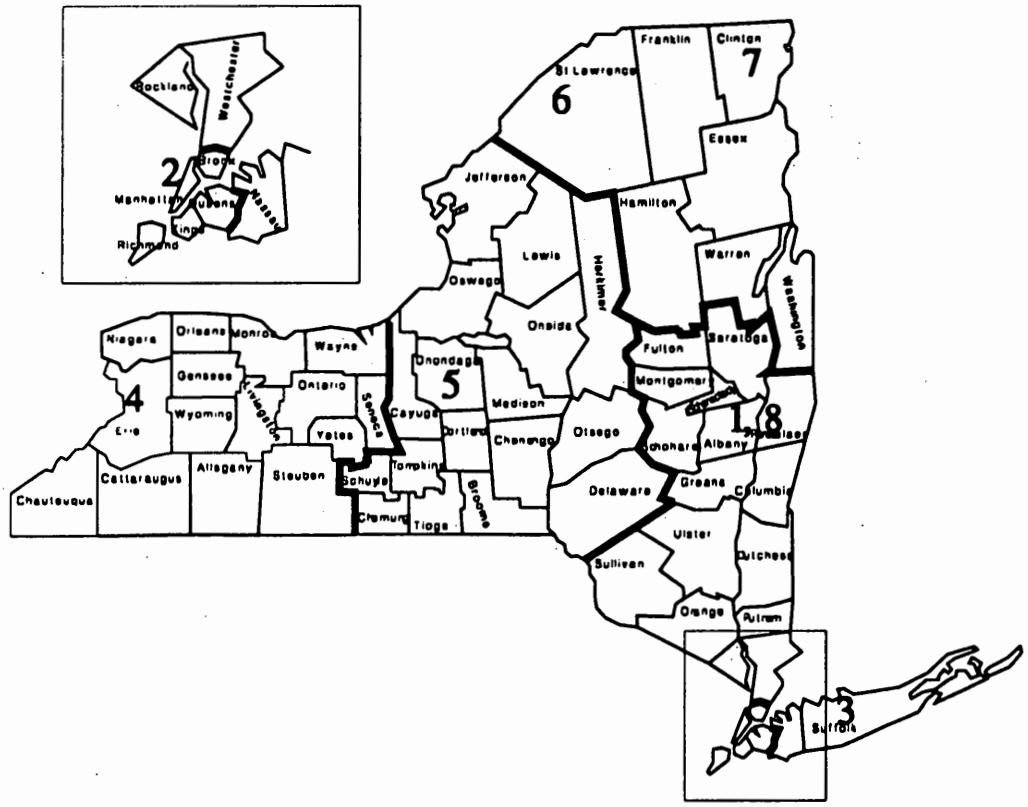

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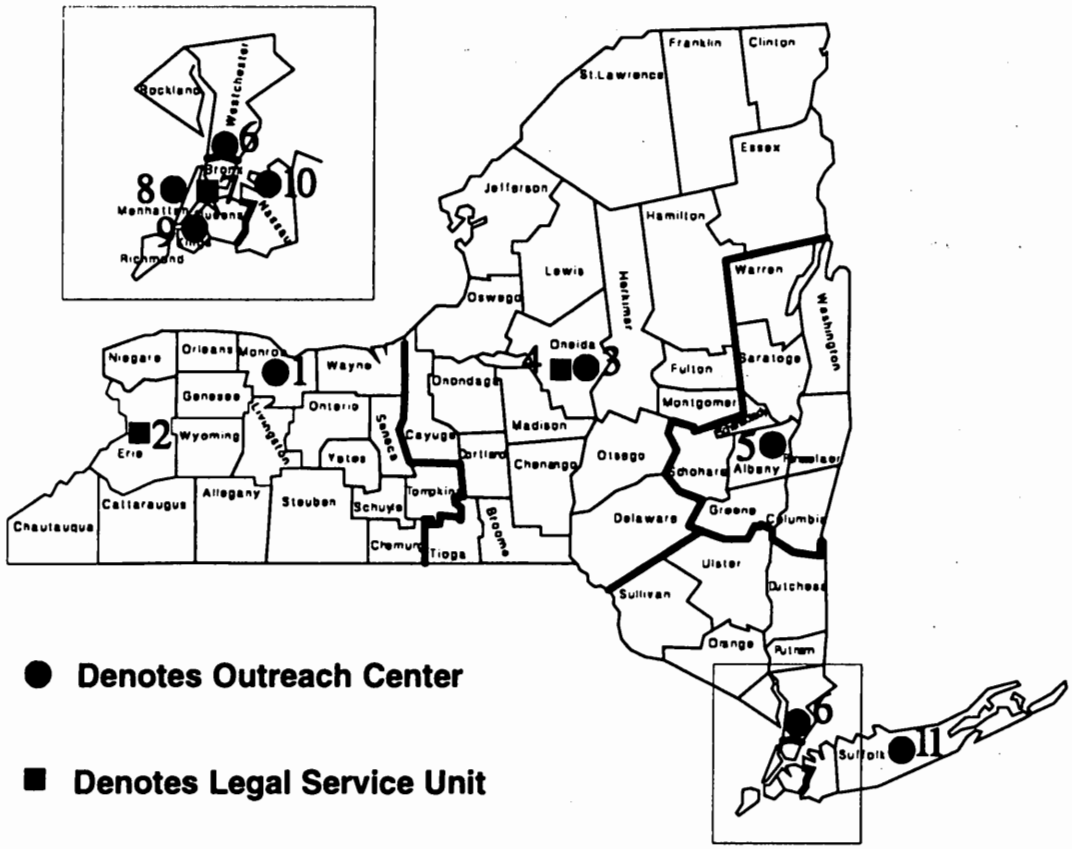

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Symposium studies shift in social services ro

By Cailin Brown
Staff writer

ALBANY — Progressive programs that provide more freedom to developmentally disabled and mentally ill individuals have also produced concerns about the ramifications of having less supervision.


Sundrum

"Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities," is the fo cal point of a two-day symposium to be held at the Desmond Tuesda and Wednesday.

More than 800 indivi 25 states are expecte program to lear how social handle ly

emphasis on consumer choice and consumer empowerment in the delivery of services," said Clarence Sundrum, chairman of the state Commission on Quality of Care. "The whole notion is that for far too

case workers suggested he get help but he refused, and one day last year he was found dead in his apartment, Sundrum said.

"That illustrates the tensions between respecting wishes and having

alized to become self-sufficie result, they are helping clie living and teaching mana

zon

A Case of Neglect?

By Michael Moss
STAFF WRITER

A group that cares for the mentally disabled in 60 apartments in Manhattan and the Bronx is facing possible decertification because of impending official reports of neglect and failure to control aggressive clients.

Th p, Project LIFE, has subjected its resi- mmary evictions, inadequate health ct even when they pose a danger to to neighbors, a watchdog state found. A separate probe raises nagement.

re staunchly denied by Project documents and testimonials d board members present- they are likely to fuel the

Commission on Quality Care for the Mentally D abled, whose report, "Crossing the Line Empowerment to Neglect," was obtained by York Newsday in advance of its expected next week.

The report alleges that one resident carried a razor, another brandished a others in the various apartments exhib aggression that Project LIFE should ed to law enforcement authorities.

Project LIFE executive director A denies many of the commission fi others were skewed to reflect group does not share.

"Our people for the most members of the community," terday. "They are minimally

would be difficult trol his eating habits. move out on his own and ed to eat and gain weight. His

sible to, Sundrum sa Case managers now helping indiv have traditionall

Lapses in Oversight Found In Residences for Disabled

By DIANA JEAN SCHEMO
Special to The New York Times

MINEOLA, L.I., Dec. 13 — A state investigation into the death of a mildly retarded woman has found serious

the house.
A 1991 state report on a suspicious death at a different adult care home prompted closer scrutiny of the home where Ms. Slather

NEW YORK STA Report: State home operator skims funds

Leased luxury cars while clients ate canned stew

The Associated Press

ALBANY — A watchdog agency's report on a group home for the mentally retarded, where operators allegedly skimmed $510,000 in state funds, depicts state regulators as asleep at the switch.

The Commission on Quality of Care for the Mentally Disabled yesterday criticized the state Office of Mental Retardation and Developmental Disabilities for failing to spot trouble at the group home. The operators of the Queens home, Community Living Alternative, leased luxury cars for themselves while their clients ate canned stew nightly for dinner, the report said.

"It's a scary thought that highly regulated system thing like this could said Clarence sion ch

LOCAL

3

GOT A NEWS TIP? Call 58

►Health

Restraints responsible in patients' deaths

Between 1984 and 1992, numb ed

By JAY GALLAGHER
Gannett News Service

ALBANY — Incidents of fo straining patients or isola bare rooms in state psy almost doubled bet and has played according to watchdog

The

Restraint involves using a straitjacket, sheets to tie a patient to a bed or other means to prevent the free use of arms and legs. Seclusion means placing a patient alone in a locked room with only a mattress.

By law, they can be used only with a written order from a doctor.

The commission, set up in the wake of Willowbrook scandal 20 years ago to monitor the care of the mentally ill and retarded, was directed by the state Legislature to look at the issue in reaction to stories about the deaths of patients while restrained or secluded.

The report found that 1,391 orders of restraint or seclusion on adults were issued in 1992, compared to 1,409 in 1984, despite a drop in the number of patients

'These reports provid substantial evidence tha serious physical and psychological harm is occurring daily.'
—Harvey Rosenth

from 23,596 to 13,133.

For children, the use of restraints seclusion jumped from 72 10 years to 342 in 1992 — even though the nu of child patients dropped from 6 483

'Unacceptable' practice blamed for 111 deaths

GALLAGHER

Incidents of patients or rooms in almost 992

"This is shocking and unacceptable," said Harvey Rosenthal of the state Association of Psychiatric Rehabilitation Services. "These reports provide substantial evidence that serious physical and psychological harm

e were no such ga Hospital. How- many at the Capital iatric Center

State scrutinizes assault at health center

By Len Maniace
Staff Writer

RAMAPO — State officials are investigating charges that a 14-year-old girl was sexually assaulted by a fellow patient at the county's mental health center, a state Commission on Quality of Care spokesman said yesterday.

The sexual assault took place an. 11 at the Dr. Robert L. Yeager Health Center's mental health inpatient unit, law enforcement officials said.

Robert E. Lee, 29, of 40 Catherine St., Nyack, was charged the next day with sodomy, endangering the welfare of a minor and sexual misconduct, county Sheriff's Patrol Detective Lt. Stanley Greenberg said.

Lee allegedly had sexual contact with the girl in the bathroom attached to her room, Greenberg said.

Lee is not charged with forceable rape, Rockland District Attorney Kenneth Gribetz, but rather having sex with a minor who legally was unable to consent.

Edward Devine, a lawyer representing the family of the girl, said yesterday that before the alleged assault, the family had asked that the young woman be transferred out of the county facility because she was being kept in unit that also included adults.

"She went up there the next day and asked that her daughter be transferred to the Rockland Children's Psychiatric Center," Devine said.

The young woman was previously treated at a private mental hospital in Westchester until her health insurance coverage ran out and then was admitted on Jan. 4 with suicidal feelings, Devine said.

Reached for comment, County Mental Health Commissioner Stanley Goldstein said Thursday he did not know whether the girl's mother had asked for the child to be transferred and said staff who would know about the case were not available.

A phone call to Goldstein's office yesterday was not returned.

Gary Masline, spokesman for the state Commission on Quality of Care, said his agency was investigating the circumstances sur the alleged sexual assault.

The girl was transferre Rockland Children's Psy Center the day after the Devine said.

Lee is being held in the County Jail on $10,000 bai berg said. Lee was initial kept under special watch, an interview with a psy those measures were drop Sheriff James Kralik yester

Gribetz said he expected the case before a grand ju two weeks.