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NEW YORK STATE COMMISSION ON QUALITY OF CARE for the Mentally Disabled

AC 92 Rev. (4/82)

STATE OF NEW YORK

STANDARD VOUCHER

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ANNUAL REPORT 1992-93

QUANTITY	DESCRIPTION OF SERVICES--July 1, 1992 to June 30, 1993	Amount
38,956	Persons Served Through PADD, CAP,& PAIMI Networks	
7,559	Complaints Acted Upon	
2,516	Recommendations Made	
786	Site Visits	
310	Deaths Investigated	
348	Surrogate Decision-Making Cases Reviewed	
116	Reports of Suspected Child Abuse Responded To	
393	Reports/Month of Suspected Adult Abuse	
8	Published Reports	
	TOTAL EXPENDITURES FOR SERVICES	
	State Purposes	
	Personal Services	$2,806,368
	Non-Personal Services	1,003,330
	Special Revenue Fund - Federal	
	Personal Services	$ 888,919
	Non-Personal Services	2,171,145
	Special Revenue Fund - Other	
	Personal Services	$ 507,172
	Non-Personal Services	163,936
	TOTAL	$7,540,870
	Discount %	
	NET	$7,540,870

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 and only due and owing, and that taxes from which the State is exempt are excluded.

Theresa J. Bonacum — Chairman

PAYEE'S SIGNATURE IN INK — Title

1992-93 — Commission on Quality of Care for the Mentally Disabled

Date — Name of Company

Foreword

The fundamental purpose of most of the Commission activities described in this annual report is first, to assist those in need of help and second, to apply the lessons learned in these activities more widely to the service system through recommendations for changes in policies and practices, laws and regulations, as appropriate.

The Commission recognizes that, as the service systems continue to evolve, an increasing number of people who once would have been served in institutions or highly regulated supervised facilities with 24 hour staffing are now living in the community with a lower level of supervision, service, and supports. With their greater independence, the safeguard for their well-being often rests to a large extent in the hands of aides, case managers, and other itinerant staff. As the roles of these staff evolve, from responsibility for ongoing supervision to a more attenuated level of support, so too will their need for continual training. Rather than depend on a brief period of initial orientation and training and on voluminous policy and procedure manuals, teaching and learning will need to be made an ongoing process. Rather than teaching rules and regulations alone, teaching will need to emphasize the judgment to be exercised by these staff in balancing the values of independence and autonomy with the responsibility for timely intervention to prevent serious harm.

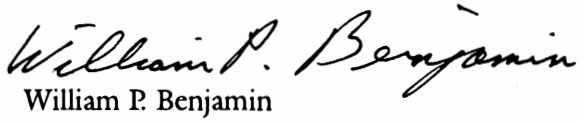
It has always been a practice of the Commission to write reports about its investigations and studies, to summarize them in our newsletter and annual report, and to disseminate them widely within the service system. The intent behind this practice is to provide a reviewable record for reflection and learning, to capture the "teachable moment" for the benefit of those who work in the service system and those who are served by it. Few things provide the Commission and its staff more satisfaction than learning how these reports have been used as teaching tools at facilities and programs to localize the lessons learned. The reader response to the survey cards accompanying last year's annual report affirmed the value that our readers also place upon these reports and case studies in their own process of critical self-examination of the programs and services with which they are involved.

In the past year, the Commission has developed an additional and new method for sharing these "teachable moments" with provider agencies through the wide dissemination of brief case studies entitled "Could This Happen in Your Program?" Drawn from the case files of complaints, site visits, and investigations by the Commission staff, these vignettes are intended to provoke reflection, discussion and critical self-examination by staff *at all levels of the service system.*

The need to seize these "teachable moments" has never been greater. Through the vehicle of these case studies, as with its other reports and publications described in this annual report, the Commission hopes to contribute what we are learning from our oversight activities to assist those on the front lines of the service system in better carrying out their critical roles. In making our modest contribution, the Commission recognizes as well the opportunities that present themselves daily to program managers and staff—in treatment planning meetings, in visits to programs, in handling consumer and family complaints, in incident review meetings—to continue the process of teaching and learning that will be critical to the success of the emerging direction of the services systems.

Clarence J. Sundram
Chairman

Elizabeth W. Stack
Commissioner



William P. Benjamin
Commissioner

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Preventing Abuse, Promoting Quality

The Commission is usually not perceived as a prevention agency. "Watchdog," "monitoring," or "oversight" are the typical terms used by public and private bodies, including the press, when describing our role and functions. Yet, at the heart of the legislation which created the Commission, and at the core of our current activities and policies is the effort to prevent the repetition of negative actions towards people with disabilities, whether it is by:

- preventing future deaths and abuse by learning from mistakes detected in Commission death and abuse investigations,;
- promoting quality assurance by responding to and actively intervening in calls for assistance;
- preventing fiscal fraud and diversion of public monies by investigating such allegations and working with law enforcement agencies on prosecution or financial recoveries;
- preventing major medical difficulties through the provision of timely consent for medical treatment, when deemed necessary, through the Surrogate Decision-Making Program;
- suggesting legislative actions to promote effective preventive policies; and
- educating and training service providers, parents, and advocates.

Some of the results of these actions are reported in the following pages.

Preventing Abuse and Deaths, Promoting Quality Care

Teaching Through Death

During the past 15 years, the Commission and its Medical Review Board have reviewed over 35,000 deaths of mental hygiene service recipients, directly investigating several thousand which appeared unnatural, unusual, or preventable. Where problems were found, recommendations and requests for corrective action were issued directly to the involved facilities by letter; and in those cases which suggested the need for public policy reform, formal reports detailing the Commission and Board's findings, conclusions, and recommendations were issued to the Governor, Legislature, state agency commissioners, facility operators, and the public at large.

Still, over the years, preventable incidents of like nature continue to occur, perhaps not at the same facility where the last one occurred, but at a new one in the same county or at a completely different type of facility half way across the state.

During 1992-93, the Commission and Board questioned how the lessons learned from one death could be better communicated to all agencies, their direct care staff and mid-level managers and not just their executive directors, to help all reduce the likelihood of a similar incident occurring under their roof or at their doorstep.

The answer was case studies: brief, two page summaries of actual cases reviewed by the Commission which present the facts of the case and questions or discussion points to aid a facility in a review of its own policies and operations with an eye toward determining "Could this happen here?" and "What do we need to do to ensure it doesn't?"

Reactions from several dozen facility directors who were sent two draft case studies as a pilot was overwhelmingly positive. The universal response was that the case study format—which names no names (of either facility or staff) and lays no blame, but rather

Deaths Warranting Further Review/Investigation

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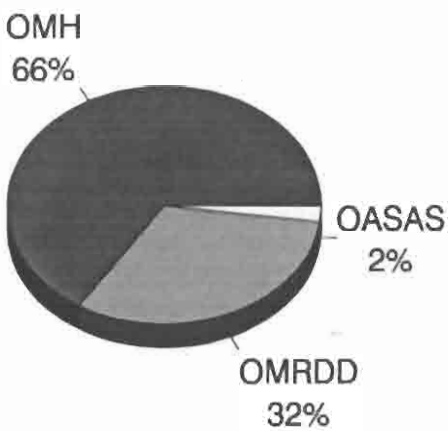
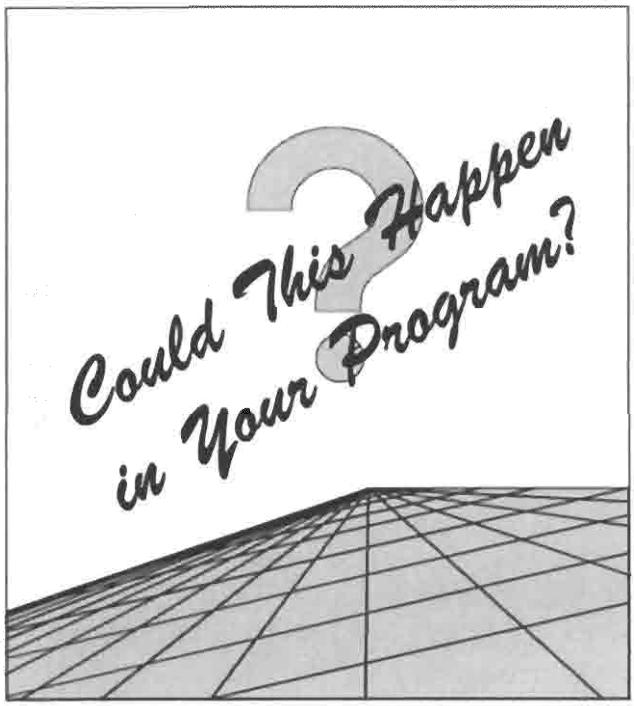


During the reporting period, 2,079 deaths were reported to the Commission. Of these, 310 were subject to detailed review and investigation because of suspicions of other than natural causes or their unusual nature or circumstances.



In the Matter of Michael Henry:

A Case of Flawed Risk Assessment and Discharge Planning

One in a continuing series of case studies to provoke reflection and discussion.

Case #1

NYS Commission on Quality of Care for the Mentally Disabled
99 Washington Ave, Suite 1002
Albany, NY 12210-2895
1-518-473-1039

presents facts and poses questions to prompt thinking and change—was an excellent vehicle for inservice staff training programs and prompting agency reflection on its own policies. Some pilot programs offered suggestions on layout changes to aid in their reproduction of the studies, while others requested hundreds of additional copies of the first two drafts for dissemination to their staff.

Based on the response of the pilot facilities, the Commission determined that, in addition to its reports of findings and recommendations to specific facilities and the public at large, beginning in 1993-94 it will publish a continuing series of case studies entitled "Could This Happen In Your Program?" On a periodic basis, new installments in the series will be sent free of charge to all mental hygiene agencies in New York State, or any other interested party who writes to the Commission, for their use in policy examination and reform, and staff training.

Preventing Deaths: Case Examples

Besides this new initiative of spreading out the lessons learned from Commission investigations of deaths to a wider audience, particularly as a preventive teaching tool for those in direct care, the Commission continued to investigate deaths of individuals who receive services from the mental hygiene system as reported in accordance with the Mental Hygiene Law (§45.15). During the reporting period, 2,079 deaths were reported. Of these, 310 were subject to detailed review and investigation because of suspicions of other than natural causes or their unusual nature or circumstances. Findings from these investigations are reported to the providers of care for corrective and preventive actions. Some case examples:

- **Recording Seizure Activity**
  During an investigation of the seizure related death of an ICF resident, it was determined that the facility did not have a means of consistently and uniformly recording clients' seizure activity. Thus, clinicians responsible for monitoring and managing clients' seizure disorders may not have been receiving complete information about their clients' clinical conditions. The Commission investigator provided the ICF's management with examples of seizure charts used by other agencies with which the investigator was familiar. Subsequently, the ICF management adopted one of the sample seizure charts provided so that staff could better record information of value to physicians and nursing staff.

- **Security Search Procedures**
  The investigation into the death of a high functioning mentally retarded person who fell from the roof of his facility, resulted in revised security search procedures at the facility. In this case, on the night of the individual's death, an alarm sounded, indicating that a door leading to the roof

had been opened. A security officer responded to the scene, looked on the roof and, finding no one, closed the opened door and returned to his post. The officer did not explore how the door came to be opened, nor did he contact residential units of the facility to determine if all residents were present and accounted for. (Just prior to the alarm sounding, the decedent was speaking with security officers in the lobby; his residential unit called the security desk to remind the resident to come back to the unit for shower time and he was sent back to his unit, walking in the direction of the wing where the alarm sounded.) A short time later his body was found on the ground by staff reporting for duty on the next shift.

Following the Commission's investigation, the facility agreed that residential units will be contacted to determine if a resident is missing and to aid in the search when an alarm sounds indicating a secured egress route has been breached.

■ **Caring for Hospitalized Developmental Center Residents**

During a visit to a medical unit of a community hospital which serves a large developmental center and psychiatric center in that region of the state, the Commission's investigator, who was following up on recommendations from an earlier death investigation, learned of a number of concerns about the staff deployed by the developmental center to assist in the care of clients while they are hospitalized; reportedly, they didn't interact with the clients, hardly knew the individuals, ignored their needs, and just sat in chairs like baby sitters. It was reported that the hospital had expressed its concerns to the developmental center, but no action was taken.

As it turned out, the staff deployed to assist in the care of clients from the developmental center were per diem staff in the employ of a private agency retained by the developmental center.

The Commission investigator facilitated a meeting of all parties, during which it was agreed that:

- The private agency would identify a small core group of per diem staff which would be deployed to care for hospitalized developmental center clients.
- The developmental center would provide this core group with training on the special or unique needs of developmentally disabled persons (e.g., daily care, feeding, positioning needs, etc.); and
- On a daily basis, hospital staff would instruct the per diem staff on what specific tasks must be accomplished with each client.

Following the meeting and agreements, the parties reported a better working relationship, and, more importantly, better everyday care for hospitalized clients who can not well express their needs.

Unless the client had gotten up in the middle of the night and helped herself to a meal of rice and beans, which she was incapable of doing independently, staff were lying about what transpired that night.

■ **Neglecting Regular Rounds, Falsifying Records**

A relatively young and healthy, although severely retarded, woman was found dead in the shower of her community residence. It was approximately 5:45 a.m., and staff discovered her during one of their regular rounds of the 8-bed residence.

The Medical Examiner, upon autopsy, verbally reported that he could not identify a cause of death, but foul play was ruled out—there were no signs of trauma, molestation, burns, drowning, etc. The staff on duty that night who discovered the body were distraught; they indicated that they had made 15-30 minute rounds throughout the night, beginning at 11 p.m., and found the client sleeping in bed. The staff speculated, in interviews with facility, police, and Commission investigators, that the client must have gotten up after their last check, documented as occurring at around 4:15 a.m., entered the shower, and died before she was discovered at 5:45 a.m.

In view of the Medical Examiner's verbal report and staff statements, the facility ended its investigation. Grief counseling was provided to the two visibly shaken night shift staff, who were returned to duty, and business carried on as usual.

Months later, the written autopsy report was forwarded to the Commission. A member of the Medical Review Board, upon reviewing it, detected an unusual finding. The stomach contained rice and beans, indicating that the client had died within several hours of eating, before the food could be fully digested. Unless the client had gotten up in the middle of the night and helped herself to a meal of rice and beans, which she was incapable of doing independently, staff were lying about what transpired that night.

The Commission alerted the OMRDD, which certifies the residence, and investigators from both agencies jointly visited the facility to review the meal menu and schedules proximate to the time of death and to re-interview staff.

The investigators found that the client was served rice cakes and beans at approximately 6 p.m. the evening before her death. She was not given any additional rice or beans afterwards which, based on the stomach contents found on autopsy, meant she died far earlier than staff reported, possibly at midnight.

Night staff were re-interviewed, told that forensic evidence contraindicated their prior testimony, and asked what really happened the night of the client's death. In tears, they individually confessed that rounds were made only at the start of their shift, which was between 11 p.m. and midnight, and none afterwards until 5:45 when the body was found. They indicated that at one point, at about 1 a.m., they thought they heard water running upstairs in the bedroom area, but didn't check; and when they found the body in the shower shortly before 6 a.m., they colluded to fabricate a story of regular rounds and falsified records to support the story.

Since the precise cause of death is undetermined, it will never be known whether this death might have been prevented had staff conducted rounds as required. Might they have found the client in distress in the shower? If so, could CPR or timely medical attention have saved her? These questions have no answers. What is clear, however, was that staff entrusted with monitoring the well-being of clients abdicated their responsibility, colluded, lied, and falsified documents about their role in the matter, and almost got away with it—to continue to "care" for residents at nighttime.

In response to the Commission and Board's findings, the agency terminated the two night shift workers and initiated a schedule of random unannounced visits to its ICF residences to ensure that night staff are carrying out their duties.

■ **Informed Consent and the Provision of Treatment**

The death of a 34-year-old inpatient of a state psychiatric center raised concerns about the care rendered by a local community hospital to which she was transferred for medical reasons. The patient, who was maintained on high dosages of psychotropic medications due to her intractable psychotic symptomatology, suddenly became weak and lethargic and began running a fever. She was immediately transferred to the community hospital with the admitting diagnosis to rule out sepsis/meningitis and/or possible medication reaction. The patient's fever continued to rise and she became incontinent and dehydrated. The hospital wished to do a Lumbar Puncture to rule out meningitis and, given the patient's incapacitated state, sought out the family's consent for the procedure. The family, which was not very close to the patient, wanted no involvement in the matter. Over the next 48 hours, the patient's fever continued to rage and her condition deteriorated with no meaningful intervention. The psychiatric center attempted on several occasions to convince the hospital that this was an emergency situation and in such situations consent from the patient or family for diagnostic work-up/treatment is not needed. On the morning of the third hospital day, the hospital gave an "administrative consent" for an emergency lumbar puncture, but by this time the patient's condition was so poor it could not be done and she died shortly thereafter. Upon autopsy, the death was attributed to Neuroleptic Malignant Syndrome (NMS), an adverse reaction to psychotropic medications a classic feature of which is extremely high body temperatures.

The Commission and Medical Review Board were of the opinion that the patient received appropriate care at the psychiatric center. Although her medication dosage was high, it was within the prescribing parameters established by the Office of Mental Health and there was no reason for clinicians to expect that the patient would have an adverse reaction to the medication. When the patient evidenced signs and symptoms of illness, psychiatric center staff promptly transferred her to a hospital. The Commission and Board, however, were extremely critical of the patient's care in the hospital. Given the Commission and Board's criticisms of the hospital's failure to secure consent for diagnostic work in a timely fashion, as well as its poor management of the patient's raging fever, the hospital provided training to medical and administrative staff on the issue of informed consent and means to secure consent and provide treatment in cases where competency to consent is an issue. Additionally, the hospital provided medical staff, residents and interns with training on the identification and management of NMS.

He requested discharge, and a release plan was hastily developed. It failed to address his problem with alcohol, reluctance to attend clinical aftercare programs, and, given his isolative/withdrawn nature, his very real residential needs. He was discharged to live at home alone. Two days later he jumped from a building to his death.

■ **Failed Discharge Planning**

The death by suicide of a young man just two days after his discharge from the psychiatric unit of a general hospital raised questions about his readiness for discharge and the adequacy of discharge planning. While in the hospital for nearly 90 days, the patient had shown little improvement in his depressed, withdrawn state. He had a history of poor attendance at outpatient programs prior to admission, and when hospitalized staff attempted to link him with an outside day program, he eloped during a trial visit. Following return to the facility, he remained isolative and depressed; progress notes even discussed the need for involuntary care at a long term treatment facility. However, he requested discharge, and a release plan was hastily developed. It failed to address his problem with alcohol, reluctance to attend clinical aftercare programs, and, given his isolative/withdrawn nature, his very real residential needs. He was discharged to live at home alone. Two days later he jumped from a building to his death. In addition to counseling the physician responsible for the patient's release and poor discharge plan, at the Commission's recommendation the facility used this case as a study in failed discharge assessment and planning and presented it, along with expectations concerning proper assessments and planning, to all inpatient and outpatient psychiatric staff.

■ **Role of All Staff in Promptly Identifying and Securing Emergency Medical Attention**

A long-term resident of a developmental center was transferred to one of the center's new community-based programs. Shortly after the transfer she developed symptoms of abdominal discomfort. By the time she was transferred to a community hospital, however, treatment of her medical problem, which would have entailed surgery, was impossible due to her grave condition and she expired within hours. Although the facility acted to discipline the direct care staff involved in the client's "hands-on-care" for their failure to take appropriate/timely action, the Commission and Board found that the circle of responsibility was far wider.

It was determined that shortly after the client's arrival at the facility she evidenced symptoms of abdominal discomfort, and that for several days prior to the emergency transfer to the hospital, direct care staff alerted administrative and nursing staff to the client's symptoms. These staff, however, did not respond appropriately: nursing staff did not assess obvious symptoms of abdominal distress, and administrative staff ascribed the client's medical symptomatology to a "behavioral" crisis–a reaction to her recent move.

Although the facility acted to discipline the direct care staff involved in the client's "hands-on-care" for their failure to take appropriate/timely action, the Commission and Board found that the circle of responsibility was far wider.

Although there were problems associated with securing emergency medical attention for the client when her condition became critical, the Commission investigation indicated that the chain of responsibility for the client's declining condition extended beyond the circle of direct care staff on duty "that evening" and involved nursing and administrative staff who were alerted earlier to the client's condition.

In response to the investigation's findings, the facility re-opened its investigation into the incident and agreed to present the case, as a case study to all treatment units, for inservice training on the role of all staff in the prompt identification and response to signs and symptoms of illness.

■ **Procedures Before and After Surgery**

Shortly after return from outpatient surgery for an eye ailment, a resident of a group home began to gag, vomit and refuse food. The eye surgeon was contacted by staff that day and attributed the patient's symptoms to a reaction to the anesthesia which would soon dissipate. A nurse affiliated with the group home was also alerted and visited the client. She assessed his vital signs, which were normal, but conducted no further physical examination. Over the next several days, the client's symptoms persisted, but no other action was

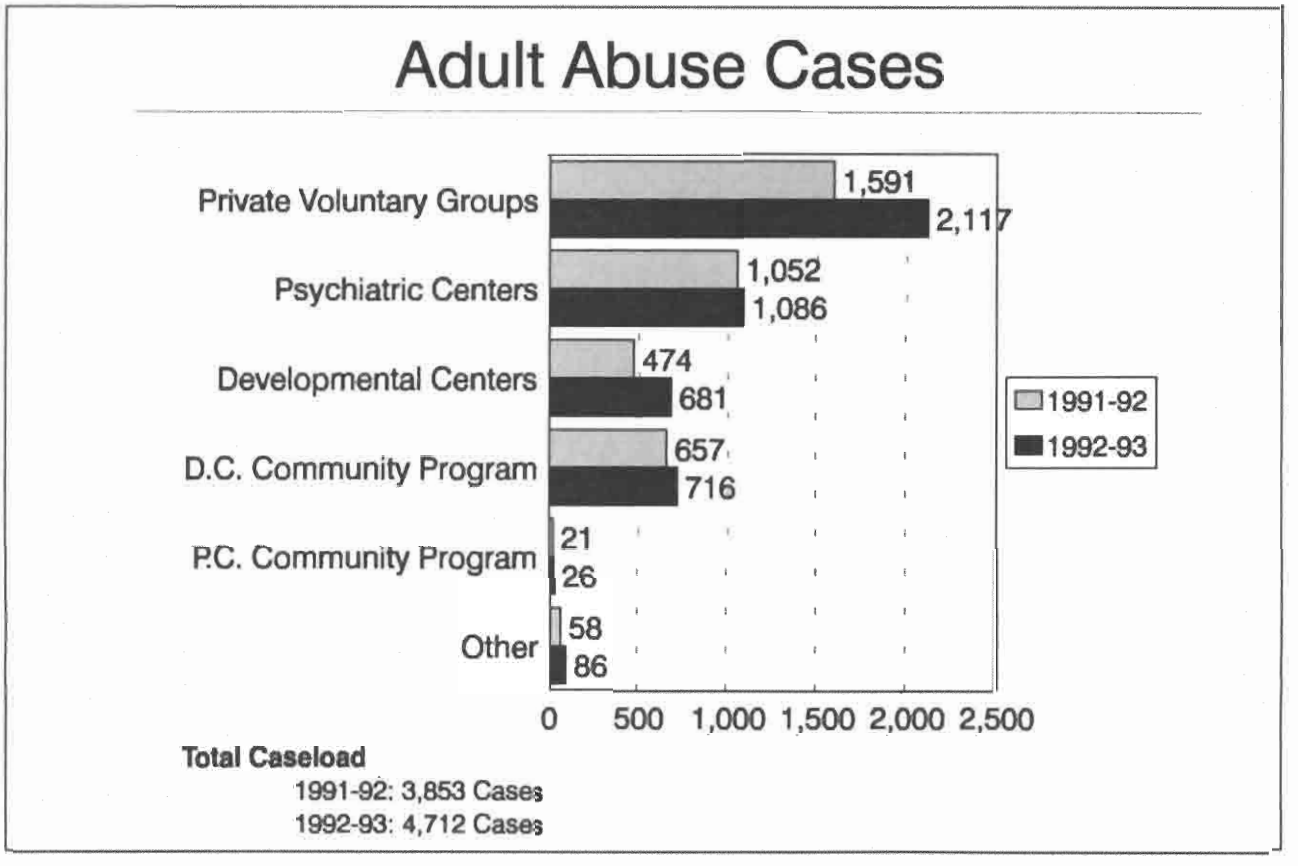
taken, even though the client was recorded at one point as moaning and groaning in pain. After more than six days of refusing solid food and bouts of gagging and vomiting, the client was found unresponsive in his bed. He was brought to a local hospital where he was pronounced dead. Due to religious reasons, no autopsy was conducted.

Although the cause of this individual's death will never be determined, the agency agreed with the Commission's analysis that care was inadequate during his final week of life. The agency instituted procedures to reduce the likelihood of a similar event occurring:

- Prior to surgery, agency nurses should provide surgeons with clients' full medical histories. In this case the client had a past history of gastrointestinal difficulties which evidently was not communicated to the surgeon before surgery or afterwards when he started to develop possible symptoms of abdominal distress which the surgeon thought might have been a reaction to anesthesia.
- Upon return to the residence following surgery, objective assessments (i.e., taking vital signs, monitoring food and fluid input and voiding patterns) of the client's health status should be conducted several times daily; and within one week, the client should be seen by his surgeon or regular physician for a follow-up exam.
- Should a problem arise during the recovery period which is apparently unrelated to the surgery (e.g., GI problems following eye surgery) the client's primary physician should be contacted as soon as possible.

Monitoring Adult Abuse

Since 1989, the Commission has devoted considerable resources to the investigation of allegations of abuse of adults in programs operated or certified by OMH and OMRDD. These programs are required to report allegations of abuse and neglect to the Commission in a timely manner. In the report period, the Commission received over 4,700 such reports. Each report is read and coded to indicate the nature of the abuse/neglect allegation and entered into a database. Basic information about the facility, alleged subject, victim, and final disposition are also entered. The Commission requests the entire facility investigation of the most serious allegations and those brought to our attention by individuals involved or those who care about them.



Commission staff review the complete investigation of the approximately 20% of the allegations chosen for comprehensive review and write the facility a letter of findings discussing the adequacy of the investigation, the reasonableness of the findings and conclusions, and the adequacy of the corrective measures. Common deficiencies uncovered include the following:

- Failure to appreciate the seriousness of an incident resulting in misclassification of the incident. This misclassification often leads to the incident receiving insufficient attention and sometimes even by-passing the scrutiny of the Incident Review Committee.
- Failure to notify law enforcement in those instances where it appears that a crime may have been committed.
- Short-circuiting the investigative process by failing to interview all relevant parties and review all relevant documents. Often investigators fail to get a full account of the events from the victim, relying only on the incident report. Other residents are not interviewed because they are out-of-hand determined to be unreliable. Case record reviews are sometimes limited to only the few days prior to the incident and past incident reports are not reviewed at all.
- Particularly in psychiatric settings, too little attention is paid to the question of staff accountability for the supervision of patients when the incident concerns patient-to-patient assaults and nonconsentual sexual activity.

Finally, the Commission's reviews often find problems in the functioning of the Incident Review Committees. They often do not look critically at the investigations and thus do not identify shortcomings. While they may make recommendations, it is rare that an Incident Review Committee will report on its effort to monitor the effective implementation of the recommendations which it has made.

The Commission believes (and many programs have acknowledged) that the careful critiques of the investigations which we provide to programs serve as road maps to administrators on how to improve the quality of their incident investigation and review activities. They also alert the certifying agencies to programs which are not doing competent investigations and need monitoring or technical assistance.

Monitoring Care and Treatment: MDUs

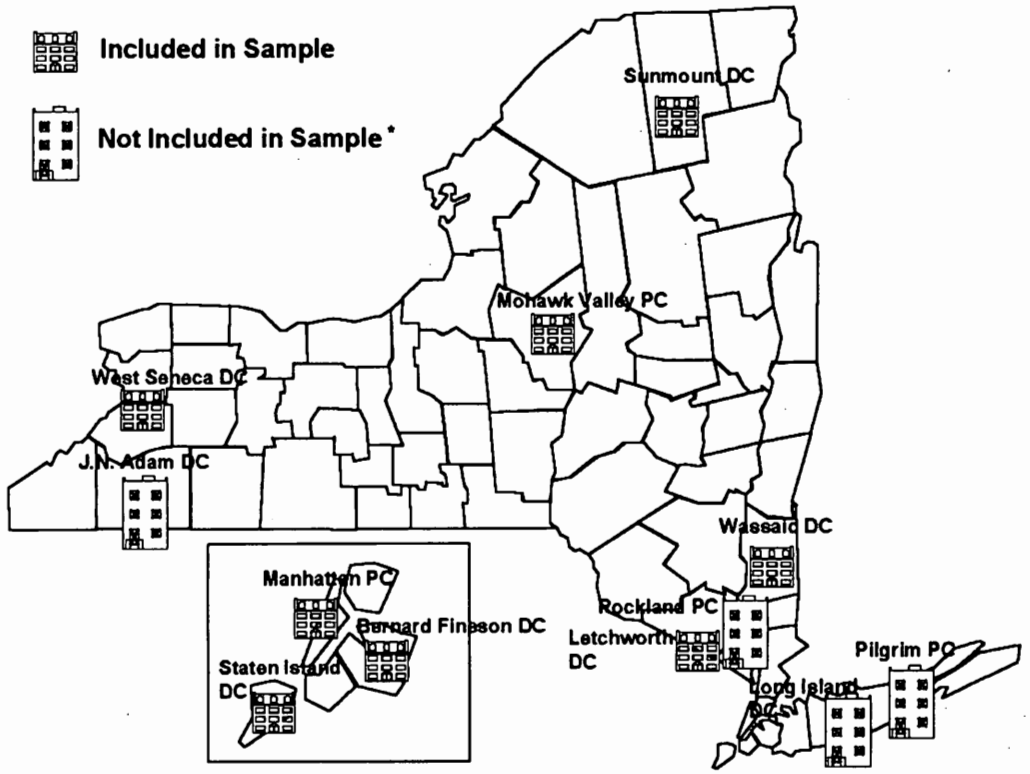
The Commission's 1993 study of specialized units serving persons with a mental illness and developmental disability, Multiply Disabled Units (MDUs), continued work begun by the Commission in its earliest days. In contrast to the findings of nearly 14 years earlier, the site visits to 8 MDUs and the comprehensive review of the care and treatment of 69 residents from these sites revealed significantly improved conditions and far more opportunity to live in the community. The present cooperative spirit between the Office of Mental Health (OMH) and the Office of Mental Retardation and Developmental Disabilities (OMRDD) which has resulted in memoranda of agreement facilitating the transfer of appropriate individuals to the auspice of the OMRDD also sharply contrasts with conditions in earlier years when residents suffered because of disputes between the offices over responsibilities.

Since 1978 over 1,000 psychiatric patients have been transferred to OMRDD—the provider which, according to the Commission study, is best able to provide multiply disabled individuals with the programs and activities which enhance the quality of their lives.

Findings:

- **Remarkable Similarities Between the Residents of OMH and OMRDD MDUs:** Most (two-thirds) of both groups in the sample had been first institutionalized before their 16th birthday, but 87 percent still had a family member or significant other with whom they maintained contact.
- **Skills and Behavior:** All but one member of the sample group was able to care for himself/herself independently or with supervision, but over 75 percent of the sample engaged in assaultive behavior in the last year.
- **Use of Medications:** all but three individuals in the sample were receiving psychotropic medications; informed consent for the use of the medications is secured in the OMRDD programs from capable individuals or their surrogate, but informed consent was not secured from any member of the OMH sample or from their surrogate, nor was there documentation in the OMH sample of monitoring for side-effects.

Multiply Disabled Unit Sites



*These MDUs have closed or are scheduled to close, with their residents moving to other MDUs or discharged to a variety of settings.

- **Restraint and Seclusion:** In the 60-day study period, there was no excessive use of these interventions in any setting.
- **Treatment Planning** was superior in the OMRDD facilities, with specific behavior plans, including a component teaching positive behavior; in contrast, OMH treatment plans relied heavily on the use of medication and group or individual therapy. Each Office has something to offer the other: OMRDD needs to add to its primarily behaviorally-oriented treatment an opportunity for residents to participate in individual or group counseling; OMH needs to learn to write and implement behavior plans which give staff clear directions in how to respond to residents' maladaptive behaviors.
- **Incident Reporting and Review Practices:** In 90 percent of the serious incidents reviewed, the facility had done a competent and comprehensive review of the incidents; in the remaining 10 percent, CQC reviewers found serious deficiencies with problems ranging from failing to notify law enforcement authorities of crimes to poor investigative practices which jeopardized the integrity of the investigation.

Recommendations:

- The Commission noted the importance of OMRDD maintaining a capacity to accept multiply disabled individuals once they become psychiatrically stable, and recommended that the commitment to do so be extended as long as necessary.
- The Commission recommended that OMH revise its medication side-effects monitoring policy.
- The Commission also recommended a centralized review by each office of the work of the Incident Review Committees.

The report is expected to be finalized early 1994.

Quality Assurance in Care and Treatment

The concerns expressed by over 400 callers from the more than 2,000 calls received on the CQC toll-free line (1-800-624-4143) focuses the Commission's attention repeatedly back to basic issues—keeping people safe in whatever setting they are served. This work carried Commission staff from OMH crisis services to OMRDD family care homes, reviewing systemic and policy issues, to the failure of caretakers to exercise care and vigilance. Note in the following examples that Commission responses to individual requests for intervention often result in changes or policies affecting many additional individuals in the future.

An HIV+ Resident and Agency Policies

The sister of a mentally retarded adult woman, who was diagnosed HIV positive and was discharged from a large residential program due to her failing health, called the Commission to express concern for the health and safety of the other residents. The Commission's review found that:

- Several residents' capacity to consent to sexual activity was very questionable and the agency had not assessed their capacity;
- The informal sex education for some residents was not sufficient to meet their needs;
- The agency had not adequately investigated the sexual relationships of the residents to determine those in need of testing; and
- Treatment goals had not been formalized for residents who had sexual relationships with multiple partners and those who were not practicing safe sex.

These findings resulted in the agency identifying additional residents for testing and counseling including community clients who had sexual contact with the HIV+ residents or their partners. The agency also reversed its policy that determinations of residents' capacity to consent to sexual activity were intrusive and violated the principles of normalization. The agency developed and implemented a policy consistent with the OMRDD guidelines concerning sexual contact and consent.

The facility also revised the treatment plans of several residents to address their problematic sexual behaviors, and the staff sex education training program was revised and expanded. In addition, the facility agreed to retest in six months the residents who had tested negative and to secure permission for HIV testing each year, at the time of their annual physical, from those persons displaying "at risk" behaviors or from surrogate decision-makers as appropriate.

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Relocation Costs, Adverse Effects on Elderly Halted

In response to the OMH's plan to temporarily relocate all patients at Central Islip Psychiatric Center to interim quarters on the grounds of Pilgrim Psychiatric Center, Commission staff conducted a site visit of both facilities and found that the temporary plan would adversely effect the targeted 357 elderly individuals and that the cost of $750,000 for design and renovation of the temporary quarters at Pilgrim Psychiatric Center, would not result in a physical plant which would meet the needs of the frail patients involved. In response to this finding, the Chairman wrote to critical legislators and expressed the Commission's concerns and objection to the plan. In response to CQC findings and other objections, the Legislature rejected the temporary relocation plan.

Family Care Negligence

At her day program, a resident was found to have second and third degree burns covering 15 percent of her body. The investigation into the cause of the burns revealed that the family care provider had given her a bath in extremely hot water. The provider stated that she was not aware that the woman had been burned when she sent her to the day program.

Commission staff informed the DDSO of the serious concerns regarding the care provided by the family care provider. At the very least, the provider was negligent in leaving the resident alone in the tub for a period of time. Commission staff advo-

cated that the DDSO take corrective measures. Following discussions regarding the incident, the family care provider voluntarily relinquished her operating certificate.

ICF Failures

An anonymous staff member at a Manhattan-based ICF contacted the Commission and alleged that the maintenance worker was verbally abusive towards a resident on two occasions. The complainant also asserted that the residence was in poor condition; that the agency van was being used solely by the maintenance worker and not for resident trips, and the clients therefore only attend local community outings; and there were errors in the administration of another resident's medication.

The Commission investigation, which included several unannounced visits, revealed that the allegations of verbal abuse had been substantiated, and the maintenance worker received written counseling. CQC staff also found significant deficiencies with the physical plant of the residence; condition and maintenance of clothing, personal hygiene supplies, and linens; the provision of in-house and community recreation; adherence to prescribed menus; inadequate food supplies; and inappropriate medication practices, which were conveyed in a letter of findings. Although the agency's reply indicated that they had implemented corrective actions to address many of these issues, it blamed the poor condition of the residence on the clients' identification with institutional living. The agency continued to schedule bogus "recreational" activities (i.e., "chill out night," "maintenance night"), did not use the van for community outings, and falsified a record to cover a medication error. The Commission's final letter asked the agency to respond to these concerns and alerted the board of directors to our concerns.

Contact with OMRDD and review of prior certification reports of all of the agency's programs confirmed that the problems the Commission observed are of a long-standing and repetitive nature. At the time of this writing, the OMRDD was undertaking the decertification of a number of this agency's programs.

Patient Idleness, Basic Needs and Rights

In response to complaints about the lack of activities for inpatients on the adult psychiatric units of a large downstate public hospital, the Commission conducted an unannounced site visit and found the allegations to be true. During the tour of the unit, most patients were still in their beds or dressed in pajamas, and there were no scheduled activities conducted during the time on the unit. Additionally, many beds did not have two sheets and some had no pillowcases.

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As follow-up, Commission staff conducted another unannounced site visit to two of the other adult psychiatric units at the facility. They found some of the same conditions on these two units: idleness, a lack of clothing, incomplete personal hygiene supplies, and shortage of linen. Additionally, CQC staff observed two non-English speaking patients who were not receiving services in their own language, whose treatment plans failed to address their language barrier and who had not received notification of their rights in their own language.

In response to the Commission's concerns about clothing, hospital staff reported that they initiated a Patient Clothing Program to supply clothing to inpatient units. Clothing maintenance is being reinforced as a therapeutic activity and community-appropriate dress is now strongly encouraged on all inpatient units. A Task Force on Therapeutic Environment was established to review recommendations for improving the environments on the inpatient units. Additional supplies of linens were provided. A new position of Associate Director of Clinical Program Development was established and filled, and the hospital took several measures to address the needs of patients who do not speak English. Department heads reinforced patients' rights to privacy and confidentiality and the nursing units were advised that all preprinted protocols and Care Plans must be individualized. Finally, the facility promised to revise the Patients' Rights Handbook and have it translated into Spanish, Chinese and nine other languages.

Right to Privacy

The Commission received a complaint from a county DSS adult protective worker that a male staff member routinely supervised a female resident while she showered. As a result of CQC investigation, the agency revised its policy to now require all personal hygiene care be provided by staff of the same gender. The revised protocol specifically outlines staff-

ing guidelines and considerations in scheduling. Only in extreme circumstances would an opposite gender staff member be required to provide personal care.

Personal Allowance

A resident at a large psychiatric center called the Commission on the toll-free number complaining that he was not receiving his personal allowance money.

In response to this complaint, Commission staff spoke with the treatment team leader on the resident's unit and learned that his Social Security checks were being sent back to the Social Security Office in error and psychiatric center staff had not addressed the issue.

As a result of CQC intervention, the facility contacted the Social Security Office and arranged for the resident's checks to be sent to the Center. In the interim, he received $35.00 per month personal allowance money.

Failures in Supervision and Monitoring

The father of a downstate ICF resident contacted the Commission to report that two weeks earlier his son was scalded and sustained first and second degree burns to his left elbow and left leg. The resident was hospitalized for two weeks and required skin grafts.

The agency investigation found that the resident was left unsupervised during his bath for only a few moments, with the water turned off, but he turned the water on by himself. Commission review found that approximately two months prior to the incident staff were informed that the hot water was "very hot" and potentially dangerous, and they were instructed to monitor the water very closely.

CQC staff also learned that around the same time, the program director had sent a letter to the business officer at the local DDSO requesting the installation of a water mixing valve. Significantly, the letter stated that "this water mixing valve was not included in the *original* installation of the plumbing system.... The lack of this installation has presented problems with water temperature and pressure.... While there is hot water, it is *above* the regulated temperature of 110-120 degrees Fahrenheit and can be a potentially dangerous situation for the residents who are physically disabled and require complete caution during all bathing." The program received no response to this letter before this incident occurred, and the valve was not installed until two weeks after the injury.

The father of a downstate ICF resident contacted the Commission to report that two weeks earlier his son was scalded and sustained first and second degree burns to his left elbow and left leg. The resident was hospitalized for two weeks and required skin grafts.

CQC review also revealed that the most recent OMRDD certification review conducted in November 1992, stated there were no environmental deficiencies. OMRDD's Certification Unit did not have knowledge of the letter written to the Business Officer. Following the Commission's review, DDSO procedures were changed to ensure that "emergency" requests affecting participant safety would be completed expeditiously—within two days.

Improper Use of Restraint

When asked by staff of an OMRDD licensed agency to review a discharge incident involving one of its clients, the Commission's review focused on the use of a restraining camisole by staff of a psychiatric center in the transportation of a discharged patient back to his community residence.

The Commission's review found that the patient, on discharge from the psychiatric center, had refused to get in the agency van returning him to his residence. A doctor ordered that he be restrained by camisole based on his history of aggressive behavior with people who try to hold him. Since there had been no assaultive incidents during his four-day hospitalization, the Commission questioned the camisole's use and the incongruity of the scene, concluding that the unseemly appearance of a non-forensic patient being placed in a camisole for discharge represented a poor discharge decision.

The psychiatric center addressed the Commission's concern stating that the use of the camisole was, arguably, appropriate. While continuing to defend its decision, the administration agreed to amend its current policies to specify the few instances in which a restraint may be used on a person being discharged, e.g., transfer of some forensic patients to another facility.

Family Contact and Communication Policies

The Commission reviewed a father's complaint that he had not heard the results of an agency investigation involving his son. In conjunction with this

and other reports, the Commission cited the Children's Psychiatric Center for failing to provide proper notification of abuse allegations. In confirming the father's complaint, the Commission raised additional concerns with the program:

- While CQC staff found that all support programs were in place at the time of discharge, all the providers of these services expressed concern they were not given enough time to adequately prepare for the child's successful return to the community;
- The agency failed to make required follow-up contacts with the discharged child; and
- The agency had failed to evaluate the child for risk of suicide after he threatened to do so.

The agency, in response to Commission findings, revised the policies and procedure for family contact and communication and retrained clinical staff of their in-care and after-care responsibilities.

Intensive Case Management Concerns

While reviewing an investigation of an alleged abuse and neglect involving a case worker in the Intensive Case Management (ICM) Program, the Commission raised concerns about the operation and oversight of the ICM program. Specifically, there were no policies to address transportation for consumers or for cash disbursements from case managers to consumers. Additionally, the poor quality of the client's treatment plan and the lack of a procedure to resolve a dispute about the service plan surfaced.

Because the concerns raised by the investigation had statewide and regional implications, the facility involved both OMH Regional and Central Offices. As a result of this review, the facility established new polices that addressed all the above concerns, and, in addition, instituted a plan to review all current cases to insure that if similar problems existed they would be addressed.

Sexual Abuse Investigation Failures

As a result of the Commission receiving numerous incidents of client-to-client sexual abuse from a developmental center, CQC reviewed the facility's incident review process, focusing on nine separate incidents and including a review of 16 client treatment records.

The Commission review was critical of the quality and comprehensiveness of the investigations. Specifically, the following were cited:

- Investigation reports failed to indicate that law enforcement agencies were notified of apparent crimes;
- Unit investigations were often not thorough and comprehensive;
- Essential background information was rarely acquired (client history, behavior plans, level of supervision);
- Staff accountability was often not critically evaluated; and
- Unit investigations failed to question the adequacy of treatment plans for clients involved in multiple incidents of sexual abuse.

In response to Commission concerns, new policies for reporting and investigating incidents were developed by the facility. The new guidelines addressed all the Commission's concerns and subsequent investigations have shown significant improvement.

Detecting and Preventing Fiscal Fraud and Abuse

As New York State closes its underused institutions to cut costs and savings are redirected into community services, not-for-profit corporations have become the predominant providers of services that had been previously provided by the State. Considering the large investment in public funds into these corporations and their common goal to provide quality services, it is in the State's interest to insure that they are fiscally responsible and provide efficiently delivered services.

Yet, even though the majority of these providers operate ethically and in the public interest, the Commission continues to see the tension between profit and care. What we find is that in some cases the pecuniary interests of management conflict with the obligations of the corporation. Examples, particularly for programmatically deficient providers, are frequently uncovered of what are effectively "profits" dissipated through excessive executive compensation, overpayment for related party (board members, operation executives, and their family members) transactions with suppliers or involving real estate sales or leases, and general fiscal mismanagement or abuse.

Recognizing the increasing need for "investigating suspected misuses of public funds" by the licensed mental hygiene providers, the New York State Legislature, in approving the Governor's 1993-94 *Executive Budget,* added funding to the Commission's operating budget for the establishment of a five-member fraud and abuse detection team.

This action is reflective of the increasing role the Commission has played in uncovering wasted dollars and profit-making abuses that have directly impacted on the quality of care delivered. In a number of studies, the Commission has found that the licensed not-for-profit corporations functioned as profit-making entities for their senior executives rather than for a public purpose. Understanding some of the abuses which may occur in not-for-profit corporations helps in developing preventive strategies.

This is not to say that these corporations are unregulated. New York's Not-For-Profit-Corporation Law attempts to regulate these agencies through their boards of directors—but the law needs help and cooperation from those being regulated to be effective. The reality is that legal controls have been negated in some corporations by establishing weak boards made up of disinterested or friendly members who either abdicate control to an autonomous executive director or simply don't understand what is expected of them. Commission audits of corporations and reviews of the conduct by their "independent" accountants, on whose reports the State relies to monitor fiscal responsibility, often find minimal board involvement in operations accompanied by failed integrity and inexcusable negligence by its accountants.

During 1992-93, the Commission maintained its efforts to prevent fraud and waste, and supported efforts to vigorously prosecute abuses as a deterrent to other providers. Based on the Commission's work, operators of facilities have been replaced, funds redirected into services and legal actions brought based on the wrongdoing uncovered. The achievement of these objectives can span long time periods because of the administrative action or legal processes that are required to yield the full benefits of the Commission's recommendations.

$1.66 Million Medicaid Settlement

In August 1993, a Stipulation of Settlement in the amount of $1.66 million was signed bringing to a successful conclusion a three and one-half year long effort by the State to recoup Medicaid overpayments to the New York Psychotherapy and Counseling Center (NYPCC) for improper billings to the Medicaid program. These improper billings were identified as a result of a Commission investigation, (*Profit Making in Not-for-Profit Corporations: A Challenge to Regulators,* December 1989) which concluded that NYPCC "has been operating, in large part, for the private interests of agency officers and their families to the detriment of the not-for-profit corporation itself." NYPCC initially responded to OMH's order to desist from its illegal billing practice and DSS' demand for restitution by filing two lawsuits and demanding an administrative hearing. After a num-

Based on the Commission's work, operators of facilities have been replaced, funds redirected into services and legal actions brought based on the wrongdoing uncovered.

ber of hearing days during 1992 and 1993, which included the appearance by the Commission's fiscal staff as expert witnesses, the settlement was entered into, the litigation against the State withdrawn, and the funds repaid.

Action to Enforce $7.5 Million Judgment

The Attorney General's Civil Recovery Bureau brought suit in 1993 to enforce a judgment to recover $7.5 million from the operator of a licensed mental health program. In July 1992, a unanimous decision of the NYS Appellate Division concluded that the State's case, which was based on a 1986 Commission audit, (*Profit Making in Not-for-Profit Care: A Review of the Operations and Financial Practices of Brooklyn Psychosocial Rehabilitation Institute, Inc.,* November 1986), proved "by overwhelming evidence" that a psychiatrist who founded and operated the Brooklyn Psychiatric Rehabilitation Institute (BPRI) established an elaborate scheme to defraud the Medicaid system. A $7.5 million judgment was issued including $5 million in punitive damages against the psychiatrist. This is one of the largest Medicaid fraud judgments ever obtained in New York State. Another $900,000 for rent owed to the psychiatrist's family while the State ran the BPRI facilities in receivership was also dismissed. In a related case, the court ruled that the judgment could be used to offset money due the psychiatrist's family for the State's acquisition of the buildings that house BPRI.

Operating Certificate Revoked

On January 29, 1993, a DSS administrative law judge (ALJ), using the Commission's fiscal staff as expert witness, revoked the license of the HI-LI Manor Home for the Aged, a 125-bed adult home serving a mentally ill population in Far Rockaway, New York. Citing an "extraordinary degree of financial mismanagement, including a quite brazen plundering of the facility and its resident fund accounts" by the home's executives, the ALJ ruled that the licensee, the Hebrew Academy of the Five Towns and Rockaway (HAFTR), failed to demonstrate the financial responsibility and the required character and competence to operate the adult home. In 1992, the Commission released a report on the home and related other human service facilities run by the HI-LI

Detecting Fraud, Re-Couping Wasted Dollars

- $7.5 Million Judgment Against BPRI
- HI-LI Manor Operating Certificate Revoked
- Close Duplicative Billing Loophole to Save $1 million annually
- $1.66 Million Medicaid Settlement Against NYPCC

administrator which documented several million dollars in funds diversion, (*Exploiting the Vulnerable: The Case of HI-LI Manor Home for the Aged and Regulation by the New York State Department of Social Services,* May 1992). The U.S. Attorney for the Eastern District of New York is investigating the wrongdoing by HI-LI's executives and is coordinating enforcement efforts for various federal and state prosecutorial agencies. The State has also revoked the licenses of several ambulance/ambulette companies owned in part by the HI-LI administrator and he has been removed from operating two other adult homes because of lack of financial responsibility. HAFTR is appealing the State's decision to remove it as licensee of the HI-LI facility.

Duplicative Billings

Stemming from an investigation of a client personal funds use complaint, the Commission's fiscal staff in 1993 identified a flaw in OMRDD's supportive community residence billing system which had allowed providers to bill the State for living expenses already paid for by the residents from their monthly SSI checks or paid for by the State pending the receipt of their SSI checks. OMRDD agreed to implement a Commission recommendation to issue a directive to close the billing loophole which will save approximately $1 million annually.

Problem Agency Closes its Doors

In November 1992, the operator of Community Living Alternative, Inc., a 10-bed intermediate care facility located in Flushing, New York, closed its doors and removed all its records to prevent the Commission from determining how the agency's spending practices contributed to substandard care and conditions. The Commission subsequently learned from records obtained by subpoena from third parties (banks, the agency's CPA, etc.) that over 25 percent of the agency's annual $400,000 income was disappearing in checks drawn to cash. The facility is now being operated by a receiver which has restored care to a proper level. Based on the Commission's investigative findings, the United State's Attorney for the Eastern District of New York and the FBI are developing charges against the operator who fled to North Carolina after the facility's closure. The Commission expects a public report on the programmatic and financial problems at this home in 1994.

OMRDD Rate Appeal Process

In March 1993, the Commission's fiscal team began an examination of the official procedures and process (rate appeal and settlements) used by OMRDD for supplementing the rates of reimbursement for services provided by intermediate care facilities and community residences. The impetus for this review stemmed from a Commission investigation of a problem provider which was issued a large rate appeal check to retroactively fund direct care staff that were never hired. The Commission's preliminary findings concerning the performance of the reimbursement system indicate a need to strengthen internal controls in the process. A public report on the process for supplementing the residential reimbursement rates is expected in 1994.

Need to Deter Negligent CPAs

Over the years, the Commission's studies of certain not-for-profit corporations have found serious problems of financial abuse which remain undetected by the regulatory system and almost invariably result in a significantly poorer quality of care.

In many cases where there were serious deficiencies of quality of care, there was a scheme to redirect funds meant for care and treatment to board members, operators, or their families. These schemes were always accompanied by a cover-up, misreporting, or lack of independence by a certified public accountant (CPA) whose reports to the program's Board of Directors and to the State failed to reveal the diversion of funds. The State relies upon the CPA's certified audits and Consolidated Fiscal Report (CFR) submitted by its licensees to ensure fiscal integrity in its programs.

Yet, under New York law an accountant is generally liable in negligence only to his or her own client. Under this rule of "privity," the accountant is liable only to those parties with whom he or she is in contractual privity unless the CPA was aware in advance that a third party would rely on his/her report for a particular purpose. Thus, the State does not have standing to initiate suit against an accountant for negligent practices in connection with the financial report on a mental hygiene program because the State is not the direct client of the accountant. Rather, the mental hygiene program, which must provide the financial report to the State, is the client of the accountant, and as such, is the only party to whom the accountant is liable for negligence. In

Indictments expected in HI-LI scam

By Randi Kreiss

"We are please to hear that indictments are imminent." With those words, the spokesman for a state panel that first shined a spotlight on substandard conditions at HI-LI Manor in far Rockaway, hailed reports of criminal charges about to be filed.

Gary Masline, spokesman for the New York State Commission on Quality of Care for the Mentally Disabled, said he was pleased to hear that sources at the Brooklyn U.S. Attorney General's office have indicated movement on the case after a year-long investigation.

The focus of the probe by Federal and state authorities has been HI-LI Manor in Far Rockaway, an adult home for the mentally disabled, owned and operated by the Hebrew Academy of the Five Towns and Rockaway (HAFTR).

David Kolatch of Lawrence, longtime executive director of HAFTR, and Beryl Zyskind, a former assistant to Mr. Kolatch and manager of HI-LI were charged by the Commission on Quality Care with misappropriating up to $4 million in state and federal funds earmarked for patient care, food and sanitation, over a seven-year period.

HI-LI was called "one of the worst" adult homes in the state by the Commission, "being deficient in virtually every area studied." Investigators said patients were inadequately fed and clothed, subjected to substandard sanitation conditions and health care.

In a comprehensive report issued in June 1992, the Commission said the means used to divert money from the patients were interest free loans, establishment of secret accounts and irregular real estate transfers. The panel said that funds listed on HI-LI's books as "management" fees actually comprised a "slush fund for luxury vehicle rentals, autos, home expenses, jewelry and fur insurance for Mr. Kolatch and/or Mr. Zyskind and their families."

At the time, Franklyn Snitow, attorney for HAFTR, said the report was "unfairly slanted" and that the school "is truly the victim of Beryl Zyskind."

Mr. Kolatch was subsequently placed on a leave of absence; Mr. Zyskind had been dismissed as the HI-LI administrator in December 1991.

The New York State Department of Social Services revoked the operating license held by HAFTR to manage the HI-LI Manor; after HAFTR appealed, the decision to revoke was upheld in February, 1993, by a New York State Administrative Court Judge.

A New York Post story this week reports that Beryl Zyskind is accused of stealing from the 125 elderly and mentally ill HI-LI residents and siphoning the money into his other businesses.

Specifically, the Post says that Mr. Zyskind is charged with depositing a $122,658 check belonging to a mentally disabled veteran into a HI-LI operating account. According to the Commission on Quality Care, the check represented several years of benefits owed to the veteran.

Investigators say Mr. Zyskind used the money to fund another of his adult homes and to cover various operating expenses. The Commission said he did not try to contact the veteran who left HI-LI to live with friends one month before his check came in.

turn, only the program, not the accountant, is liable to the State. And the program is obviously unlikely to pursue litigation against an accountant who has colluded to conceal improper fiscal practices or whose negligence has failed to disclose such practices either to the board of directors or the State, or both.

In its position as creator, licensor, funding source and regulator of the mental hygiene system, the State is clearly a "relying party" with respect to accountants' financial reports on mental hygiene programs. Indeed, the State is really the primary party-in-interest. The programs are operating pursuant to a State license to care for the State's mentally disabled persons, which includes a specific regulatory audit requirement. State and/or federal monies pay for the audits. And, the State intends to rely on the financial reports rather than auditing the thousands of programs itself to ensure the integrity of the programs and the character and competence of the operators.

Thus, the Commission has been proposing statutory or regulatory changes to put the State "in privity" with any and all accountants who complete financial reports and audits for licensed mental hygiene programs. Under its proposal, an accountant who negligently prepares a financial report on a mental hygiene program would be liable to the State for damages the report causes or contributes to causing.

The benefits of these proposals, if adopted, will be:

- the protection of public funds and the State's mentally disabled clients who are served by the mental hygiene programs;
- deterrence of the misuse of the funds, which the Commission has found invariably has an adverse effect on quality of care;
- the deterrence to accountants' misleading or careless audits of the efforts of program operators; and,
- a source for recoupment of not only State funds, but also personal funds of the clients which have been misused or stolen in some cases.

Prevention Through Timely Medical Treatment: The SDMC Program

The Surrogate Decision-Making Committee Program (SDMC), by providing timely consents to major medical treatment, has proven to be an effective prevention tool, preserving and maintaining the health of thousands of individuals since its inception.

Created in 1985 as a demonstration, the SDMC program was made permanent in 1990 and authorized for expansion in 1992 by creating a mechanism for the Commission to enter into agreements with local community dispute resolution centers. During the past year contracts were developed and signed with three centers and the program expanded, now operating in a 20-county area. Projections for expansion into two more counties are foreseen for the near future.

During the reporting period, the SDMC program reviewed 348 cases in which 296 individuals were given consents to receive major medical treatment which had positive effects. Since its beginnings, the program has expeditiously assisted 2,778 individuals in decisions related to major medical treatment.

The 230 dedicated volunteer members operate through four-person panels, composed of a health care professional, a lawyer, a former patient or relative or advocate, and a person with expertise or interest in the care of persons with mental disabilities. Panel members assist people with mental disabilities, who lack the capacity to provide informed consent or have no family members or guardians, and provide (or refuse) surrogate consent on their behalf, promoting the person's autonomy and best interest. As the program continues to expand, new members are being recruited and trained throughout the state.

NYSAC News **January/February 1993**

County Government Volunteers Speed Medical Care to Mentally Disabled

Keith Byron

Senior Assistant Dutchess County Attorney Keith Byron chose a career in county government, but after hours he renders an extra service to local, mentally disabled citizens.

Byron is a volunteer in an award-winning program providing an alternative to the court system in obtaining consent for major medical treatment. He acts on behalf of individuals unable to provide their own informed consent and who have no family or guardian to act on their behalf.

Byron is a volunteer panel member in the state's Surrogate Decision Making Committee Program. The program services individuals living in residential programs of the state's Department of Mental Hygiene. If a resident is deemed mentally incapable of making a decision regarding a medical treatment, a Surrogate Committee panel is authorized to provide substitute consent or refuse the proposed treatment after applying a "best interests of the resident" test.

Keith Byron has served on the Dutchess County Surrogate Decision Making Committee since its inception in 1986. Each of these committees operates with a four member volunteer panel made up of an attorney, medical professional, family member (a person who has been a consumer of mental hygiene services or whose family members have been consumers), and advocate (a person with expertise or interest in the care of the mentally disabled).

The panel meets with the client being considered for a proposed medical procedure prior to making its decision about mental capacity and consent.

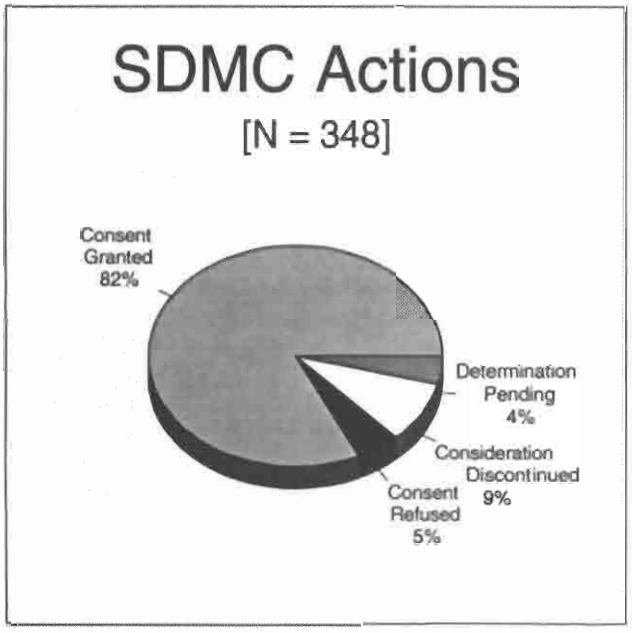
Since the program began in 1986, the surrogate decision making group has functioned in a 14 county area and is administered by the New York State Commission on Quality of Care for the Mentally Disabled. Previous to the current surrogate process, invasive medical treatment decisions were subject to a court review which was not only time-consuming and costly, but often delayed treatment with resultant pain, discomfort or deterioration of the resident's medical condition. The surrogate decision making system is a more timely, less expensive, easily accessible, and a more personalized alternative to the judicial process.

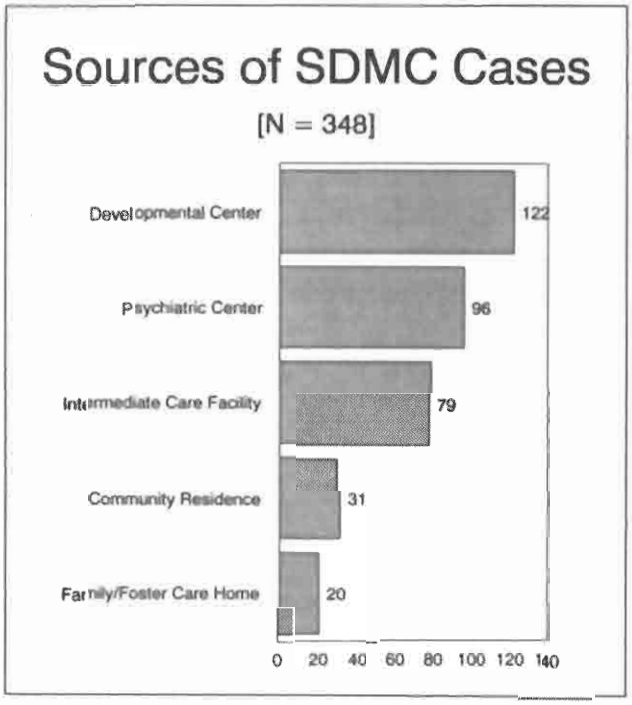
In his role as a surrogate decision making volunteer, Keith Byron has participated in 106 hearings involving 420 cases. These hearings are held in the Hudson Valley area and involve travel on his own time to and from the hearing site, usually a state facility. According to the latest state figures, some 2,600 facility residents have been served by Byron and his fellow volunteers. "What makes this program work is the selfless contributions of so many volunteers who carefully scrutinize the merits of every case before they make a decision," said Clarence J. Sundram, chair of the commission. "This program is an example of the contributions that a public-private partnership can make in improving service to people who are mentally disabled."

Preventing Abuse, Promoting Quality Through Legislation

Legislation on mental hygiene issues also has served extremely important purposes in correcting and preventing abuse and promoting quality of care and treatment. Over the years the Commission has suggested a number of proposals to the Governor and Legislature which have since been codified into law, e.g., Chapter 553 of the Laws of 1992 prohibiting self-dealing and low interest loans for executives in mental hygiene programs; Chapter 145 of the Laws of 1991 requiring senior executives of DMH-licensed agencies entering into less-than-arm's length real property transactions to disclose the material facts of the transaction in writing to their boards of directors and to the DMH commissioners as a condition for public funding; Chapter 730 of the Laws of 1992 clarifying the authority and access of the Commission in investigating deaths of individuals in adult homes; Chapter 675 of the Laws of 1989, a major reform statute pertaining to guardianship; Chapter 354 of the Laws of 1985, the establishment of the Surrogate Decision-Making Committee (SDMC) program; the Child Abuse Prevention Act of 1985 authorizing the Commission to investigate all allegations of child abuse or neglect that originate in residential settings licensed or operated by the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities.

An example of a legislative proposal suggested by the Commission for promoting improvement of care and treatment and prevention of failure in discharge planning was passed by the Legislature and signed by Governor Cuomo during the reporting period as Chapter 135 of the Laws of 1993. This law will allow a patient in a facility to have a friend or advocate of his or her choice to be present when facility staff develop the treatment or discharge plan. The Commission's discharge planning study [see below] pointed out the need for facility staff to be attentive to developing and nurturing informal supports for individuals while they are hospitalized to promote avoidance of the need for rehospitalization. The inclusion of a family member or other significant individual of the patient's choice in the planning process will provide important information and assistance to the facility pertaining to the needs of the patient and the existence of informal caregivers who may collaborate with the facility and support the individual in appropriate treatment and discharge planning. In addition, the participation of this individual will promote advocacy and selection of appropriate treatment goals and planning for services upon discharge.





Prevention Through Education and Training

Education and training are powerful preventive tools, and the Commission, particularly through its Protection & Advocacy contract programs, has been engaged in significant educational efforts over the years. Some examples of the training initiatives during the past year are listed below.

PADD Trainings

Each office in the Commission's Protection and Advocacy for Persons with Developmental Disabilities (PADD) program sets an agenda for the year for providing trainings, conferences or small workshops to groups throughout the assigned catchment area. The topics are generated according to the needs of a particular group and trainings, and, besides being excellent preventive tools, serve as significant ways of providing outreach. The following represents a sampling of statewide PADD trainings:

- The Albany central office of the PADD program sponsors an educational and training unit which has been conducting a statewide series of educational advocacy trainings for parents who wish to serve as their own advocates. In particular, the project has addressed minority families and has conducted bi-lingual trainings. This year the project has responded to requests for training on Transition Planning from school to work.
- How to develop Plans for Achieving Self-Support (PASS) has been a topic of considerable interest and has been presented in PADD conferences in Long Island and Batavia in the Western part of New York State. PASS plans assist individuals to optimize their entitlement and purchase the services necessary for reaching full independence. In particular, individuals have expressed an interest in PASS to assist in their transition from school to work.
- "Guardianship and Future Planning" remains the most frequently requested training topic for the New York City PADD program. Parents are concerned about the future of governmental support for residential care and they are planning to leave their resources to their disabled sons and daughters in a way which will enhance their lives.
- In the Mid- Hudson PADD program, the staff attorney and paralegal conducted trainings on "How to be Your Own Lawyer" concentrating on self-advocacy techniques.
- The aftermath of the *Zebley* decision (liberalizing the definition of disability for childhood Supplemental Security Income) occasioned many training opportunities. In the North Country and Broome County PADD offices, attorneys have conducted trainings on applying for retroactive benefits under *Zebley* and establishing Social Security and Medicaid Trusts to protect the rather substantial benefits.
- New York Lawyers for the Public Interest has had significant success in using radio and television for educational opportunities. Attorneys from the office have been guests on interview shows in which they discussed the Americans with Disabilities Act.
- The classroom provides the best forum for both the Long Island and Albany Law School PADD programs. Here the PADD representatives influence future attorneys, teachers, and human service workers to help insure better community integration.

Disabilities and the Law

During this reporting period, the cable TV series produced jointly by the Commission and the New York State Bar Association developed a powerful tape on the issues surrounding individuals with deafness. The show was taped entirely on location in New York City using a professional director and actors. The story involves an attorney with deafness who becomes a mugging victim and it chronicles his trip to the hospital and his need for sign language interpretation through all stages of treatment. There is a demonstration of some simple signs which would help health care professionals like Emergency Ser-

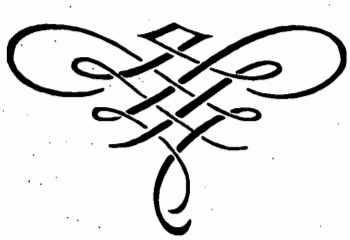
vice workers to communicate with their patients in life threatening situations. Major Albany TV networks, public TV, and cable channels throughout the state aired the show as a public service.

PAIMI Outreach and Public Education/Constituency Training

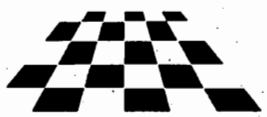
The Protection and Advocacy for Individuals with Mental Illness program provides opportunities for public comment on its activities and priorities. This year, in addition to three public meetings which were scheduled in conjunction with three of the recipient-run small grant projects, PAIMI staff and advisory council expanded the opportunities for comment by participation in conferences of both recipient and family organizations as well as a noted advocacy organization. These included the statewide conference of the Mental Health Association in New York State as well as the statewide conference of the Recipient Empowerment Project and in both instances spent a block of time soliciting and listening to comments from constituencies.

During this reporting period, the Commission's PAIMI program also entered into contracts with six recipient or family groups around New York to provide innovative projects which are meant to enhance the program's goals. The Commission decided to use approximately $50,000 in previously non-obligated PAIMI funds to assist in the establishment of worthwhile advocacy projects. These contracts were for one year projects only, so that if project wishes to continue its activities it would need to seek funding elsewhere to do so. The following are the projects which received PAIMI support during this report period:

- **Mental Health Association in New York City/ Bronx** was awarded a grant to develop its Consumer Advocacy Peer Support project (CAPS) which provides outreach and rights information for metropolitan New York City regarding both specific PAIMI services and the rights of persons involved with mental health treatment in general. The project is staffed by consumers of mental health services. CAPS has developed a bi-lingual (English/Spanish) packet of information which it uses in its outreach activities, and has distributed it widely throughout New York City.
- **Advocacy Coordinating Coalition of Greater Rochester** was funded to provide a self-advocacy training project for recipients of mental health services in a variety of PAIMI-eligible living situations around the metropolitan Rochester area. Trainers are current or former recipients of services. Additionally, once recipients have received advocacy skills training, they will also be offered training in dispute resolution techniques.
- **Community Living Associates, Inc.**, a recipient-run organization in Albany received an award to develop a peer advocacy project at the Capital District Psychiatric Center.
- **WSKG-TV**, a public television station in Binghamton was awarded a grant which partially funds the production of a 30-minute documentary program focusing on the mental health recipient empowerment movement, which includes both family and recipient perspectives as well as information on PAIMI services. Once the program has been completed, it will be distributed to the other public television stations in New York State as well as be available as a training tool.
- **The Alliance for the Mentally Ill in New York State** was awarded a grant to develop an outreach program for family members who are minorities throughout the state. This project will provide several sites for training of minority family members and will also print and distribute widely information both on AMI and the PAIMI program in several languages, including Chinese and Korean as well as English and Spanish.
- **AMI/Albany Relatives**, a local chapter of family members, was awarded a grant to establish the GIFT project (Grants Involving Fun Together), which will provide normalizing and non-stigmatizing recreational and socialization opportunities for recipients of mental health services in the Capital District.



Tracking the Transition to the Community



Willowbrook Closure

During this reporting period, on March 11, 1993, a ceremony was held in New York City concluding 21 years of litigation involving the Willowbrook Developmental Center. At one time Willowbrook was the largest institution for people with mental retardation in the world (almost 6,000 residents), and infamous for inhumane conditions exposed to the public by the media. The official ending of the litigation at this court signing ceremony legally and dramatically concluded one era and marked the transition to a new one.

In a statement to the Court on the occasion of the settlement, the Commission Chairman stated:

> "The signing of that judgment [Willowbrook Consent Decree] was an acknowledgment by government of its obligations not only to protect a class of people long forgotten behind the walls of institutions, but also to affirmatively create opportunities for them to return to society, to become a part of the community and to lead more normal lives. I have no doubt that, when the history of mental retardation in this century is written, the signing of the Willowbrook Consent Judgment will be regarded as a significant turning point in public policy."

Now the focus of concern in public policy is tracking the transition of individuals with mental disabilities to more "normalized" life in the community. What types of services and safeguards are necessary? What kinds of monitoring and oversight is in place? In the past few years, these have been central concerns of the Commission's oversight role.

Discharge Planning Practices

One of the many aspects of successful transition to the community is careful discharge planning for persons who have been hospitalized to assure their access to continued mental health treatment, appropriate housing, and necessary rehabilitation services and supports to live successfully in the community.

In an effort to improve service provision and accessibility to patients with serious mental illness, the Office of Mental Health and the State Hospital Review and Planning Council piloted new inpatient and outpatient reimbursement methodologies that provided incentive payments of approximately $20 million to hospitals and community mental health programs.

In response to a request by the Office of Mental Health and the State Hospital Review and Planning Council to evaluate the effectiveness of these new reimbursement methodologies and to determine whether these fiscal incentives had any adverse impact upon patients, the Commission conducted a study of the discharge practices of 10 hospitals across the state and retraced the experiences of 100 patients admitted to and discharged from these facilities.

The findings of the Commission's review are sobering. The Commission concluded that the incentive payments which resulted in the expenditure of approximately $20 million in 1992, failed to influence changes in provider practices as intended. There were, however, some aspects of discharge planning which improved greatly since they were last studied by the Commission in 1988. On the positive side:

- more patients had a clearly identified discharge plan in the hospital record;
- more patients were given a referral to an outpatient program with a specific appointment upon discharge; and
- housing arrangements were made for all patients upon discharge.

At the same time, many other unsatisfactory conditions did not change. Inpatient stays continued to be used largely for crisis stabilization, patients and families were usually not meaningfully involved in the preparation of discharge plans or provided with much voice or choice in services to be provided, and once discharged, patients were typically left on their own to negotiate a complex web of human service programs operated by multiple state, local, and private agencies.

Follow-up of the 100 discharged individuals in the Commission's study, revealed significant gaps in

Willowbrook Closure

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- Clarence J. Sundram

care. Over one-third of the individuals had been rehospitalized at least once during the six-month follow-up period, nearly one-fourth made no known service contact, and most received only two hours of clinical services monthly. Many of these 100 individuals also experienced financial problems, or changes in residence, or serious illness, or drug and alcohol abuse. In addition, nine individuals had been homeless for some period of time during the follow-up period, seven had trouble with the law, and two had died.

The Commission believes that in order to improve discharge outcomes for patients, fundamental changes in policy goals need to occur. It is imperative that patients and families become meaningfully involved in treatment planning, in identifying the types of services needed upon discharge, and in obtaining the supports necessary to reintegrate into the community. This will require greater emphasis on vocational, social, and psychiatric rehabilitation services rather that continuing almost exclusive reliance on low levels of clinical services, as well as increased emphasis on consumer-directed services and family support programs. Finally, the Commission believes that the use of *clear, visible, substantial, measurable, beneficial,* and *closely monitored* fiscal incentives to change provider behavior and practices should continue to be explored.

In response to the findings of the Commission's report and in recognition of the concerns of individuals with serious and persistent mental illness, the Office of Mental Health has discontinued the State's Alternative Reimbursement methodology (ARMs) for inpatient and outpatient mental health services. The Office of Mental Health is also developing an educational/advocacy program for family and recipient organizations which will address some of the discharge planning issues of psychiatric units of general hospitals identified in the Commission report.

NEWSDAY **April 29, 1993**

Follow-Ups Are Key

Report notes flaws in mental-health system

By Jim Puzzanghera
STAFF WRITER

Homeless and abusing drugs, Mike was involuntarily admitted to a Long Island hospital in 1991 for psychiatric treatment, and was diagnosed with depressive, personality and substance-abuse disorders.

Mike, a pseudonym for a 22-year-old patient, was not at a psychiatric center because the state in the late 1980s shifted responsibility for short-term, acute mental-health care to general hospitals. He was released after five days, with appointments for a mental health clinic and a drug treatment program.

That specific discharge plan, according to a new state report, was a great improvement over discharges from general hospitals five years ago. But Mike's case also points up one of the major problems those hospitals are having in treating the mentally ill—six months after his discharge, the study found that Mike had not kept his appointments and that nobody at the hospital or the clinic knew where he was.

"This is the first line of entry. . .so the functioning of these hospitals becomes extremely critical in the functioning of the whole mental health system," said Clarence J. Sundram, chairman of the state's Commission on Quality of Care for the Mentally Disabled. "The general hospitals are doing a reasonably good job of crisis stabilization. . .what the study suggests is that we're doing a less thorough job in assessing what it is that the patient is going to need to live in the community."

The commission's study, to be officially released today, found that although 97 percent of the 100 patients studied had a clearly stated discharge plan when they left the hospital, 22 percent received no follow-up services during the six months after they were released.

The result was that 38 percent of the patients were rehospitalized during those six months, with 13 percent returning more than once. The rates were higher in New York City and on Long Island, where 50 percent of the patients in the study were rehospitalized, compared with 24 percent upstate.

The findings spurred the commission to make three major recommendations: that patients and their families be more involved in discharge planning; that the state Office of Mental Health provide more vocational, social and family-support programs; and that the mental health office rework the Medicaid reimbursement system that has failed to provide incentives for hospitals to reduce the high rate at which patients return.

"We certainly believe that discharge planning could be infinitely more improved. It ranges from abysmal to poor," said Sadie Hofstein, executive director of the Mental Health Association of Nassau County, an advocacy and educational organization.

State Mental Health Commissioner Richard Surles wrote to the commission that he agreed with the recommendations and already was working on a new Medicaid reimbursement system and an educational and advocacy program for families. Providing more diverse outpatient services is a long-term goal, but restructuring the system will be difficult, Surles said.

The commission's study follows one in 1988 that found that, although 85 percent of the patients discharged had outpatient services arranged by the hospitals, only 40 percent had specific appointments. The number with specific appointments increased to 80 percent in the latest study, which involved a random sample of 100 patients at 10 hospitals statewide. . .

Adult Homes

New York's mental health system is changing from a largely institutionally-based system to one where most individuals with serious mental illness will be treated in the community. Community-based services can provide more freedom, more chances to obtain daily living and vocational skills, and more opportunities for individuals to enjoy their adult life with fewer restrictions on their civil liberties.

For persons with serious mental illness, the transition from institutional-based care to community services has not been without casualty—the most serious being death. Two deaths involving individuals who were discharged from state psychiatric centers to chronically deficient adult homes poignantly revealed the failure of psychiatric centers to meet their legal responsibility for discharge planning and follow-up, and community and social service agencies to coordinate and deliver medical and outpatient mental health care, and case management.

The Commission highlighted the stories of Serina Williams and Nicholas Cooper as illustrative of the problems that have evolved for many individuals who had lived much of their lives in institutions and then were abruptly expected to adjust to living in the community, often through placement in adult homes with long histories of poor conditions.

Both Serina Williams and Nicholas Cooper (pseudonyms) had spent more than 30 years of their lives in large state institutions, and, for both, discharge into the community marked many changes in their daily lives and personal responsibilities for their self-care. Neither adjusted to these live changes well. At the adult home, Serina was mute. She was unable to shower or dress herself, or complete her activities of daily living. Serina's days were spent sitting in the home's lounge, pacing the floors, and

Gloversville Leader-Herald **August 25, 1993**

Report criticizes 'safety net'

ALBANY, N.Y. (AP) — A watchdog agency has sharply criticized the state for discharging mentally ill patients who have lived for decades in psychiatric centers without adequately arranging for their care in the community.

The report from the Commission on Quality of Care For the Mentally Disabled on Tuesday cited the cases of two deaths related to the discharge of two long-time psychiatric center patients.

It gives new ammunition to advocates who are pressing the state to spend more money on the thousands of mentally ill patients who have left state institutions over the last decade.

"Many long-term patients...are simply not ready to live outside the hospital without considerable support and supervision, which does not currently exist in most communities," the report by the Commission on Quality of Care For the Mentally Disabled said.

The state Office of Mental Health said it is working aggressively to correct any shortcomings.

The population of New York's psychiatric centers has dropped from more than 21,000 in August 1983 to 10,511 now, state officials said. Many of those cutbacks came during the state's financial troubles over the last few years.

The commission's report focused on a 73-year-old man who was discharged from the Pilgrim psychiatric center in Long Island into a local adult home after 35 years in mental hospitals. The man, who was not identified, was discharged in July 1991 eight days after his treatment team concluded he should stay in the hospital, the report said.

He died that October. Despite concerns raised about his dirty appearance and mismanagement of medication at the Brentwood adult home, there is no evidence that anyone from Pilgrim contacted him during his last month of life, the report said.

A 60-year-old woman, who had been in various state-run institutions since 1949, was shifted to the New Queen Esther Home for Adults in Queens in 1991.

A year later, after worries about her behavior raised by staff members were ignored, the woman allegedly assaulted an elderly adult home resident who later died from her injuries, the report said.

The commission said the same budget pressures that are forcing the state to discharge patients are also preventing the development of services that will help those people in the community.

"There is no single place to which patients can go to have all their needs met for food, clothing, shelter and medical and psychiatric care, nor a reliable mechanism to assemble and deliver a comprehensive and dependable package of these services to them," the report said.

A spokesman for the Office of Mental Health said investigations are continuing into the two deaths. He also said the department will soon begin a pilot program designed to more effectively get these services to patients.

"We regard these as anomalies, not part of an ongoing pattern," spokesman Roger Klingman said.

Responded Clarence Sundram, commission chairman: "I wish that was so. Unfortunately, we have investigated too many cases of patients that have been inappropriately discharged into facilities that were incapable of meeting their needs."

While these cases haven't resulted in deaths, there has been some long-term neglect.

The commission recommended the state Office of Mental Health more rigorously follow its own guidelines for discharging patients and extend these rules to the psychiatric units of regular hospitals.

Unfortunately, what currently exists in many communities is a loose "patch work" of programs serving persons with serious mental illness; there is no one place or reliable process to coordinate and deliver services to meet the individuals' long-term needs for food, clothing, shelter, medical, and psychiatric care.

"smoking like crazy." Nicholas had similar struggles. He generally looked dirty and unkempt and needed frequent reminders to shave, shower, and change his clothes. Nicholas thought he was a fighter pilot waging war against the Japanese, however, he spent his days walking alone in the community and hanging out at the local shopping plaza.

Both Serina and Nicholas were discharged to adult homes, New Queen Esther Home for Adults and Brentwood Adult Home, which had been cited by the Department of Social Services for many serious deficiencies in the provisions of basic custodial care and services for years. At their best, adult homes are designed and funded to provide a significantly lower level of support and supervision than the state psychiatric centers where Serina and Nicholas had spent most of their adult lives. Their discharge to adult homes, known not to even meet these minimal compliance standards, could not ensure that they would receive the level of support, assistance, and mental health services they needed.

The Commission highlighted the stories of Serina Williams and Nicholas Cooper as illustrative of the problems that have evolved for many individuals who had lived much of their lives in institutions and then were abruptly expected to adjust to living in the community, often through placement in adult homes with long histories of poor conditions. Many long-term patients are not ready or able to live outside the psychiatric center without considerable support and supervision. Unfortunately, what currently exists in many communities is a loose "patch work" of programs serving persons with serious mental illness; there is no one place or reliable process to coordinate and deliver services to meet the individuals' long-term needs for food, clothing, shelter, medical, and psychiatric care.

The Commission's report recommended that plans for further inpatient census reduction at state psychiatric centers include commitment of adequate resources to develop a range of community residential and support services for severely impaired individuals who have for years depended on the protection and care of state institutions. The Commission also recommended that the Office of Mental Health extend discharge planning and follow-up requirements to psychiatric units of community hospitals and also urged the Office of Mental Health to assess the level of care needed by adult home residents with mental illness and to develop a more appropriate model of care to better address their needs.

As a result of the Commission's report, the Office of Mental Health halted admissions to one of the adult homes, which was subsequently closed by the Department of Social Services. The Department has also taken enforcement actions against the second adult home, although the Office of Mental Health has taken no formal actions to halt discharges to this facility from neighboring state psychiatric centers.

As of this writing, there are several proposals in the 1994-95 Executive Budget and 1994 legislative proposals. The Executive Budget includes an adult home initiative providing for Supportive Case Management teams, which, besides providing a context for transferring staff who would have been laid off from closed or downsized psychiatric centers, offers new prospects for accountability in such areas as discharge planning and case management. Legislative initiatives include a proposal for a quality improvement program to enhance funding for adult homes that have met or exceeded state standards, and the establishment of a special Commission oversight team for adult homes and an Adult Home Advocacy Program administered by the Commission. If approved, these initiatives will begin a process of reform identified by the Commission in its 1990 report on adult homes, *Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services, and Regulation.*

Parents Who Are Mentally Retarded

Being a parent and being mentally retarded have never been mutually exclusive, but in most New York communities today service providers are more aware of these parents and their special parenting assistance needs—as well as their high risk of losing the custody of their children if ample supports and training are not provided. Like these service providers, the Commission too has been periodically called upon to assist parents with mental retardation as they struggle to meet the parenting needs of their children and often with child protective workers and family courts to maintain the custody of their children.

Over the past year the Commission had the opportunity to study and learn more systematically about the needs of parents who are mentally retarded. In several New York communities, special parenting programs funded by the New York State Developmental Disabilities Planning Council (DDPC), were established to meet the needs of these families and helping them to remain together. The Council asked the Commission to evaluate the effectiveness of these programs, most of which had been operational for about two years, to make recommendations to strengthen their effectiveness, and to explore options, as appropriate, for the continued long-term funding of the programs. In the course of its study, the Commission profiled 41 families using the eight programs (about half of their service population), met with program administrators and family workers, visited families in their homes, and interviewed child preventive services programs in the communities, which were usually also serving the families.

In a two-volume report, the Commission found that the well-being of the 41 families varied considerably, with some having done well, while others experienced many problems often associated with alcohol abuse by one or both parents, social isolation, and reluctance to participate or follow the advice or parenting support programs in which they were involved. In addition, the problems of some families often had serious implications for the children. The Commission found that nearly half of the families had been the subject of at least one allegation of child abuse or neglect to the State Hotline, and approximately one-fourth of the children living at home with the 41 families did not receive adequate medical care, dental care, or nutrition.

Heterogeneity also seemed to be the trademark of the eight parenting programs. The Commission's report documented the efforts of these eight unique programs to find suitable housing for families, to make important arrangements for medical and dental services, and to provide regular in-home training for parents in tasks as varied as changing diapers, planning nutritious meals, and using public transportation.

Despite the programs' well-intentioned efforts to provide services, and, in many cases, to befriend families, many of the families had on-going difficulties. Noting that many of the families experienced continuing crises, even with services, and that many of the children were at high risk, both because of their parents' disabilities and their own identified handicapping conditions, the Commission advocated that programs develop more formal risk management procedures and better working relationships with local child protective and preventive service agencies. The Commission also strongly recommended to government policymakers that long-term studies of these families be undertaken to better understand their needs, strengths, and difficulties as children grow from infancy through childhood to adolescence.

Utica Observer-Dispatch **July 31, 1992**

'Superhuman' image stressful

Some parents of developmentally disabled children sometimes have hard time coping with responsibility

Health: New York doesn't do enough to protect the developmentally disabled from abuse, a state commission says.

By MICHAEL J. WOODS
Observer-Dispatch

Parents who care for their developmentally disabled children at home often feed "frustrated, angry, even guilty at themselves for not being superhuman," a local advocate said yesterday.

If these families don't get occasional help, if they aren't able to have a respite now and then from their difficult caretaker's role, the stress can be overwhelming, said Donna Wenz, director of the Utica-based Parent Advocates for the Retarded and Developmentally Disabled. In a worse case scenario, developmentally disabled children may end up being abused by the same parents or other family members who have made the difficult decision to love and care for them.

"Stress can lead to abuse," Wenz said. "Families have to be almost superhuman to provide this kind of 24-hour care."

She was reacting to a report by a watchdog group that said the state should provide more help and training to such families, and make more facilities available for them to take periodic breaks.

The state Commission on Quality of Care for the Mentally Disabled, which did the study, said that of 4,000 annual reports of abuse or neglect of a mentally ill or developmentally disabled person in New York, 9 percent involve the person's parent or other family member.

For the developmentally disabled in day treatment programs, one out of four cases of abuse involves the family, and the typical victim—seven out of 10 times—is a young woman, the commission said.

Wenz said she was not aware of any abuse cases locally, but she said she has heard a range of emotions expressed by parents—from frustration to anger—to suggest that respite services might be one way to counteract any tendency toward abuse. . .

Watching Over the Children

In recent years, the Commission has placed an increasing priority in monitoring services to children in the mental hygiene system. Chapter 548 of the Laws of 1989 recognized that oversight of services for children in out-of-home placements is particularly important, since many of these children have no natural advocates who are in a position to watch over them. Accordingly, this legislation enhanced the ability of the Commission to monitor the care and treatment of children in mental hygiene facilities. Besides the Commission's role of investigating allegations of child abuse and neglect emanating from these residential facilities (in addition to interventions by quality assurance and advocacy staff discussed elsewhere in this report), the Commission has manifested a significant oversight presence for children with disabilities.

Children in the Mental Hygiene System

Over the past year, the Commission has learned much about the system of mental hygiene services for children. One of the aspects of the service system that has become undeniably apparent is that the system is calling for significant structural reform—a reform that requires serving children and their families more effectively and uses more efficiently the substantial amount of public money devoted to the system.

During 1992-93, the Commission's activities on behalf of children included two major policy studies—one described the lives of 100 children from 18 residential programs across New York State, along with an additional 34 children who had been discharged two years ago; the other comprehensively reviewed the care and treatment provided to children and adolescents at 10 psychiatric services of general hospitals. Both of these systemic studies, prompted serious questions and concerns such as, "Are we getting what we pay for"? "How do we reform costly, fragmented services"? "What makes services better"? "Are some practices clearly out-of-bounds"?

Residential Services

The Commission's study of residential programs revealed that children usually receive a "safe haven," but their placements frequently mark the beginning of a long journey through multiple child care systems. Ironically, it seemed that the price of protecting these children from the harmful conditions in their families was often at the expense of the attributes of a normal childhood. With a first-hand look, the Commission saw that these children were often robbed of their childhood, first by the desperate conditions in their family lives, and then by the very design of the service systems that kept them moving from one placement to another.

Other troubling findings were that:

- treatment failed to focus on crucial issues such as prior history of abuse and neglect, dysfunctions within the family, sex education, and vocational training,

The Commission's study of residential programs revealed that children usually receive a "safe haven," but their placements frequently mark the beginning of a long journey through multiple child care systems.

- 75% of the children had no psychotic symptoms or diagnoses and almost all were receiving psychotropic medications, many without adequate monitoring by staff, and most without signed informed consent by the parent/guardian for administration of the drugs, and
- the different service systems appeared to work rarely as partners in a common effort to meet the needs of children and families, rather they appeared to narrowly focus on performing their own specialized task.

The Office of Mental Health shared some of the Commission's concerns about the care and treatment of children with serious emotional disturbances and responded to some of the many challenges and recommendations outlined in the Commission's report. For example, the Office of Mental Health:

- restated their commitment to a community-based system of care for children with serious and emotional disturbances and have made the development of that system a priority;
- established a work group to review the use of psychotropic medications and chemical restraint in children's state-operated inpatient programs and make recommendations for all children's residential programs; and
- made it a priority to ensure permanency planning for children, and, if appropriate, the placement of siblings together in residential programs.

Although the Department of Social Services found that the Commission's report "raised important and troubling questions about the needs of children with emotional difficulties," it did not put forth any proposed solutions to the concerns and challenges raised

in the Commission's report. Rather, DSS suggested that the Commission's report be modified by taking into account the DSS' concerns, and that the Commission's proposed solutions not only be desirable, but also practical and achievable.

Children's Psychiatric Units in General Hospitals

Related issues also surfaced during the Commission's review of 10 children's and adolescents' psychiatric units of community hospitals. Although there were pockets of exemplary practice at some hospitals, and obvious efforts by staff and administrators to go the extra mile to make things better for kids existed at other hospitals, practices noted in some hospitals clearly seemed far from creating a therapeutic environment for the treatment and nurturing of children with emotional problems.

For example:

- Mechanical restraints and frequent PRN and STAT administrations of psychotropic medications seemed to be common forms of behavior management on one hospital's psychiatric unit for 7 of 12 children who were between the ages of 5 and 11 years.
- At four hospitals, regular opportunities for children and adolescents to go outside were not a priority of hospital staff, with some children on these units never having had the opportunity to go outside for their entire hospital stay.
- At one hospital, there were no pictures on the walls, windows had no curtains/shades, bedrooms were barren, and many beds were missing pillows, linens, and bedspreads. At another hospital, roaches were crawling on table surfaces and floors.

The picture, however, is not all bleak. Many hospitals and residential programs serving children, eagerly responded to the challenges articulated in the Commission's reports. For example:

- some programs make children and family involvement in treatment a priority;
- at some hospitals nursing staff took steps to ensure children know what medications they were taking and why;
- some programs began measures to reduce STAT and PRN medications;
- some began extra initiatives to ensure a fuller schedule of active programming;

Legislative Gazette **April 5, 1993**

Commission wants child psychiatric care reform

By KRIS DOLINSKI
Gazette staff writer

Significant reform is needed to help children with emotional problems and their families, according to the State Commission on Quality of Care for the Mentally Disabled.

That reform, said Commission Chairman Clarence J. Sundram, must include more efficient use of the money spent by the Office of Mental Health each year to provide a stable environment for children in facilities.

Reform also must include assigning one caseworker per child and improved monitoring of psychotropic medication to children.

The commission noted that 95 percent of the money in the mental health system spent on inpatient care for children goes for hospital-based services which cost $210,000 per bed annually, state psychiatric centers which cost $178,000 per bed annually and residential treatment facilities costing $78,000 per bed annually.

According to the report, about 60 percent of the children in state psychiatric centers were ready for release but remained in expensive facilities because of a lack in family-based treatment programs and community residences which only cost between $36,000-$53,500 per bed annually.

Steven Sanders, Assembly chair of the Mental Health and Developmental Disabilities Committee, said his proposal for community reinvestment of dollars saved by closing state psychiatric centers would make funding available for the development of the needed community programs.

His counterpart in the Senate, Nicholas Spano, said children do not need the institutional setting of the psychiatric centers, "where they are often overmedicated, do not get the family-level support they need, and come away with a stigma that can follow them for the rest of their lives. We must establish a community-based system of care for these children as soon as possible."

Sundram said children are also placed through multiple child care systems because of changed diagnoses, growing up, bad behavior or even success in programs.

Sundram added that moving children from one system to another—moving them from the Department of Social Services to a mental facility to the Division of Youth—is not upholding the commission's ideal of consistency in a child's life. "These children are often robbed of their childhood, first by the desperate conditions in their family lives that bring them to the attention of the child care system, and then by the very design of the service systems that keep them moving from one placement to another," the commission report said.

"Adults have a single overarching obligation: to provide children a safe, stable and nurturing environment in which to grow into responsible citizens. We simply have to do better."

- some stood above others in efforts to create personalized and comfortable therapeutic environments; and
- some were more conscientious about making discharge a positive experience.

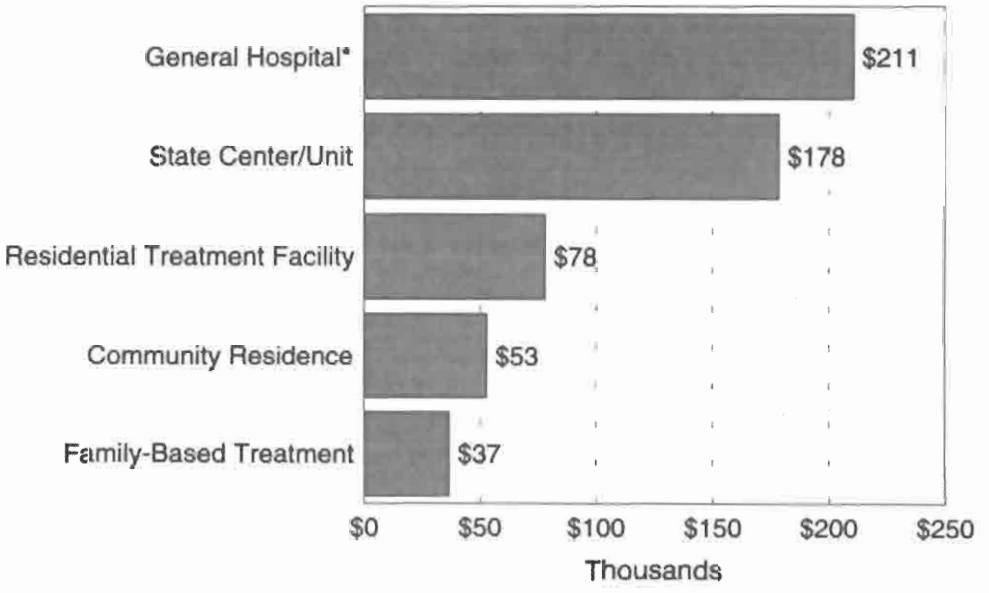
The Commission's reports, however, also included several systemic recommendations that have yet to see fruition. The Commission believes that there needs to be a development of integrated services through "block grants" to localities, pooling the various current funds for family and children's services, with incentives to tailor flexible family and child-centered approaches driven by the family's and children's needs rather than diagnostic labels, eligibility, or the type of program in which they are enrolled. A single point of entry for children thought to require out-of-home placements, and waivers of eligibility and continued stay criteria to promote permanency planning and allow children who have improved and no longer have mental health diagnoses to remain in successful family placements, are also recommended by the Commission.

Additionally, the Commission's reports repeat earlier recommendations urging clear guidelines requiring the cautious use of psychotropic drugs and chemical restraints, along with the provision of information on intended effects and likely side effects of medication, and written informed consent from parents/guardians, and more explicit Office of Mental Health guidelines governing the use of physical restraints and seclusion with children.

Although responses to the Commission's reports have been largely favorable—the Office of Mental Health concurred with many of the recommendations, the Commissioner of Education expressed support for several of the key recommendations, the Council on Children and Families endorsed the recommendations—the Department of Social Services disagreed with many of the findings and recommendations, citing legal, funding, and other barriers. There is one recommendation, however, that no one can afford not to endorse, and that is: "Adults have a single overarching obligation: to provide children a safe, stable and nurturing environment in which to grow into responsible citizens. We simply have to do better."

Annual Costs of Children Residential Care by Program Type

[FY 1989-90]



* Estimated based on 10 hosptials' costs which accounted for 65% of all days of inpatient psychiatric services provided to children in Article 28 hospitals.

Monitoring Child Abuse

The Commission has been entrusted with the investigation of reports of child abuse and neglect accepted by the State Central Register (SCR) on behalf of most children living in residential programs certified by the Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities. During the report period the Commission investigated 116 SCR cases, the majority in programs operated or certified by the Office of Mental Health. Cases are generally investigated in 60 days, and a recommendation is forwarded to the Department of Social Services (DSS) to indicate or to unfound the case. Cases are indicated when there is "some credible evidence" that the child has been abused or neglected as defined in DSS law. An abused or neglected child is one who has incurred some harm or been placed at substantial risk of harm by other than accidental means by the actions of the subject named in the report. If the investigation uncovers no harm, no risk of harm, or no breach of duty on the part of the subject, the case is unfounded.

The largest number of cases involved allegations of physical abuse, followed by cases alleging sexual abuse. In the 75 cases of allegations of physical abuse, many involved situations where staff were trying to physically intervene with a child or youth, often attempting to take the youth down or attempting to get the child into a quiet room. In the midst of these interventions, it was not uncommon for a child or a staff member to sustain a minor injury—scratch, small rug burn or bruise. The Commission's work, in addition to determining whether the child had been abused or neglected, was to help the facility look critically at the response of staff as the incident was unfolding to identify what, if any, additional actions could have been taken by staff to defuse the situation and avoid the need for a confrontation.

The 15 SCR cases related to restraint and seclusion alleged that the child was improperly or unlawfully restrained with a mechanical restraining device, e.g., restraining sheet or four-point restraint and thereby suffered a physical injury or impairment of his/her emotional or mental condition.

The case examples which follow provide a fuller picture of the nature of the Commission's SCR investigations, including the types of allegations, some techniques for finding information under particular circumstances, and the outcomes. They also illustrate an important aspect of the Commission's work on SCR cases: the identification and recommendation of corrective actions and the review of their effective implementation—essential components of our work to make children and youth served by the mental hygiene system safer.

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The Commission is often able to identify staff training needs and agency policies that are unclear and incomplete. Unmet clinical needs of the children and youths are often revealed in the course of investigations, the need to work more closely with families and keep them apprised of what is going on is an issue that also frequently surfaces. The need for more activities such as homework, participation in the larger community, and engaging recreational activities to keep children happy and busy also figure regularly in many abuse/neglect cases because, as reported above, the children who have little to do and a lot of free time often get into contests of will with staff members. Punishments, angry feelings, physical interventions and then allegations of having been hurt commonly follow. As one would expect, the Commission staff are also able to identify the strengths and weaknesses of the facility's investigation and are able to assist facilities in improving their procedures for the identification and review of incidents.

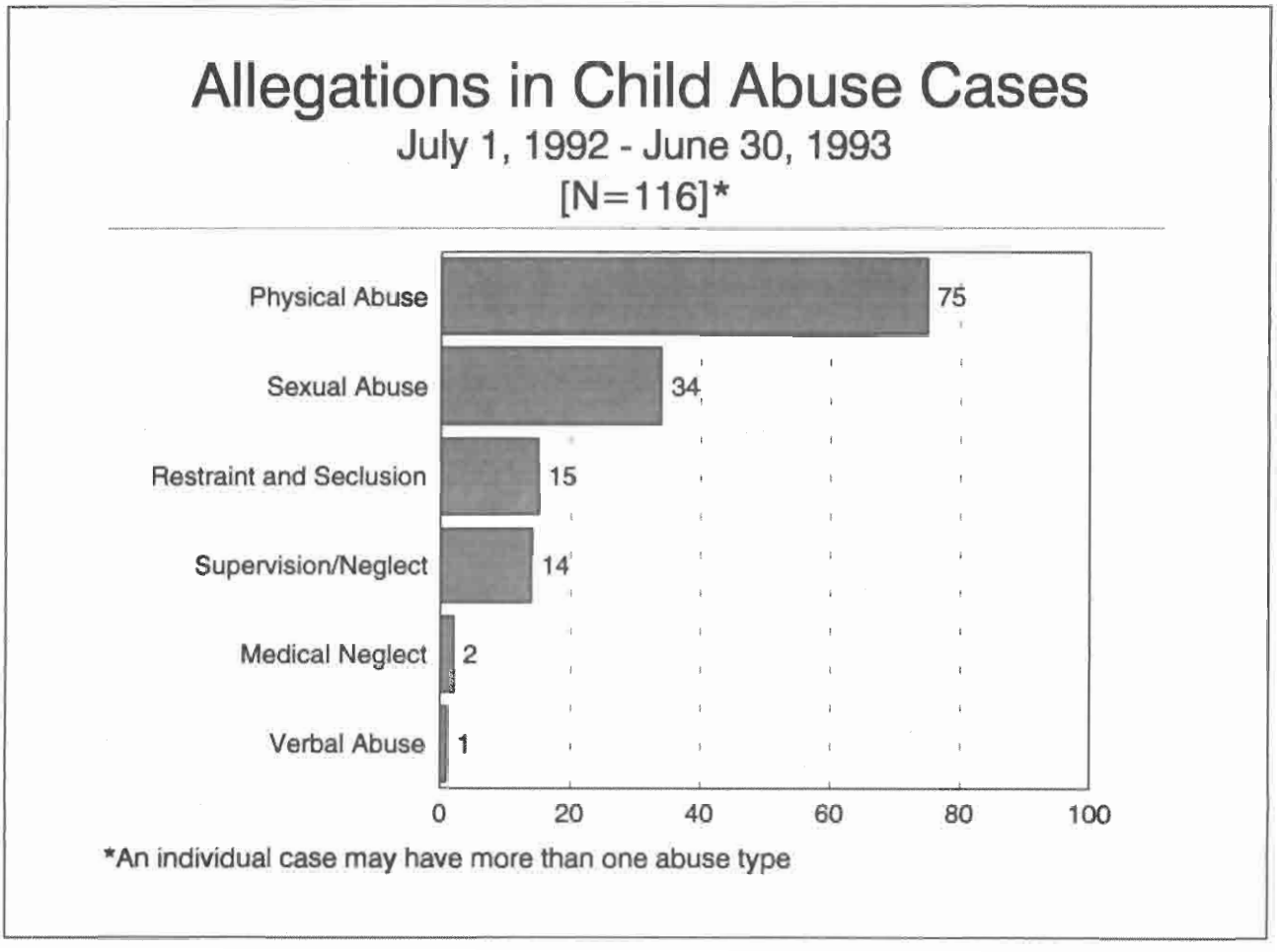
- A friend of Laura's told staff that Laura (14-years-old) had told her that she had been kissed and fondled by staff member, Mr. A. When staff inter-

viewed Laura she denied that anything like this had happened. Three days later, however, she admitted to staff that the allegations she had made to her friend were true. She explained that on three separate occasions Mr. A. had kissed and fondled her: once when she was in her bed, once in the swimming pool, and once on a bus trip. On the latter occasion he had put two fingers into her vagina. Laura was examined by a physician at a local emergency room. This exam revealed no injury or sexually transmitted disease and indicated that Laura's hymen was intact. Her psychiatrist determined that she was credible.

Mr. A. denied any wrongdoing. No witnesses saw anything unusual during the bus trip. It was verified that it was dark, and Laura and Mr. A. were sitting together on the same seat. Laura's friend to whom she had originally confided said that she had witnessed Mr. A. fondle Laura at the pool. About a week into the investigation, Laura produced a love poem in Mr. A.'s handwriting which she said he had given to her. Mr. A. countered saying that he had simply agreed to Laura's request to put her own words into verse. A second patient stepped forward and alleged that Mr. A. had offered to kiss her also and to "rub all your problems away." Further investigation revealed that Mr. A. had been warned by several staff, including supervisory and senior clinical staff, to stop spending so much time with Laura and being "inappropriately exclusive" with her. The Commission consulted expert medical testimony which confirmed that the intact hymen was not inconsistent with the allegations.

The Commission recommended that this case be indicated for sexual abuse. Mr. A. resigned during his CQC interrogation and the case was referred to law enforcement.

- Donna, a 14-year-old youth, reported to her Parole Officer that she had had a sexual relationship with a staff member at an OMH facility where she had resided earlier in the year. She named the staff member but told the Parole Officer that she would deny the allegation if questioned about it. The youth's mother contended that she had a letter from her daughter to the male staff member which referenced the affair. Donna's clinical his-



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tory was complicated: she had made several false allegations of sexual abuse against facility staff in the past; she had also made allegations of sexual abuse against family members who were arrested and convicted of the charges. The Parole Officer, the police, the facility, and CQC agreed that multiple interviews of the youth would be unwise. She was interviewed by a caseworker with whom she was familiar with the police observing in the room. She denied the affair adamantly. When her mother was asked to produce the corroborating letter, she could not find it and said she remembered that there was no sexual content to the letter. The case was unfounded for lack of credible evidence of sexual abuse.

- J.J., a 14-year-old resident of a large OMH children's facility, alleged to his mom that two days earlier he had been hit in the face "five or six times" and hit in the head several times while he was being placed in the seclusion room. The Commission's investigation revealed that there were no witnesses to the seclusion, and the youth had sustained a one-half inch cut on his upper lip and a nickel-sized lump on the left side of his head. The subject reported that J.J. had been yelling and cursing much of the evening, a fact confirmed by the other children and staff. According to the subject, he was attempting to remove J.J.'s sneakers before he put him into seclusion (J.J. had previously tried to choke himself with the laces when in seclusion) when J.J. struggled hard, attempted to bite the subject's knee, and bumped his head against the edge of the door. The Commission recommended that this case be unfounded because the injuries did not require any treatment—an injury must be more serious than a minor injury according to the child abuse statute to support a finding of abuse or neglect—and there was no evidence of substantial risk of harm. Because J.J.'s injuries were not consistent with his allegation of having been repeatedly struck on the head and face, and because the employee had promptly called the nurse to examine J.J. when the incident had occurred, and had made a case record note and filled out an incident report, there was insufficient credible evidence that the employee had breached his duty and thereby harmed J.J.

- Fifteen-year-old Marcus complained that a staff member had grabbed him by the throat and choked him for "less than a minute." Investigation revealed insufficient evidence to support the allegation and the case was unfounded. The Commission found other serious issues which it brought to the attention of the administration.

  First, Marcus' discharge summary from his former placement noted his inappropriate sexual behaviors (flashing and touching females), his expressed confusion about his sexual identity, and allegations that he was having sexual contact with other young males. Although he was beginning to display the inappropriate sexual behaviors at his new residence, this was not being addressed in his treatment plan. In explanation his therapist noted that she had not verified the information in the discharge plan and therefore believed that no treatment goals on sexual issues were warranted. After consultation with the CQC investigator, the therapist agreed to verify whatever she needed to and formulate appropriate treatment objectives with the assistance of a sexual abuse consultant. The Commission also criticized the facility's investigation of the incident as the investigation listed the allegation, the steps taken by the investigator and the conclusion. It provided no findings and thus, no support for its conclusions. When the facility determined that the allegation was false, administrators returned the subject to the same unit to work. They neglected to inform Marcus of the results of the investigation and to advise him that the subject was returning. No work was done to help the child and the subject readjust to being together. The facility promised to deal with these issues differently the next time they arose.

Early Intervention for Infants and Toddlers with Disabilities

As a result of the legislation which becomes effective in July 1993, New York has a statewide program to serve infants and toddlers with disabilities or developmental delays and their families. The program, known as the Early Intervention Program for Infants and Toddlers with Disabilities, is administered by the State Department of Health in coordination with several other state agencies including the Office of Mental Retardation and Developmental Disabilities, Office of Mental Health, Office of Alcoholism and Substance Abuse Services, and the Commission.

Because of the legislation, families will not longer have to file petitions with Family Court to obtain special education services. Instead, families can obtain a wide range of services for their child and family by filing a request for an evaluation with their county early intervention official. In addition, other persons such as the family's doctor or day care provider are to refer children thought to be eligible, unless the parent objects to their child's referral. Parents will be able to select an evaluator from a listing of qualified professionals, and if the child is found to be eligible, similar to special education, this program provides for the active participation of the parents in developing a service plan, commonly referred to as an Individualized Family Services Plan (IFSP).

The IFSP must be developed jointly by the parents, a member of the evaluation team, a county early intervention official and a service coordinator selected by the county to assist parents through the process. The IFSP process is designed to allow parents to play a crucial role in identifying those services needed by their child and family members. Whenever possible, these services are to be provided in a "natural environment" such as the child's home, day care program, or other place that is typical for children of this age without disabilities to attend. Some of the services available through this program include health and nursing services, special instruction, physical and occupational therapy, speech and hearing services, assistive technology, and family training, counseling, home visits, and parent support groups. In addition, respite services can also be provided.

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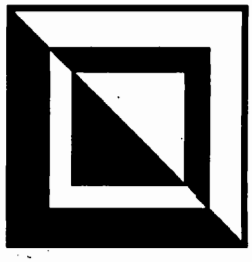
Under the Early Intervention Program, all services including evaluations are to be provided at no cost to the parents. Although the law provides for the use of private health insurance to pay for evaluations and services, deductibles and co-payments required under a policy will be paid for by the child's county. In addition, the law provides protection from having the costs of early intervention services applied to annual or lifetime caps, as long as the insurance policy is subject to the jurisdiction of the State Insurance Department.

Unlike the Family Court process, the Early Intervention Program provides extensive protections for parents to resolve concerns or complaints. Parents can request an impartial hearing and mediation to resolve individual complaints. In addition, parents and other interested persons can file a systemic complaint with the Department of Health if it is believed that a county, evaluator, or service provider is not abiding by the law or regulations.

In order to ensure that parents are aware of their rights, the Commission hosts a full time project aimed at assisting families of children from birth to age three. As a result of this activity, the Commission has produced a comprehensive rights manual required to be given to parents, conducted a training program for mediators on due process procedures, and, most importantly, has held numerous training sessions for parents to explain the benefits of this program and their legal rights.

Protecting and Advocating for People with Disabilities



Through the administration of the extensive networks and broad federally-mandated protection and advocacy programs, the Commission is able to engage and oversee a wide range of interventions and advocacy including individual case assistance, technical assistance, administrative, legal, and class actions. The summaries and examples of accomplishments listed below provide some sense of the nature and achievements of these programs in the areas of protection and advocacy for people with disabilities.

Protection and Advocacy for Persons with Developmental Disabilities

During the past year, over 21,000 New York State citizens with developmental disabilities were served by New York's Protection and Advocacy for Persons with Developmental Disabilities (PADD) program administered by the Commission. In addition to providing its own direct service and training activities, the Commission administers the program from its central office in Albany through contract with private, non-profit legal services and advocacy agencies. Among the activities of the PADD program, case advocacy services were provided to 1,670 individuals, 8,494 individuals received training, approximately 1000 persons were represented in class action litigation, there were 3,591 abuse and neglect reviews, and 4,592 responses to requests for information, materials, referrals, and technical assistance services. The following cases are illustrative of the types of protections and advocacy achieved by the PADD program.

Reasonable Accommodation for SAT Exams

The Scholastic Aptitude Exams (SATs) conjure up many anxiety filled memories for everyone who has experienced them. For a young man with visual and hearing impairments, his anxiety was heightened by the Educational Testing Service which was unwilling, at first, to grant him a reasonable accommodation to his testing needs. He desired a sign language interpreter for the exam instructions and a bold print test booklet. When the Educational Testing Service balked at the request, the young man's mother sought the assistance of New York Lawyers for the Public Interest (NYLPI), the PADD Legal Support Unit for New York City. The NYLPI attorney convinced the testing group that such an accommodation was mandated under the Americans with Disabilities Act (ADA). The testing service agreed to the interpreter and the bold print document but insisted that for security reasons (cheating from bold print would be easier) the student had to take the exam in another room. Because of time constraints the youngster took the exam in another room but later the testing service conceded that, in the future, this student or other students would not have to go to another room and precautions would be taken to prevent cheating by others.

SSI Benefits for a Child with Cystic Fibrosis

Although individuals with Cystic Fibrosis have a debilitating disease which ultimately leads to death in young adulthood or even adolescence, many individuals appear to function like their peers. Such was the case on appeal of a denial of Supplemental Security Income (SSI) for a child with this disease. Childhood eligibility for SSI has been changed allowing for benefits to be based on a functional assessment of the child as compared to chronological peers. This has accounted for many more children being eligible for benefits but in this case the child had achieved average height and weight and was performing average school work. However, what convinced the Administrative Law Judge that this child merited SSI benefits was the report from the child's treating physician which indicated that the degenerative nature of the disease would require a great deal of intervention to keep the child functioning at this level and that he was certain to become more impaired in the future. Benefits retroactive to the initial date of filing in 1988 were granted by the Administrative Law Judge.

Community Integration Support

"Community integration" does come with risks, and supports are necessary to enable the individual to prosper without succumbing to frustration. The individual in question has mental retardation and had successfully completed a Board of Cooperative Educational Services (BOCES) locksmith training program. With the help of his companion, and a rather supportive rural community, (local bank, accountant, and assorted neighbors), the man established a successful lock repair business. However, without his knowledge, his female companion cancelled his car insurance after a domestic dispute. While stopped for a traffic infraction his lack of insurance was discovered, and later the traffic court judge ordered that his license be restricted. Subsequently, the young man was stopped for another traffic infraction, and this

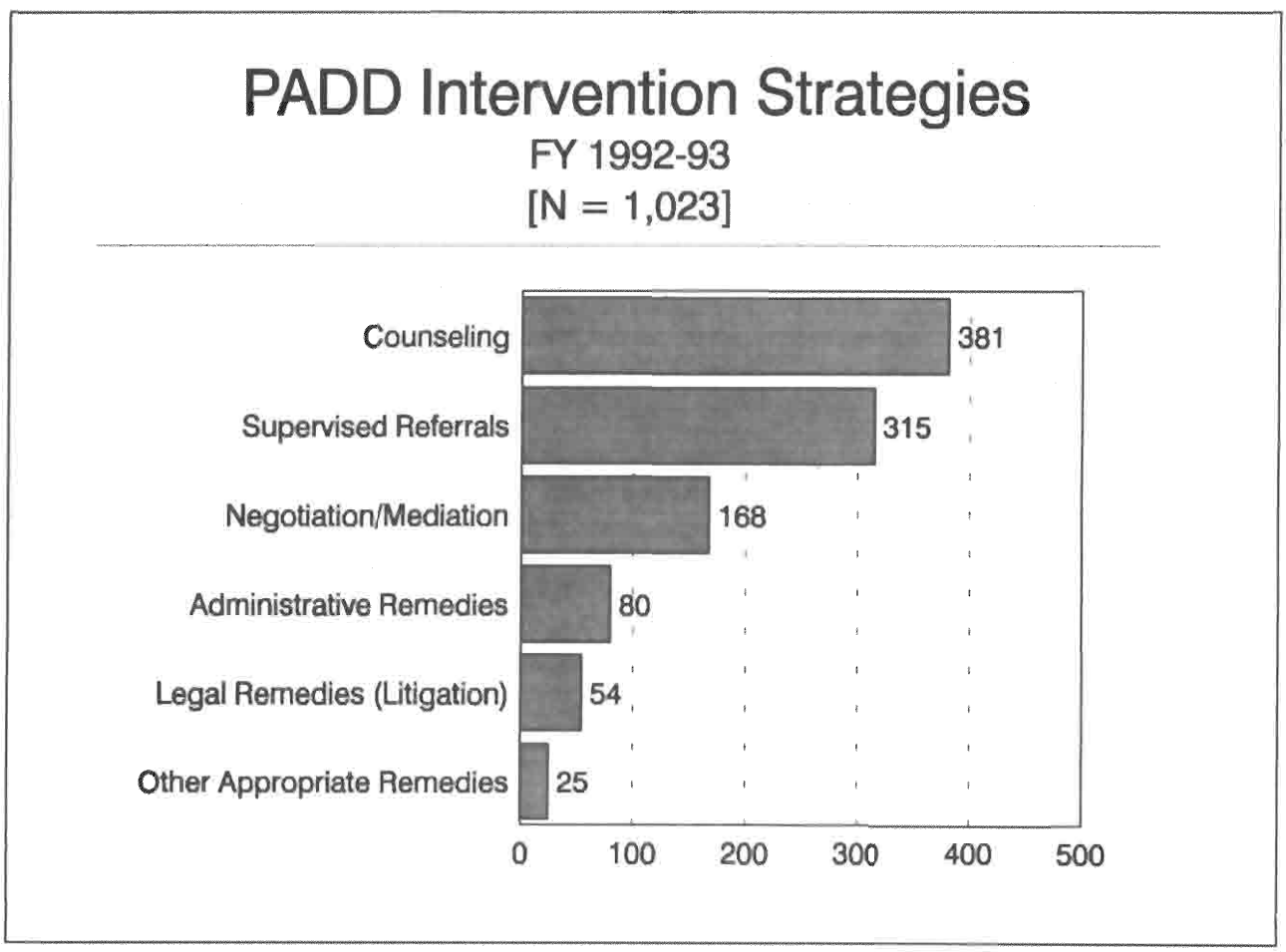
time was accused of driving outside of his license restrictions. At this point, the PADD attorney at Broome Legal Services appeared on behalf of the man, and because the man's new companion kept such excellent work records with regard to customer signatures on completed work orders and explicit travel directions, it was easily proven that the man had been working within the restrictions of his license. Further, with the attorney's insistence all restrictions were removed.

Facilitated Communication

Facilitated communication which involves an assistant guiding the hand of the non-verbal individual over a keyboard or other communication device has been the subject of much controversy. At issue is whether the assistant or the subject is doing the real communication. However, the PADD program has treated requests by individuals seeking facilitated communication like any other request for adaptive devices. In the western part of the state, a 19-year-old student was in jeopardy of losing the only aide that he ever had who was trained in facilitated communication (FC). The Committee on Special Education (CSE) notified the parents that they intended to remove the aide because the student was becoming too dependent on her. The advocate from the Western New York Advocates for the Developmentally Disabled PADD program met with the CSE and reached an agreement which retained the aide but, in addition, the aide would be utilized to train other individuals in the student's life to serve as facilitators. Further, the CSE agreed to obtain an independent evaluation by an expert in FC to be used as a guideline for measuring the student's progress.

Home Visitation for A Young Woman Living in a Community Residence

Home visitation is extremely important for individuals living in community residential facilities. Although parents may have sought placement in such a facility, it does not indicate that the family wishes to abandon the child. Conversely, requests for frequent visitation is not indicative of a desire to have the individual return home. On Long Island, a family faced this dilemma of a residential provider threatening to discharge their daughter to home because the mother had been requesting extended home vis-



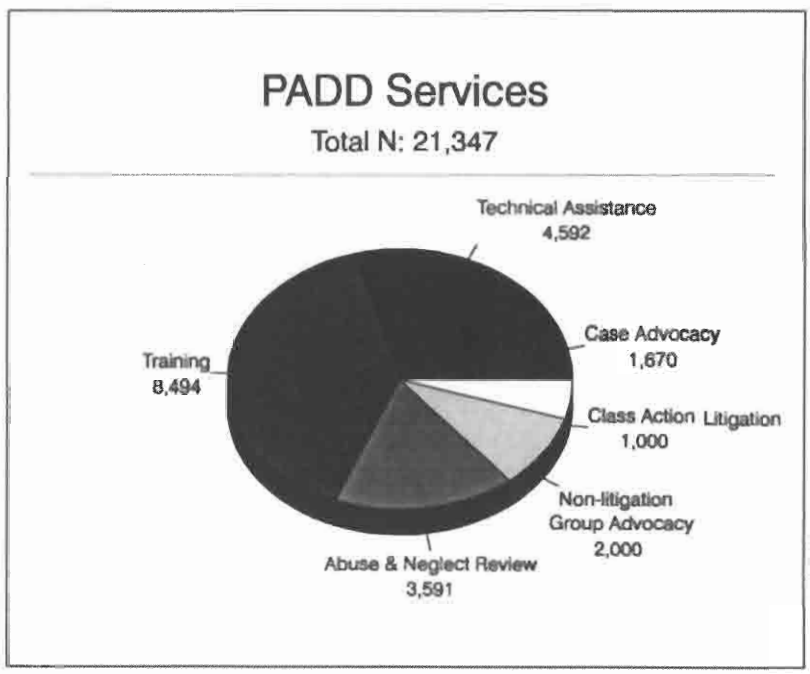
its. The advocate from the Long Island Advocates, Inc. PADD program intervened on behalf of the family and convinced the provider that a discharge was inappropriate because the mother was unable to provide permanent care. In addition, the advocate was able to convince the provider through mediation that this inability by the mother to provide permanent care did not preclude her from liberal visitation. The young woman remains at the facility with continued interaction with her mother.

Support for Individuals with DD Returning from Prison

The New York State Division of Parole has reached out to the PADD Program for assistance in appealing to the responsible state agencies to provide service to individuals with developmental disabilities who are returning from prison. The Division of Parole reported that it was encountering a reluctance to serve such individuals because they are considered a placement risk. The Commission's New York City PADD outreach office was asked by the Division of Parole to intervene on behalf of a former New York City resident who was approaching his time for release from prison. He needed a supervised residence in order to live successfully in the community but neither the State Office of Mental Retardation and Developmental Disabilities nor the State Office of Mental Health would provide such service. The PADD advocate invoked the dispute resolution mechanism which exists between the two offices which heretofore only applied to individuals seeking placement from the community. The responsible agent in New York City for convening such a panel is the New York City Department of Mental Retardation, Mental Health and Alcoholism Services (NYCMRMHAS). The Associate Commissioner of NYCMRMHAS wrote a letter requesting representation from both state agencies at a dispute resolution meeting but before the meeting took place the State Office of Mental Retardation did a forensic re-evaluation and agreed to assume responsibility. Upon discharge from prison the individual was placed at a local Developmental Center while awaiting a community placement. As a result of this advocacy, there are plans in New York City to develop a special residence for individuals with developmental disabilities who are returning from prison.

Countering Illegal Representative Payee Practices

Misuse of Social Security benefits by *representative payees* should not be tolerated especially when a municipal government is involved. 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) intervened to stop an illegal practice by the NYC Human Resources Administration (HRA). At issue was HRA's policy to assume the Supplemental Security Income benefits of children placed out of state under the Individuals with Disabilities Act (IDEA). This Act specifies an entititlement to a free and appropriate education but HRA which assumes the "room and board" piece of the residential placement hoped to recoup some expenses by becoming *representative payee* for the benefits. Many times HRA applied for this designation of *representative payee* from the Social Security Administration without parental knowledge. The NYLPI attorney wrote a letter to HRA citing that states are prohibited under *Mclain v. Smith,* 793 F. Supp.756,761 (E.D. Tenn. 1989) from assuming children's benefits to pay for educational services. The HRA, after consultation with Counsel, quickly conceded that it had made a mistake and offered a written assurance that the policy would be discontinued and full financial restitution would be made to every child.



Protection and Advocacy for Individuals with Mental Illness

The Commission's Protection and Advocacy for Individuals with Mental Illness (PAIMI) program is a federal program established by Congress to protect the rights and advocate for persons with mental illness. During the past year, the PAIMI program served over 6,000 individuals, including 1,803 individuals in case advocacy, with typical problems of alleged abuse (over 1,400 complaints), neglect (over 300 complaints), and appeals for protection of rights (approximately 170 appeals); 655 individuals in class action or non-litigation advocacy representing groups of individuals, 1,154 individuals receiving information and referral services, and 2,600 individuals in public education and constituency training activities. Examples of the cases, strategies employed by PAIMI staff, and outcomes are listed below.

Juvenile Delinquency Charges Dropped

Neighborhood Legal Services was successful in *Matter of J.B.* in which they obtained an order dismissing a Juvenile Delinquency Petition filed against their client. The individual in question had a history of emotional problems and speech difficulties. He became involved in two charges of criminal mischief and theft at a local recreation area. Subsequently, he was sent to a counselor, where he began acting out due to frustration at his speech delay problem and became assaultive. He was transferred to the local psychiatric center based on this event, but was released shortly afterwards and the Juvenile Delinquency Petition was filed. PAIMI staff at NLS convinced the court that their client should not be the subject of a Juvenile Delinquent proceeding in Family Court, but rather should be served through the special education system. Advocacy by PAIMI led to the provision of speech therapy and counseling as well as an appropriate residential placement.

Access to Treatment

Neighborhood Legal Services successfully advocated in *Matter of J.S.* for a client who had been denied admission to a Continuing Treatment Program because she saw a counselor at another program. The Continuing Treatment Program had a policy of requiring their clients to receive all services through their agency. After consultation and negotiation, which included the NYS Office of Mental Health, the program evaluated J.S. for admission and also agreed to reconsider their policy of requiring a single source provider of services.

Federally Subsidized Apartment Maintained

North Country Legal Services successfully advocated on behalf of an individual who had recently moved into a federally subsidized apartment complex for the aged and disabled. Their client needed a psychiatric hospitalization shortly after the move, and the apartment manager informed her that she would not be allowed to return to the apartment upon discharge. NCLS advised the apartment manager regarding their client's rights both as a tenant and as a disabled individual—making him aware that he had an obligation to reasonably accommodate her disability and not to threaten eviction at the first visible sign of her illness. The client has returned to her apartment with no further problems.

Assistance to Obtain Specialized Treatment

North Country Legal Services assisted a client in obtaining treatment in a specialized program for Multiple Personality Disorder, located in Texas. Prior to contacting PAIMI, the client had been deterred from submitting an application for Medicaid prior approval for payment to be treated in this program because of a misinterpretation of New York State regulations. With assistance from an advocate, treatment recommendations and plans were obtained both from the Texas facility and from the client's treatment professionals here in New York and the prior approval process was closely supervised to a positive conclusion.

Adolescent Maintained in School Program

North Country Legal Services assisted a 14-year-old girl with a long mental health history of violent and self-abusive behavior who was not being allowed to return to an in-school program by the local Committee on Special Education. The young woman was

to be sent to a residential placement program, a plan to which both the client and her mother objected adamantly. Advocacy involvement persuaded the CSE to agree to an alternative in-school program which was considered to be the least restrictive alternative, and the young woman is doing well there.

Access to Sign Interpreter Services

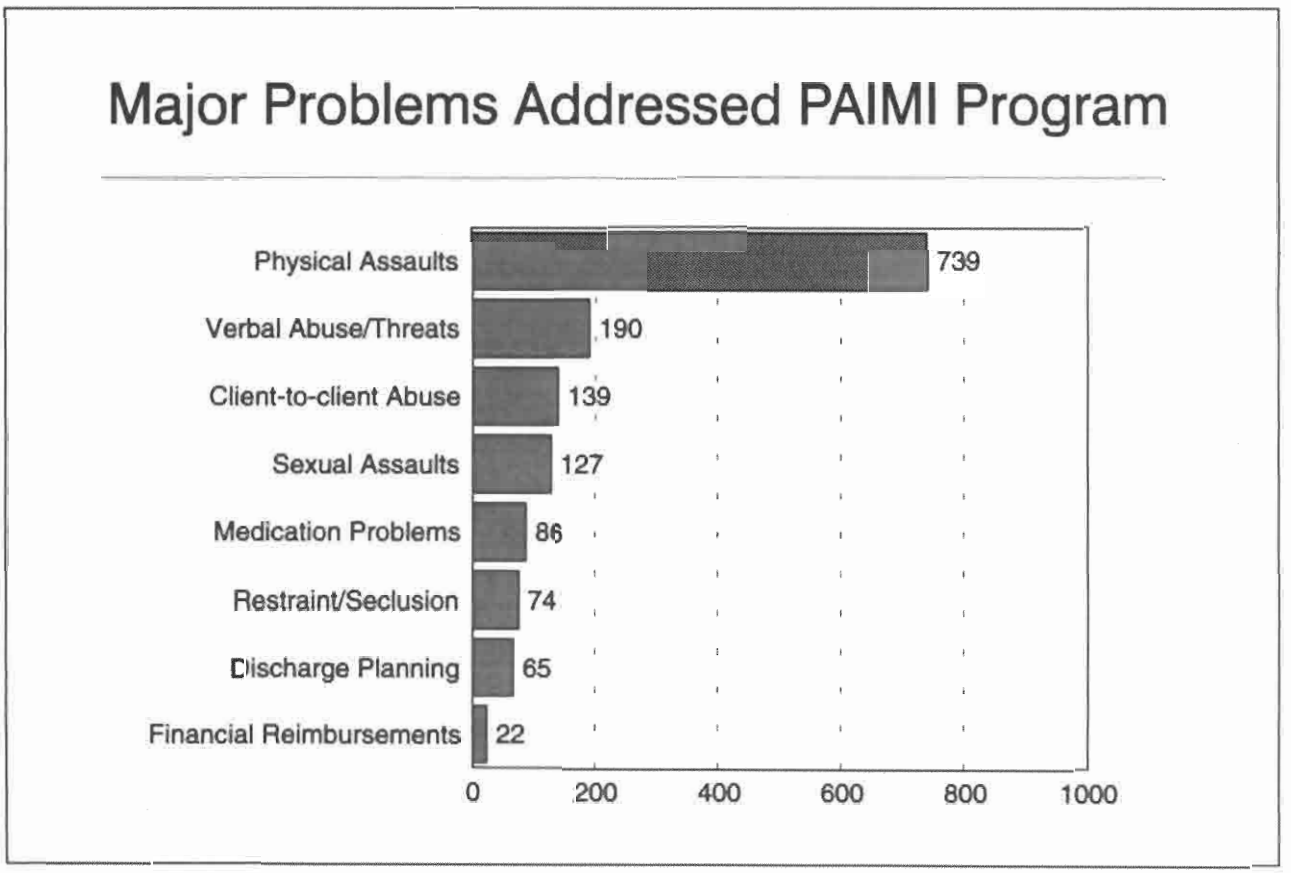
Legal Services of Central New York assisted an individual who had admitted herself to a private psychiatric hospital after the admission officer assured her that the facility would make arrangements to accommodate her hearing impairment. However, shortly after her admission the client was advised that the facility would provide a sign language interpreter only for sessions with her psychiatrist, but not for any other programming or group therapy. In conjunction with the Department of Justice (which had been contacted by a relative of the client), PAIMI began to draft pleadings alleging a violation of the ADA. At that point, the facility agreed to provide interpreter service for all programming and for all services provided by the facility for which the client requests a sign language interpreter.

Employment Discrimination by a Mental Health Service Provider

Disability Advocates, Inc. represented an individual with a psychiatric disability who was employed at a local mental health services agency. The client had been forced to resign her position when she required emergency housing services for herself from that agency. These emergency housing services were not available anywhere else in the community, and yet the client was not allowed to both be an employee of the agency and a recipient of the services it offered. A monetary settlement was obtained.

Permanent Dental Repairs

Disability Advocates, Inc. successfully advocated on behalf of a former patient at a psychiatric center who had been injured by another patient while he was hospitalized. The facility had initially authorized payment to repair the damage to his teeth, but, after temporary repairs had been made, had refused to pay any more. The temporary repairs had deteriorated over time and the individual sought assistance from DAI to obtain payment from the facility to replace the temporary repairs with permanent ones. As a result of advocacy, the facility agreed to pay in full for the permanent dental repairs.



Client Assistance Program

The Commission and its statewide network of participating Client Assistance Program (CAP) agencies continue their strong commitment to securing quality vocational and related services for New Yorkers with disabilities. During this past year, CAP staff were full partners in an array of state activities to identify and address a number of systemic issues. In particular, CAP worked cooperatively with other interested parties within the New York State Interagency Council on Vocational and Related Services, and within the two state vocational rehabilitation agencies' advisory councils to address systemic barriers. Included among these activities was a comprehensive review of the services provided by New York State Commission for the Blind and Visually Handicapped, an Interagency Council activity, coordinated by the New York State Commission on Quality of Care for the Mentally Disabled.

Increased utilization of Social Security work incentives was another Interagency Council priority in which the Commission played a leadership role. Through the Council's Cross Systems Training Committee, CAP was instrumental in the development and introduction of a statewide campaign to promote the use of Social Security provisions which support individuals in the transition from a reliance on benefits to employment and self support. In the area of transition from school to work, the Client Assistance Program also developed and piloted a parent/consumer training model to promote awareness and access to a number of new transition services required under the Individuals with Disabilities Education Act (IDEA).

While the Commission is 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 assistance provided to individuals enables CAP to assess how well the laws, regulations, and policies are actually being implemented to assist people with disabilities. The network of CAP advocates tirelessly advance respect for individual rights through a comprehensive understanding of vocational service systems, mediation, and advocacy.

CAP continues to serve an increasing number of individual consumers. In 1992-93 the 1,248 individuals who received case services represent an 8% increase over last year, and a 15% increase in individualized advocacy services for New Yorkers with disabilities since 1988-89. In each case, CAP advocates and attorneys provided an array of services to resolve disputes between consumers and federally funded vocational and related service programs. Typically, individual case services require ongoing intervention on the part of a CAP advocate to address a consumer's unique circumstances. As in previous years, CAP has been highly successful in achieving resolution of issues for consumers of services. This year, 96% of the cases which resulted in a decision in this report period were resolved to the consumer's satisfaction.

In addition to individual advocacy services, 1,604 persons received technical assistance and 2,325 individuals received routine information and referral services. CAP training initiatives reached 6,220 individuals.

Mediation and negotiation continue to serve as the bedrock of CAP service delivery with 95% of individual case services resolved without resorting to administrative or legal appeals.

Some typical CAP case examples are listed below.

Choice in Determining a Vocational Goal

Mr. S., a VESID consumer who is deaf, approached CAP determined to reach his goal to become a UPS truck driver. VESID had placed Mr. S. in a part-time shipping and receiving position at Waldbaum's where he stocked shelves. Mr. S. was highly motivated to secure full-time employment and also wanted to secure medical benefits.

CAP found that VESID had never developed an Individualized Written Rehabilitation Plan (IWRP) for Mr. S. and that the VESID-sponsored diagnostic vocational evaluation (DVE) failed to adequately measure Mr. S.'s true abilities. VESID's position was that Mr. S. was successfully placed on a job and there was no support for "upgrading" his position. CAP and Mr. S, however, were confident that his current placement was not commensurate with his capabilities.

Following successful mediation with the VESID counselor, Mr. S. was provided with a more in-depth assessment which determined he was indeed a good candidate for truck driving. However, there remained some uncertainty as to New York State Department of Transportation requirements for commercial truck drivers. The VESID counselor was not optimistic about Mr. S's prospects for employment in the field and no further investigation took place.

CAP called the NYS Department of Transportation and secured the requirements for deaf truck drivers. As a result, Mr. S. was sponsored for additional training and obtained a full-time position with UPS.

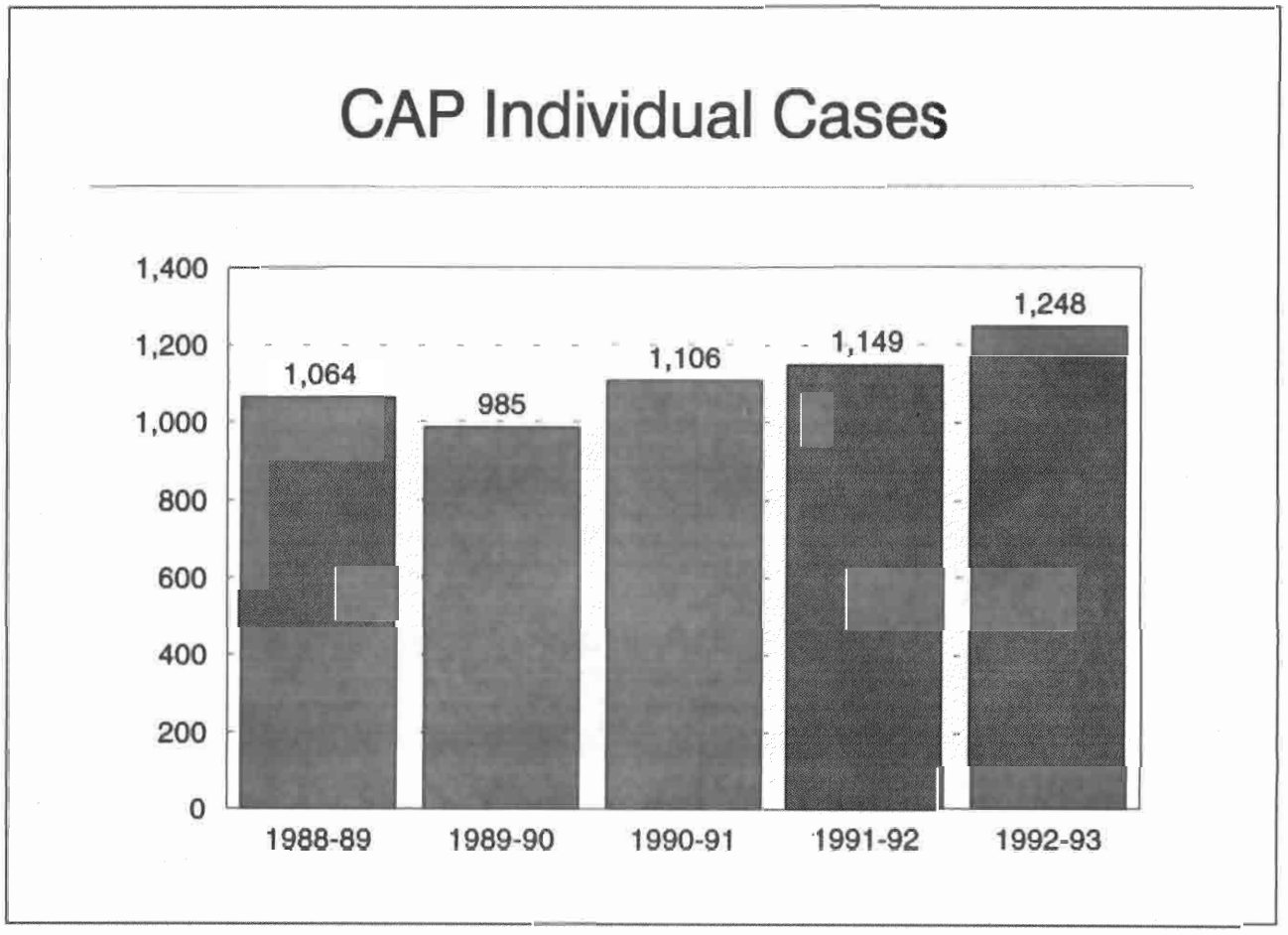
Part-Time College Sponsorship

Ms. L. is a VESID consumer with significant learning disabilities who was participating in a one-year Office Technologies Program at a local Community College. She was attending on a part-time basis, which enabled her to take advantage of the college's resource center for academic support. Part-time studies also allowed Ms. L. to participate in a work-study program through a Fortune 500 company.

Ms. L was supported by her VESID counselor when she requested VESID sponsorship for attendance in the second year of the program. Her request was ultimately denied by the senior counselor who indicated the VESID policy governing one-year programs were very specific and did not allow for part-time attendance. CAP was able to point out that the VESID policy does make allowances for part-time attendance over a two-year period as long as the cost does not exceed the VESID cap of $4,815. Upon receipt of this information, the senior counselor reversed the decision and a check in the amount of $1, 083.90 was issued to the consumer to cover program costs for the second year. In addition, the senior counselor wrote a gracious letter to the CAP advocate and Ms. L., acknowledging the error and thanking CAP for the assistance in correcting the mistake.

Limit on Out-of-State Services

Mr. E. is a VESID consumer who is a quadruple amputee and was denied sponsorship to a Pennsylvania-based university. After researching a number of college support programs, Mr. E. determined that



the Pennsylvania-based program was the only one available to meet his extensive personal care and medical needs. VESID's position was that he could obtain all the necessary services at a Long Island-based university. VESID indicated that the medical justification provided was not sufficient to justify waiving the VESID policy which typically limits college sponsorship to in-state programs.

CAP intervened on behalf of Mr. E. and appealed to the District Office Manager of the Queens VESID office. As a result of this mediation, CAP was successful in securing VESID sponsorship for Mr. E. at the Pennsylvania-based university.

Mr. E.'s case suggests that VESID should re-examine its policy on out-of-state college sponsorship with an appreciation that extensive services, not currently available within New York, may be required to accommodate individual consumer requirements.

Counselor Change

Ms. F. is a CBVH consumer who contacted CAP for assistance in securing a counselor change. When the CAP advocate intervened it was obvious that the level of animosity between Ms. F. and her counselor was extremely high, and the counselor's respect for Ms. F.'s preferences was very low.

Ms. F. planned to continue her education when she contacted CBVH for services. The CBVH counselor recommended homemaker status (a goal focused on managing one's home environment) and would not consider other vocational goals. Ms. F. wrote to the counselor and explained that she did not understand the counselor's continued focus on the homemaker goal and remained interested in an educational goal. Ms. F. was also unsuccessful in securing CBVH support to purchase low-vision aids prescribed by her optician.

While support from CBVH was at an impasse, Ms. F. was successful in securing support for mobility training and other rehabilitation services from her local independent living center.

When repeated efforts to mediate a resolution with the counselor failed, the CAP advocate convened a meeting between Ms. F., the CAP advocate, and the CBVH senior counselor. The CBVH senior counselor agreed to assign another counselor to the case and ultimately Ms. F.'s educational goal and related service issues were resolved.

Ms. F. has subsequently successfully completed one year of full-time college study and is enrolled in her second year.

Testing Practices for Learning Disabilities

Rochester CAP represented two VESID consumers with learning disabilities at administrative reviews (an informal appeal to the VESID district office manager). Both reviews centered on CAP's contention that the VESID-sponsored testing failed to accurately measure these consumers' prospects for employment.

CAP presented evidence which contradicted the findings of the LD evaluation and successfully advocated for a broader battery of testing.

System-wide, it appears that several VESID district offices continue to rely on outdated criteria (i.e., IQ measurements based entirely on WASAR and RAT tests) for establishing the presence of a learning disability. The Individuals with Disabilities Act (IDEA), which specifically references learning disabilities and other accepted definitions for learning disabilities, is considerably broader than the standard against which VESID typically defines learning disabilities.

Employment Discrimination

Mr. K. is a CBVH consumer who was successfully employed by a Fortune 500 company for a number of years. He voluntarily left his job with long-term disability benefits when he experienced seizures on the job. After Mr. K.'s physician determined he could return to work, management at his former department identified a number of erroneous reasons why Mr. K. could not return to work. Management pointed to problems with Mr. K.'s eyesight, which had never impeded his performance in the past, and the seizures, despite the documented medical clearance. Ultimately, he was told that he could not return to work.

Mr. K's circumstance was complicated by an alleged long-term disability overpayment for over $9,000, prompting collections to seize all assets in his checking account.

The CAP advocate wrote a letter to the President and CEO of the company, which stressed Mr. K.'s past contribution, his current abilities, and the company's potential exposure to discrimination, which brought a quick response. In a very short time, Mr. K. was back at work with increased pay, increased vacation time, and all seniority restored.

Vocational Goal Assessment

Mr. Q. is a VESID consumer, with a diagnosis of mental illness and a back injury, interested in pursu-

ing employment as a tractor/trailer driver. Mr. Q. approached CAP for support in pursuing a fair hearing after VESID refused to sponsor him for tractor/trailer training.

CAP suggested that if Mr. Q. was to successfully challenge VESID, he would have to secure medical clearance from a physician, documenting that his medications would not impede his ability to function as a tractor/trailer driver. CAP also suggested he secure clearance from his orthopedist addressing his back injury. Finally, CAP suggested he explore the field further by contacting the tractor/trailer association for information and support.

Since Mr. K. was not able to obtain the clearances, he stopped blaming VESID. CAP then suggested he set up a meeting with his VESID counselor and therapist to explore other career options. At the meeting, a new goal of auto body repairer was identified and Mr. Q. is very satisfied with his new career option. Mr. K. is scheduled to begin training.

Mr. K.'s case illustrates how CAP frequently complements VESID services by keeping consumers productively engaged in the rehabilitation process while mediating successful outcomes.

Career Advancement

Ms. J. is a VESID consumer who is deaf and has an orthopedic impairment. At issue was a dispute over VESID's refusal to amend her Individualized Written Rehabilitation Plan (IWRP). Ms. J. approached CAP because she was not satisfied working in housekeeping, and was interested in pursing a career as a chef.

The CAP advocate met with Ms. J's counselor to discuss the feasibility of her new vocational goal. The VESID counselor questioned Ms. J.'s ability to successfully function as a chef in a restaurant. As a compromise acceptable to all parties, VESID agreed to amend the IWRP with a short-term goal of employment in food management and a long-term goal of chef.

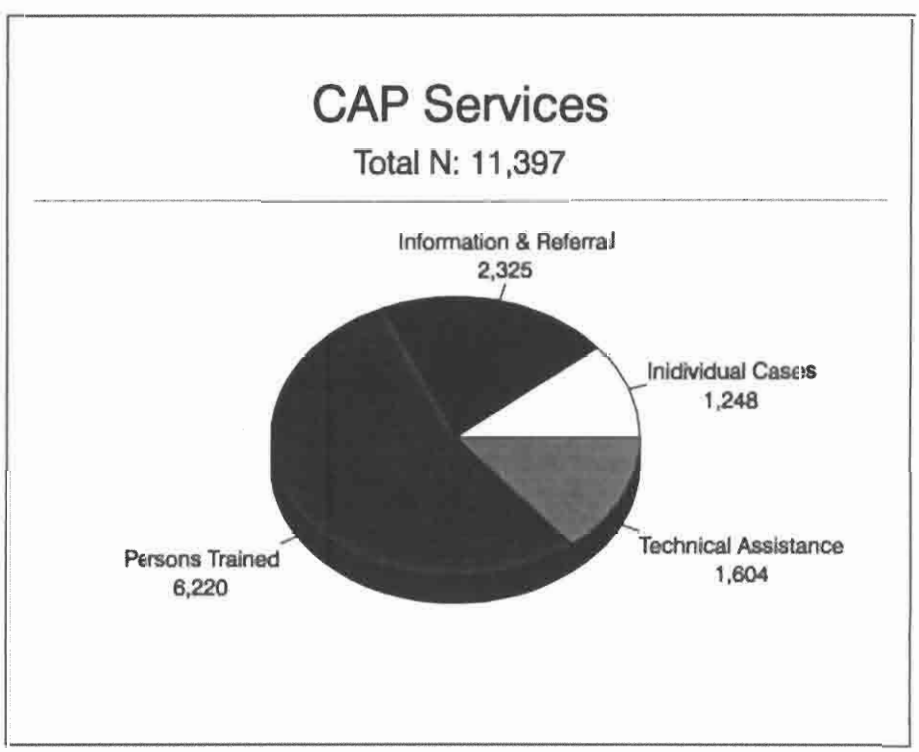
VESID sponsored Ms. J. in a food service management certificate program and Ms. J. now has full-time employment at a residential program where her duties include both food service and housekeeping. For now, Ms. J. is very satisfied and is not sure if she really wants to go on to chef school.

Economic Need Determination of Supports for College Students with Learning Disabilities

Ms. T. and family contacted CAP for help to secure sponsorship in a learning disabilities support services program at college. VESID had denied sponsorship based on Ms. T.'s family income.

In the interim, Ms. T.'s mother had lost her job and CAP advocated for a re-evaluation of the family's economic need. Following a lengthy re-evaluation process, it was determined that Ms. T. was eligible and ultimately received sponsorship in the LD support services program and tuition assistance.

Ms. T.'s case raises a question of equity for learning disabled students who can benefit from LD support services available through distinct support programs available at select colleges. At the core of these comprehensive programs are individual support services (i.e. tutors, note-takers, and readers) which, if accessed separately, are exempt from an economic need determination. When these same services are accessed through a comprehensive LD support program however, they are subject to an economic need determination.



The PAIR Program

The Protection and Advocacy for Individual Rights (PAIR) program extends the advocacy services provided by the Client Assistance Program (CAP) and Protection and Advocacy for Persons with Developmental Disabilities (PADD) program, so that a person otherwise not qualified for PADD services, e.g., someone receiving assistance from Independent Living Centers, will be able to obtain representation in matters affecting legal rights, such as employment and housing discrimination, which CAP or PADD may not be permitted to deal with under the current federal laws. These legal and advocacy services also assist in particular ways to deal with special cases relating to implementation of the Americans with Disabilities Act (ADA).

PAIR funding is derived from the Rehabilitation Services Administration of the U.S. Department of Education. Through this grant, the Commission provides additional funding to New York Lawyers for the Public Interest (NYLPI) in New York City and Neighborhood Legal Services (NLS) in Buffalo to provide assistance in the New York City and Western New York regions. Some of the more representative PAIR cases are listed below.

Health Insurance Discrimination under ADA for HIV and AIDS

In a case with national attention and significance, *Mason Tenders Union District Council Welfare Fund v. Donaghey,* New York Lawyers for the Public Interest (NYLPI) represented a construction worker who was HIV positive. The defendant in the case was informed by his union's benefits plan that he would no longer be reimbursed for any treatments or medications related to HIV or AIDS. In 1992, NYLPI and the Gay Men's Health Center in New York City filed a complaint with the Equal Employment Opportunity Commission (EEOC) on his behalf and that of another plan member alleging that the benefits plan violated the provision of the ADA by discriminating against persons with disabilities. The EEOC found that the plans did in fact violate the provisions of the ADA. The EEOC found that the plan had no actuarial studies or reports supporting or recommending the AIDS coverage exclusion before it was adopted and that the plan covered other illnesses with similar costs. While the EEOC was still attempting to conciliate the charges, the Fund filed a "preemptive strike" lawsuit seeking a court ruling that it had done nothing wrong and was not even covered by the ADA. The EEOC has since filed a lawsuit against the plan on behalf of the clients in NYLPI's complaint.

In November, NYLPI achieved a major victory in the lawsuit brought by the Mason Tenders Welfare Fund against the individual plan members, in which NYLPI is the plan members representative. At oral argument on the Fund's motion for summary judgment, Judge Sprizzo ruled from the bench that the Fund was covered by the ADA, and therefore has a legal obligation to justify its AIDS coverage exclusion. This is believed to be the first such ruling on this issue holding that a benefit fund is subject to the ADA. It will hopefully benefit not just NYLPI's clients, but members of other benefit plans with similar exclusions that will now know that they are not beyond the reach of the ADA.

Guide Dog Accommodation

Neighborhood Legal Services filed a federal court action, *Nelson v. Ryan* against the Commission for the Blind and Visually Handicapped alleging that it discriminated against it's blind employee by not granting paid leave to attend training for his guide dog. NLS argues that the guide dog is necessary for employment and, as such, paid leave would be a reasonable accommodation under ADA provisions.

Court Access

Neighborhood Legal Services successfully intervened with a town court which initially refused to provide an auditory loop system for a hearing impaired person who had court sessions to attend. After NLS raised ADA provisions concerning reasonable accommodations, the auditory loop system was provided.

Theater Project: 34 Theaters in NYC and ADA Compliance

NYLPI filed complaints with the U.S. Department of Justice against 34 movie theaters and off-Broadway theaters in New York City which are in-

accessible to people with hearing-impairments. Before filing the complaints, NYLPI wrote letters to over 70 theaters advising them of their obligation under the ADA and state and city laws to install assistive listening devices. The theaters which did not comply or did not intend to comply were the subject of the complaints. After filing the complaints, NYLPI learned that one theater was also not wheelchair accessible and advised the Department of Justice of the situation.

Psychotropic Medication Disclosure to Employer

NYLPI advised an individual taking lithium to control his bipolar disorder who was asked to provide information on his prescription medication use to his employer in conjunction with testing for illegal drugs. The employee did not want his employer to know about his disability. The employer requested the information because some prescription drugs can cause tests for illegal drugs to come up positive. NYLPI believes that the ADA allows employers to inquire about prescription drug use only if the drug test comes up positive and the information is necessary for an employee to exonerate himself. NYLPI advised the individual to file a complaint with the EEOC and remains involved in any complaints filed, since this issue is one which is important to many people with disabilities.

Employment Barriers

NYLPI advocated successfully on behalf of Mr. S., an individual with a psychiatric disability whose employer and union were creating barriers to his return to work as a mechanic's assistant for a private school bus company. The employer insisted that Mr. S. meet with two consulting psychiatrists, even though Mr. S.'s own psychiatrist said he was fit to return to work after a bout of clinical depression. The stated purpose for this requirement was to evaluate Mr. S.'s fitness to drive school children. However, this was not an essential function of Mr. S.'s job. After NYLPI wrote letters and made phone calls to the employer and the union, the employer agreed to let Mr. S. return to work.

Life Insurance Disability Waiver

NYLPI successfully advocated on behalf of a client with a psychiatric illness whose life insurance policy included a waiver of premium in event of permanent disability, but whose insurance company was refusing to grant the waiver even after the client was declared eligible for SSDI and received a rating of "permanent partial disability" in his workers' compensation case. After several letters to the company by NYLPI, including a statement of intention to litigate, the company granted the premium waiver.

Legal Actions

- Enforcing Constitutional Rights
- Entitlements
- Appropriate Placements
- Assuring Due Process
- Education Services
- Family Rights
- Protections from Harm
- Employment Rights

Legal Interventions

Litigation has been a tool of last resort in federal advocacy programs administered by the Commission. However, over the years, the power to intervene by litigation has been used effectively in actions which resulted in enforcing constitutional rights, and, in some instances, clarified or expanded rights and entitlement to services and benefits for individuals with disabilities. The following are case examples of legal actions pursued by the advocacy programs during the past year.

PADD Legal Actions

Appropriate Placement Found for "Boarder Babies"

Association to Benefit Children v. New York City

In New York City there has been a recurring phenomenon of children with disabilities being left to languish in municipal hospitals. In the mid 1980's such was the case for nearly 40 children characterized as "boarder babies." Through intervention by the New York City PADD program, these children were placed in alternate facilities. However, with the AIDS and Crack epidemics the municipal hospitals again were faced with a new group of boarders, some of whom simply never left the hospital after their birth.

New York Lawyers for the Public Interest (NYLPI), the PADD Legal Support Unit for New York City, was asked by the Association to Benefit Children to assist in moving these children back to their families or to other suitable placements. In addition to handling cases themselves, NYLPI has access to forty member law firms which offer *pro bono* assistance. A member firm accepted the case and brought the above action. The lawsuit alleged that the City and State had failed to provide appropriate care and service for these children. Very quickly a consent decree was formalized and a settlement was reached for placement of the five named children. The law firm will monitor the continued compliance with the decree.

Mother With Developmental Disabilities Spared Support Payments

In the Matter of McCann

The Long Island PADD office assisted a woman who became pregnant while in a community residence and had to place her twin boys with the Department of Social Services because the community residence staff were unable to accommodate both the mother and her children. The placement of the children led to an eventual child support hearing against the mother who was nearly destitute.

In the Department of Social Services case, the issue was over a requirement of the mother to pay the department a minimum of $25 per month in child support. The boys' mother received SSI and a small sheltered employment wage. However under New York State Child Support Guidelines, Family Court Act Sec. 413 (1) (g) every parent must pay a minimum of $25 no matter what the parent's circumstances. Utilizing a Family Court Fourth Department decision in *Rose v. Haney,* which concluded that the New York law is pre-exempted by the Federal Child Support Statute which allows for mitigating circumstances, the LIA attorney convinced the Hearing Officer to order no payment.

Medicaid Funded Motorized Wheelchairs Granted In Some Cases

Maniscalco v. Bane

Powered assisted wheelchairs open up a world of independence for an individual with disabilities. However in the case of individuals living in congregate care settings with access to persons to push their manual chairs, the State Office of Health Systems Management, which must make prior approval decisions for Medicaid funded services, has set a policy which calls for the denial of power wheelchairs for individuals with access to an "assistant."

The PADD office for Nassau and Suffolk Counties, Long Island Advocates, Inc. (LIA), was asked to represent a resident with developmental disabilities of a local nursing home. The local OHSM denied prior approval of his request for a motorized wheelchair because he had access to the staff at the home to bring him to his desired destination.

After the administrative remedies were exhausted at the appropriate hearing levels, the LIA attorney commenced this Article 78 proceeding in State Supreme Court. Using the argument that the Federal Medicaid Law permitted the use of equipment to foster greater independence, the LIA attorney was

able to bring about a settlement resulting in Medicaid payment for the chair. However since this was a settlement, there was no precedential value to the case. Other OHSMs throughout the state continued to deny prior approval for such equipment requested under the same set of circumstances.

Czelusta, Hazel et al. v. Dowling & Chassin

When it became apparent that power wheelchairs were no longer going to be won on the administrative hearing level and the Long Island case, though victorious, did not set precedent, it seemed time for a Federal Court challenge. In Buffalo, there was a group of children who were denied power wheelchairs because they had access to aides in their schools. This group came to the attention of the Western N.Y. PADD Legal Support Unit, Neighborhood Legal Services.

The PADD attorney joined legal forces with the public benefits attorney at Neighborhood Legal Services. They will co-counsel on *Czelusta et. al.* which has been filed in the U.S. District Court in Buffalo. The claim, as has been made previously in wheelchair and other equipment cases, is that the Medicaid statute requires that assistance be given to maximize a person's independence. Also, with the passage of the Americans with Disabilities Act, there is a reasonable accommodation argument and further, an allegation of discrimination pursuant to Sec. 504 of the Rehabilitation Act. Briefs have been filed and oral arguments will be presented in early 1994.

Due Process Assured for Erie County Children

Colson v. Sillman et, al. (U.S. District Court, Buffalo)

All entitlement programs establish a right of "due process" which enables the beneficiaries to appeal any adverse decisions by the governmental sponsoring agency. However, in New York State, there exists a State-sponsored program entitled the Physically Handicapped Children's Program (PHCP) in which there was no means available to appeal an agency's decision. Sponsored by the New York State Department of Health pursuant to N.Y. Pub. Health Law Sec. 2852, local counties of Health may participate voluntarily in PHCP and offer to its citizens financial aid for needed medical services. An applicant for service must apply to the local County Department of Health and meet specific criteria as to age, family income, diagnosis, and exhaustion of other potential sources of payment and further prove that there is a medical necessity.

In *Colson*, a group of children forming the "class" were denied their requested equipment as not being medically necessary after meeting all the Erie County Department of Health's criteria for eligibility for PHCP. The PADD program, Neighborhood Legal Services, argued that each child has a property right in the requested services and that the failure of the PHCP to provide them with the services without a hearing or other means of appeal deprives them of their due process rights under the Fifth and Fourteenth Amendments to the Constitution. After almost seven years of protracted litigation, Federal Judge Richard J. Arcara ruled in favor of the children. Citing the prevailing Public Health Law Sec 282, "The department *shall*...provide...medical services for physically handicapped children where services are necessary and helpful in the rehabilitative process, the statute confers on applicants who meet the threshold criteria for entry into PHCP, more than a 'unilateral expectation'...it confers a property interest." Judge Arcara continued that each plaintiff had demonstrated that he/she had a property interest and consequently was entitled to due process under the Constitution.

Erie County was instructed to put in place by May 1,1993, due process procedures that PHCP must henceforth follow. Although the issue has been resolved with Erie County, the New York State Department of Health has decided to appeal to the Second Circuit which will leave part of the case unsettled.

Housing Rights Affirmed For An Individual With A Neurological Impairment

Thomas A. Queen v. Corinth Housing Development Company, Seiden & Sons, Inc. et. al.

Surviving a traumatic brain injury can be a very difficult task especially as one tries to reintegrate into the community. Albany Law School (ALS), the Commission's Protection and Advocacy Program for Persons with Developmental Disabilities serving the Capital District, represented a young man with a traumatic brain injury who was facing eviction from the Adam Lawrence Apartments in Corinth, New York. The apartment complex was funded through the federal Farmers Home Administration (FmHA) and is meant to serve individuals who are elderly or disabled. The predominantly elderly tenants signed a petition complaining that the young man was loud, struck walls in the hallway as he walked by with his cane, and that his guests used loud and profane language. The young man uses a wheelchair, but he can walk with the assistance of a cane and experiences balance problems. ALS staff objected to the eviction stating that their client was not advised of his rights under the FmHA

grievance procedures and that the eviction was based solely on his disability.

While awaiting a hearing in Corinth Town Court, the ALS attorney filed a civil suit in the US District Court in Albany seeking a preliminary injunction of the eviction. US District Court Judge Con Cholokis denied the injunction stating that there was insufficient evidence that the man was discriminated against because of his disability. However, while appearing in the Corinth Town Court, the ALS attorney was able to negotiate a settlement with the landlord which resulted in a new apartment for the client, monetary damages, and the ALS and client input into new FmHA grievance procedures. Given that FmHA is a federal program, the new procedures will impact all U.S. citizens with disabilities.

Education Services under Section 504 Upheld

James B. v. Wappingers Central School District

At issue was the school district's refusal to provide educational services to a child with developmental disabilities and psychiatric disorder, while the child was residing in a private psychiatric facility. The Mid-Hudson Legal Services (MHLS) PADD program demanded and received an independent evaluation of the child at public expense, but the school district maintained that the child's disability did not warrant services under the Individuals with Disabilities Act (IDEA). The MHLS attorney then requested services under section 504 of the Rehabilitation Act. The district provided no response to this request, because in the twenty years since the original passage of "504," Wappingers never instituted evaluation and placement procedures for students with disabilities under this separate act.

The lawsuit was commenced in Federal Court asserting a right to special education services under Sec. 504. The school district's response was immediate and satisfactory. The district created a "504" Committee and referred the child to the Committee on Special Education which classified him for special education services. After his hospitalization, the child was placed in a CSE recommended private school.

Inappropriate Discharge Averted

Kimberly L. v. Columbia County Department of Social Services and Case #417 Albany Law School

Both cases involved the precipitous discharge from a specialized group home operated by Vanderhyden Hall in Troy New York. This traditional child care facility had developed a group home for children with developmental disabilities and contracted with County Departments of Social Services for placements in the group home of children from those respective areas. However, Vanderhyden Hall decided that it could no longer serve this population and advised Columbia and Albany Counties that the home would be closed and all children had to be removed. Columbia County is served by the Mid-Hudson Legal Services PADD program, and Albany by the Albany Law School.

Columbia and Albany Counties planned to move the children without providing any due process rights, i.e., appeal of the appropriateness of the new placement, status quo provisions, etc. The only route of appeal seemed to be at the Family Court which was the initial point of entry for both children. Attorneys from the Mid-Hudson Legal Services (MHLS) and Albany Law School (ALS) offices filed petitions in the Columbia and Albany County Family Courts alleging that the Courts had jurisdiction to maintain the children at the group home despite the closure plans until such time as an appropriate placement could be found.

During the many court appearances, at which it was becoming difficult to convince the courts of their obligation, the children were referred to the local offices of the State Office of Mental Retardation and Developmental Disabilities (OMRDD) for placement in the area of the Vanderhyden Hall group home where the children had attended community schools and had made friendships. Unfortunately, the cases came to two separate conclusions.

In the Columbia County case, the Department of Social Services moved the child to a downstate facility. This happened despite the fact that there was a promise of an upcoming placement in a local OMRDD-licensed facility. This case continues in Columbia County Family Court with a MHLS petition requesting that the court order placement from downstate back to the OMRDD placement. Simultaneous complaints have been filed with the State Department of Social Services and the State Education Department. Resolution is awaited in this case.

The Albany Law School case was more successful with the Family Court ordering continuance at the group home until a new placement was found. Fortunately, a new placement has been found which meets all of the child's needs. He is happily residing in his new home.

The issue of the lack of due process rights in Department of Social Services-funded programs still remains and may need legislative intervention, which PADD will pursue.

Medicaid Benefits To Continue

McMahon v. Perales et al (U.S. District Crt. WDNY)

Individuals began losing their Medicaid once they became eligible for Social Security Disabled Adult Child's benefits. This class action lawsuit, against the State and Erie County Departments of Social Services and the federal Department of Health and Human Services, challenges their failure to implement the Social Security Act provisions of 42 USC Sec.1383c(c). This section requires that individuals who, after July 1, 1987, lose their entitlement to SSI as a result of the receipt or increase in the monthly amount of their Social Security Disabled Adult Child's benefits, shall continue to receive Medicaid automatically as if they are still SSI recipients. The action claims that the State has not implemented policies and procedures to ensure that those individuals who are eligible for continued Medicaid are properly certified as eligible.

The typical class member is an adult with mental retardation who receives Social Security Disability benefits on the earnings record of a parent who dies, retires, or becomes disabled. Frequently, as a result of this new eligibility for Social Security, individuals lose SSI and with it their automatic entitlement to Medicaid. The provision in 42 USC Sec 1383c(c) allows the individual to continue Medicaid eligibility as if he or she were still receiving SSI.

After two years of litigation and negotiation, a final settlement is about to be reached. In fact, the New York City legal support unit, New York Lawyers for the Public Interest, won continued Medicaid for its client under the same set of circumstances by citing the *McMahon* case. More than one thousand individuals statewide will have restoration of their Medicaid benefits as a direct result of this settlement.

PAIMI Legal Actions

Assistance with Release of CPL Patient

Legal Services of Central New York, Inc. was successful in assisting an individual who had been ordered to be retained for another two years under New York's Criminal Procedure Law, despite the opinions of his treatment team that he could safely leave the psychiatric facility. *In the Matter of An Order of Release and An Order Of Conditions Pursuant to CPL 330.30 in Relation to H.H.,* PAIMI represented H.H. at a day-long trial and then filed a Petition for Review and Rehearing. After the PAIMI attorney arranged for presentation of testimony from knowledgeable professionals, the State offered to settle the case by granting H.H. a thirty day "trial period" to determine whether he could meet the Order of Conditions. After the trial period, which was completed with no problems, PAIMI's motion for a directed verdict was granted and H.H. was released pursuant to an order of conditions.

Protection of the Right to File a Lawsuit

Legal Services of Central New York assisted an individual in filing a notice of claim after an injury which happened three years ago. In *H.W. v. State of New York,* the plaintiff was injured at a state psychiatric center where she was an inpatient. A portion of one of her fingers was amputated during a struggle with a therapy aide who was employed at the psychiatric center. PAIMI filed a Notice of Motion to File a Claim, Supporting Papers, and Proposed Claim on behalf of H.W., alleging among other things, that H.W.'s mental disability and incarceration during the past three years kept her from following through on filing a timely claim for damages.

Parental Visitation Ordered

Problems around denial of parental visits to individuals with mental illness continue to be brought to the attention of PAIMI attorneys. In this case which was handled by North Country Legal Services, Inc., the custodial parent had denied visitation in violation of an order of the Supreme Court of Orange County. After PAIMI involvement in this problem, through their representation of the non-custodial parent, the judge appointed a law guardian for the child and ordered several evaluations of the home and family. He also ordered visits to commence immediately, pending the outcome of the ordered evaluations. Since that time, visits have continued and even a month-long visit over summer vacation was obtained.

Conservatorship Opposed/Transfer Stopped

Neighborhood Legal Services, Inc. and New York Lawyers for the Public Interest, Inc. worked cooperatively *In the matter of the Petition of J.B. for Appointment as Conservator for N.F.,* with a successful outcome. A daughter filed a petition for conservatorship over her mother simply because she wanted to move her mother from a nursing home in Queens County to Buffalo and her mother objected to the move. After the court ordered affidavits regarding the appropriateness of the transfer and the desires and capabilities of N.F., the daughter withdrew her petition for

conservatorship. A final Stipulation and Oral Order were signed, resolving the case.

Adult Home Resident Protected

Disability Advocates, Inc. was successful in preventing an eviction from an adult home in *Sacks v. McGivern*. Their client resided in an adult home and was being evicted as the home's owner claimed that the client was not appropriate for adult home level of care. DAI became involved and, in cooperation with the home's owner, the family members of the client, and the local Department of Social Services, the eviction was prevented and an alternative placement was developed which was both more appropriate for the client and acceptable to him.

Employment Discrimination Suit Settled

Disability Advocates, Inc. assisted in a settlement in *Svoboda v. Paul Smith's College,* an employment discrimination suit. The plaintiff was employed as an associate professor at the college, and was hospitalized near the end of her first semester of teaching. The plaintiff was then placed on extended sick leave without pay, notwithstanding the fact that she produced evidence from her treating physician that she was capable of returning to work. Her contract was also not renewed for the following year. Just before a trial was to be held, the parties agreed to settle the action. A Stipulation of Discontinuance was filed during November, 1993, and provided that the terms not be disclosed other than the parties satisfactorily resolved their dispute.

Damages for Confidentiality Breach/PAIMI Standing Upheld

E.K. v. New York Hospital-Cornell Medical Center arose as a result of a hospital social worker allegedly releasing confidential information regarding the plaintiff's care to a third party without her consent and contrary to her explicit instructions.

Initially, the defendants sought to have this action dismissed because the pleadings did not name E.K., although the defendants had been notified of her identity. It is ironic that the defendants sought to compel the plaintiff to publicly reveal her identity as a condition of pursuing her claim for breach of confidentiality. Defendants also made many frivolous allegations regarding the professional actions taken by Disability Advocates, saying that DAI had abused their "governmental authority" by investigating the complaint and then using the results of that investigation to file a lawsuit. The court rejected all the defendant's frivolous accusations and upheld the authority of a PAIMI agency to investigate alleged rights violations pursuant to PAIMI authority and to commence litigation regarding the matter investigated.

The parties have reached a settlement agreement in this case and the defendant has paid E.K. $15,000 in settlement of her claim.

Insurance Coverage Questioned

Touro College's Mental Disability Law Clinic is representing a defendant against whom a hospital obtained a judgment as a result of his failure to pay a hospital bill. In *Long Island Homes v. Davis,* the client entered an alcohol recovery program only because he was told that his insurance would cover all the expenses related to the treatment program. He later learned that this was not the case, and a judgment was obtained against him for the bill. The Law Clinic has filed a third party complaint against their client's insurance company as well as defending him against the judgment.

Liability for Involuntary Treatment Questioned

Touro College is also representing an individual who was involuntarily hospitalized at Bellevue Hospital Center and is now facing a bill for the hospitalization. *Rodriguez v. City of New York* raises the issue of whether or not someone who is involuntarily hospitalized at a non-state facility is liable for care and treatment charges. The plaintiff also seeks to expunge her hospital record and asks for damages for both her wrongful confinement and the administration of medication without first providing information regarding the possible side effects of such medication.

Class Actions

Updates on Some Previous Cases: Two Significant Victories

Regular Access to Outdoors and Recreation

New York Lawyers for the Public Interest, Inc. was successful in negotiating a settlement this past year with the NYS Office of Mental Health in its lawsuit *Jean D. et. al. v. Cuomo, et. al.* At issue here was the fact that a majority of individuals in New York State psychiatric centers did not have access to the outdoors and to recreational facilities at the centers. There were many reasons, unrelated to patient needs, which determined whether patients were assigned to locked wards and whether they were able to leave the wards or to use recreational or other facilities. Many persons with escorted grounds privileges were unable

to use those privileges because staff were unwilling to take patients outside.

NYLPI, with Mental Hygiene Legal Service, First and Second Departments as co-counsel, filed a class action lawsuit on behalf of all patients in psychiatric centers alleging that the State was violating their constitutional rights and unlawfully discriminating against them by denying them access to fresh air and exercise. The complaint also asserted claims under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act. A class was certified which consisted of all patients at Pilgrim and Manhattan Psychiatric Centers and numbered approximately 2,000.

After conducting 50 depositions, employment of three experts, preparation of a 177-page pre-trial order, and litigation of a number of discovery issues, close to the trial date the case was settled. Some highlights of the settlement are:

- The hospitals will adopt a policy of an expectation that daily access of at least one hour per day to the outdoors for all patients.
- Each ward will schedule at least one outdoor activity daily.
- Logs will be maintained which show the days patients with only escorted privileges actually go outside. These logs will be monitored both at the hospital quality assurance office and by an independent monitor to be provided by NYLPI.
- After a nine month phase-in period, any ward in which 95% of the patients do not actually go outdoors on 16 days per month (15 during the winter) must prepare a corrective plan. The standard is one day less per month on geriatric wards. (The 16 day standard roughly approximates the frequency with which unescorted patients currently go outside on their own at the two hospitals.)
- There are individual thresholds which trigger review of patients who do not go outside at least 14 days per month, in order to avoid possible neglect of individual patients on wards on which almost all patients but a few go out regularly.

It is anticipated that the Office of Mental Health will implement the settlement statewide, and a joint strategy is being developed between regional PAIMI and Mental Hygiene Legal Service offices throughout the state to insure that this implementation will take place.

Community Residence Program Accessibility

Disability Advocates, Inc. reached a settlement this year with the Office of Mental Health in its lawsuit, *Pruitt v. Surles*. The named plaintiff in this action had been ready to be discharged from a state psychiatric center to a supervised community residence for 18 months, but no residential program within that region of the state was accessible to someone in a wheelchair, and so he remained hospitalized.

In 1990, Disability Advocates filed a class action lawsuit on Mr. Pruitt's behalf in U.S. District Court for the Northern District of New York seeking relief under Section 504 of the Rehabilitation Act and the Fair Housing Amendments Act, among other claims. There followed lengthy and complex negotiations to develop a plan to remedy the unlawful exclusion of physically disabled, mentally ill individuals from full participation in the OMH community residence program. In March 1993, the plaintiff and the Office of Mental Health signed a stipulation of settlement to remedy the problem. By terms of the settlement, the Office of Mental Health has agreed to the following:

- OMH has amended its regulations which govern the construction and modification of community residences to require that the residences be developed in accordance with federal accessibility requirements.
- OMH will adopt new regulations governing the licensing and operation of community residences which will include new rules which are designed to ensure that persons with mobility impairments are not unnecessarily excluded from community residences because of fire safety concerns and to ensure that persons with disabilities enjoy appropriate access to community residence programs and activities;
- OMH will make structural modifications necessary to provide accessibility to persons with mobility impairments at nine "24-bed prototype" State-operated community residences at a cost of approximately 1.4 million dollars.

As a result, the availability of accessible community residence beds is expected to meet or exceed five percent of the beds in each OMH region upon the completion of currently planned residential bed development.

New Class Action

Counterclaims for Damages Challenged

The PAIMI system filed a new class action lawsuit this year, *Siegel, et. al. v. Surles, et. al.*, which is being co-counseled by Disability Advocates, Inc. and the Mental Disability Law Clinic at Touro College. The plaintiffs in this case have all suffered injuries while inpatients at state psychiatric facilities and have all brought or seek to bring damages lawsuits in the Court of Claims, but their attempts have been thwarted due to counterclaims brought by the State for the cost of their care and treatment. These counterclaims mean that the plaintiffs have little hope of any net recovery against the State and have great difficulty in retaining counsel. The result is that the deterrent effect of civil liability for harm caused to patients by unsafe conditions is absent.

A complaint was filed in New York County in September, 1993. Plaintiffs are seeking a declaration that the State's practice insulates it from liability for injuring patients, and therefore violates the public policy of the State of New York, and violates patients' rights under the due process and equal protection provisions of the New York and U.S. Constitutions and the First Amendment of the U.S. Constitution.

There was a similar case last year, *Acevedo v. Surles,* in which the U.S. District Court invalidated the prior practice of the Office of Mental Health in which it assessed charges in the form of a verified claim against patients who sue the State in the Court of Claims. Plaintiffs in the *Siegel* lawsuit believe that this new practice of counterclaiming against damages awards violates the same portions of the Constitution as did *Acevedo.*

CAP Legal Actions

Right to Challenge State Policy in Federal Court

Marshall v. Switzer and Gloeckler

An interim Second Circuit Court of Appeals ruling in the case of *Marshall v. Switzer, Gloeckler* represents one of the most significant CAP achievements

Albany Times Union **March 19, 1993**

Group homes will become accessible to disabled

BY HARVY LIPMAN
State editor

Clarence Pruitt spent a year-and-a-half of his life in the state's Harlem Valley Psychiatric Center in Dutchess County—not because he needed the care provided there, but simply because he's a paraplegic.

While Pruitt's psychiatrists had determined the wheelchair-bound schizophrenic was ready to be discharged to a group home, they couldn't find one that was accessible to people with physical disabilities.

When he finally was transferred to a community residence in 1990, Pruitt was placed in a group home that was only partially accessible to wheelchairs.

Two of its three floors were not accessible. The facility has an exercise room in the basement, and Pruitt wanted to use its weight machine to improve his upper-body strength, which is critical for a paraplegic.

He could barely struggle up the stairs to the second floor, where house meetings and other social gatherings are held.

Pruitt was not alone. A survey by the state Office of Mental Health found that about 3 percent of psychiatric center patients ready to be discharged had a physical disability which was delaying or preventing them from finding spots in community residences.

In 1990, Pruitt became the main plaintiff in a lawsuit charging the state Office of Mental Health with violating a 1973 law requiring any program that receives federal funds to be accessible to the handicapped.

On Thursday, Pruitt's lawyers and those representing OMH announced they had reached a settlement in the case which will guarantee that at least 5 percent of all community residences for the mentally ill will be accessible to the physically disabled.

Under the agreement, the state has already begun retrofitting nine community residences built in the mid-1980s, putting in wheelchair lifts and making other changes that will make them accessible.

"They also will rewrite the regulations concerning the development of community residence beds... to insure that people with mobility impairments have full access," said Clifford Zucker, director of the Albany-based Disability Advocates, Inc.

The settlement also changes the fire safety code under which OMH operates. The old rules said that physically disabled individuals who couldn't get out of the building in three minutes without any assistance would not be allowed in a group home.

The new regulations adopt a code developed by the National Fire Protection Association, which takes into account a number of factors including whether the facility has sprinklers, how many staff are on duty at all times and the location of the individual's bedroom.

OMH assistant counsel John Tauriello said the agency had already begun implementing the changes before the final settlement agreement was signed.

Tauriello said the new regulations on making community residences handicapped accessible will apply to any programs located in newly constructed buildings or in facilities undergoing "major renovations."

Pruitt has already been one of the beneficiaries of the new rules. "They've put wheelchair lifts into the community residence where Mr. Pruitt lives," Zucker said, "and he's been able to continue living there."

in 1992-93. The *Marshall* ruling affirmed an individual right of action in federal court for consumers of vocational rehabilitation services. This long-standing CAP case is challenging a VESID vehicle modification policy which prohibits the purchase of factory installed equipment, which had been prescribed in Mr. Marshall's case.

In response to VESID's motion to dismiss, the lower court ruled that vocational rehabilitation consumers do not have an 'individual' right to challenge a state agency in Federal Court under Section 1983 of federal civil rights law. The ruling which was centered on a decision in a child welfare case (*Artist M. v. Suter*) where the Supreme Court ruled an individual right of action did not exist for recipients of child welfare services.

The Court of Appeals rejected the application of the (*Suter*) standard to recipients of vocational rehabilitation services, and affirmed "enforceable rights, privileges, or immunities within the meaning of Section 1983." The court cited Title I of the Rehabilitation Act requiring states to develop a plan which "shall" provide, at a minimum, for the provision of specified vocational rehabilitation services. The court also referred to State Plan requirements. State vocational rehabilitation programs "shall" provide that an Individualized Written Rehabilitation Plan (IWRP) be developed for each eligible handicapped individual. Each IWRP "shall" include a statement of the rehabilitation goal for, and specific vocational rehabilitation services to be provided to, the client.

While *Marshall* has been remanded back to the District Court for resolution, the Appeals Court ruling represents a significant national precedent for protection of an 'individual' right to vocational services and will serve as a critical basis for consumer protection in future appeals nationwide.

Maximizing Employability

Polkabla v. Commission for the Blind and Visually Handicapped

In another landmark CAP case, New York Lawyers for the Public Interest (NYLPI) settled an Appeals Court case in *Polkabla v. CBVH.* Ms. Polkabla is a Commission for the Blind and Visually Handicapped (CBVH) consumer who had completed paralegal training and was denied sponsorship to law school.

While employed as a paralegal, it became apparent that Ms. Polkabla was extremely capable and was encouraged by her supervisor to pursue a career as an attorney. Ms. Polkabla was subsequently accepted into Fordham Law School, but was denied CBVH support, based on the agency's claim that their obligation for training was satisfied with the paralegal training.

The State Appellate Division relied on the "clear language" of the federal Rehabilitation Act and its legislative history, in ruling that vocational rehabilitation services are mandated to assist persons with disabilities to "maximize their employability" and to, in fact, reach their "highest level of achievement."

Following a CBVH assessment of Ms. Polkabla's mobility, communication, and daily living skills, NYLPI secured a favorable eligibility determination, and received payment from CBVH for the expenses associated with her studies at law school.

Connections Between "Default Status and Disability" and "Maximum Efforts"

Steinkohl v. Gloeckler

Neighborhood Legal Services (NLS), the Western New York CAP legal office, initiated an Article 78 complaint against the New York State Department of Education and VESID in *Steinkohl v. Sobol, Gloeckler.* Mr. Steinkohl has a history of substance abuse which prompted default of his student loan, and despite the existence of a negotiated payment schedule, he was denied VESID sponsorship for college. VESID's position is that a link between Mr. Steinkohl's disability and the default was never established and that he failed to make adequate efforts to repay the loan.

CAP will attempt to demonstrate that VESID has narrowly interpreted direction from the Rehabilitation Services Administration which grants state agencies considerable latitude linking an individual's disability to the default and in determining that "maximum efforts" were undertaken to resolve a loan default.

Increasingly, VESID consumers who are recovering from substance/alcohol abuse or mental illness find themselves in the default status. Through *Steinkohl,* CAP will also seek clarification on what constitutes "maximum efforts" to resolve default loans and will seek a clear standard by which consumers can demonstrate the connection between default status and their disability.

Home Modification Policies

Bridger v. Office of Vocational and Educational Services for Individuals with Disabilities

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 home modifications which would enable Ms. Bridger to pursue her vocational goal as a clerk typist/secretary. VESID had approved modest home modifications which were ultimately constructed poorly and which resulted in a hazardous circumstance for Ms. Bridger. In addition to calling for changes to assure safety, CAP will also argue that the home modifications approved were not adequate to meet Ms. Bridger's individualized needs.

The Bridger case highlights a number of long-standing problems CAP has experienced with VESID policies and practices governing the provision of home modification services.

Cognitive Remediation

Goldstein v. Office of Vocational and Educational Services for Individuals with Disabilities

New York Lawyers for the Public Interest (NYLPI) filed an Article 78 complaint in New York State Supreme Court in the case of *Goldstein v. Sobol and Gloeckler.* Mr. Goldstein is a VESID consumer who experienced a head injury and was denied VESID support for prescribed cognitive remediation therapy. NYLPI represented Mr. Goldstein at a hearing in the last reporting period, and after receiving an unfavorable hearing decision, initiated an Article 78 proceeding. The case was referred and argued to the Appellate Division and a decision is pending.

The *Goldstein* case illustrates an array of issues with regard to counselor discretion, under-utilization, and inadequate reimbursement, for cognitive remediation services.

Employment Consistent with an Individual's Abilities

Woodford v. Gloeckler

Neighborhood Legal Services filed an Article 78 complaint in State Supreme Court challenging VESID's denial of graduate school sponsorship for Ms. Woodford who is pursuing a career in social work. CAP had represented Ms. Woodford at a fair hearing, and initiated the Article 78 complaint when the 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 enables individuals to pursue "meaningful careers."

Woodford represents a critical issue in vocational rehabilitation services, questioning whether the state vocational rehabilitation agency is only required to provide services which allow for entry level employment, or whether the level of services should be provided consistent with an individual's abilities.

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 the case of *Polkabla v. CBVH*, [see above] where 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."

Career As An Attorney

Moore v. Commission for the Blind and Visually Handicapped

In *Moore v. Commission for the Blind and Visually Handicapped,* New York Lawyers for the Public Interest (NYLPI) settled another case similar to the previously mentioned *Polkabla* on behalf of Mr. Moore, a student at the City University of New York Law School who was denied assistance from CBVH to pursue a career as an attorney. During the 1991-1992 reporting period, the Supreme Court ordered the court case transferred to the Appellate Division. Once NYLPI learned of its victory in the *Polkabla* case, NYLPI attempted to settle *Moore* out of court. Initially CBVH was hesitant to settle the case, prompting NYLPI to file a brief in the Appellate Division. CBVH ultimately agreed to settle *Moore* agreeing to pay Mr. Moore all eligible expenses associated with law school.

Intensive Independent Living Skills Training

Singer v. Sobol

Neighborhood Legal Services (NLS) filed an Article 78 complaint in New York State Supreme Court after the VESID Deputy Commissioner reversed a fair hearing decision in support of Ms. Singer. The Deputy Commissioner's decision denied Ms. Singer sponsorship in an intensive independent living skills training program.

Ms. Singer is a woman with cerebral palsy who was attending a Pennsylvania-based college, and living away from home for the first time. 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, the college administers a comprehensive independent living skills program which was equipped to improve Ms. Singer's ability to negotiate the campus and varied activities of daily living.

VESID denied sponsorship to the independent living program and Ms. Singer's sponsorship for college, based on their policy which limits out of state sponsorship.

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, articulated in the Rehabilitation Act, allows for the out of state sponsorship.

Unfortunately a six-month delay ensued from the time of hearing until a decision was rendered, highlighting the need for a specific policy in instances when a hearing officer fails to meet federally mandated fair hearing timeliness. Despite the ultimately favorable hearing decision, and CAP's claim that Ms. Singer's right to services had been abridged by the delay in the hearing process, the VESID Deputy Commissioner overruled the decision and remanded the case back to the local VESID office to seek commensurate services within New York.

Home Modifications

Tredo v. Office of Vocational and Educational Services for Individuals with Disabilities

The Legal Aid Society of Mid-New York (LASMNY) filed an Article 78 complaint in State Supreme Court in the case of *Tredo v. Gloeckler.* The CAP advocate at the Resource Center for Independent Living had unsuccessfully represented Mr. Tredo at a fair hearing. CAP argued that due to a significant delay in the development of Mr. Tredo's service plan (Individualized Written Rehabilitation Plan) he was forced to expend funds in the amount of $1,267 for construction of a ramp to access his home.

The hearing officer ruled in favor of Mr. Tredo, directing VESID to assume responsibility for the purchase of the home modifications, and noted that VESID's refusal to reimburse Mr. Tredo contradicted the VESID State Plan and federal regulations. The VESID Deputy Commissioner subsequently overruled the hearing decision and denied purchase of the home modification services.

The Article 78 complaint calls on VESID to amend Mr. Tredo's service plan (IWRP) to include the home modifications prescribed and necessary for him to continue his studies in the field of gemology.

CAP Fair Hearings

A fair hearing is an administrative appeal before a hearing officer when an applicant or consumer of vocational rehabilitation services has been unsuccessful in resolving a complaint through mediation and negotiation. Fair hearings are important avenues for dispute resolution and consumer due process, in that the record of the fair hearing serves as the basis for appeals in state and federal court, if necessary. In the reporting period, CAP continued to experience a high level of hearing activity, providing representation at 25 fair hearings. Examples:

Delay in College Sponsorship

The Upper Hudson CAP advocate at the Capital District Center for Independence successfully represented Mr. P. at a fair hearing to secure reimbursement for college expenses. The expenses were incurred due to VESID's failure to make a timely eligibility determination.

Mr. P. was in recovery from alcoholism when he first established VESID eligibility and was sponsored at a community college. Mr. P. subsequently was convicted of a criminal offense and incarcerated in a correctional facility. With his release pending, Mr. P. attempted to resume VESID sponsorship for college. He contacted a treatment facility where he would receive ongoing services, and contacted the college's disabled student services coordinator. In early January 1993 Mr. P. submitted a new application for VESID services, and following his release in late January, resumed his college studies.

The record indicated that by late June, Mr. P.'s eligibility had not been determined, despite an administrative review which established that VESID was in receipt of all documentation necessary to establish eligibility. The hearing officer ruled that Mr. P. had taken all the appropriate actions to re-establish VESID eligibility, and that VESID acted capriciously in failing to respond. The hearing officer then directed VESID to sponsor Mr. P. in his college studies and to reimburse him for expenses of $1,150.

A due process issue was also raised in Mr. P's case in that a hearing was not held for 75 days following Mr. P.'s request for a hearing. VESID is mandated by federal regulation to conduct hearings within 45 days. In addition to directing VESID to reimburse Mr. P. for college expenses, the hearing officer called on VESID to clarify whether the time limits, referred to in policy, constitute working days or calendar days.

Occupational Goal

The Long Island CAP advocate at the Long Island Advocacy Center successfully represented Mr. G., at a VESID fair hearing to secure training for employment as a computer repair person. VESID was supportive of Mr. G's goal and sponsored his enrollment in three courses. VESID contended that the courses qualified Mr. G for entry level employment as a computer repair person, when in fact he was only qualified to function as a computer refurbisher.

In an effort to supplement his fixed income, Mr. G. took marginal employment as a refurbisher with a local computer firm. When he approached VESID for additional assistance in pursuing a technical school certificate for computer repair (required by the firm in which he was employed), VESID denied sponsorship based on the erroneous assumption that he was qualified to function as a computer repair technician.

At the fair hearing, CAP documented the industry standard which calls for computer repair technician to hold a training certificate. VESID was directed to provide Mr. G. with additional training leading to a certificate in computer repair.

Neuropsychological Exam

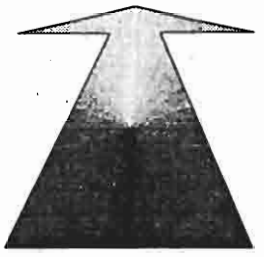
Long Island CAP also provided representation at a fair hearing on behalf of Ms. P. who is a VESID consumer with a learning disability and mild retardation. VESID determined that Ms. P. was ineligible for vocational services based on the findings of a VESID sponsored "neuropsychological exam".

Ms. P's attending psychologist strongly disagreed with the findings of the "neuropsychological" and identified glaring problems in the administration of the evaluation.

At the hearing, a New York State Board Certified neuropsychologist testified that the exam in question was inadequately administered. The expert witness identified critical aspects of the evaluation which were administered inconsistent with accepted practice in the field and inconsistent with VESID's own policy on neuropsychological evaluations. The hearing officer ruled in favor of VESID, and CAP is considering an appeal in federal court.

Ms. P's case highlights deficits in VESID policy and practices regarding neuropsychological evaluations. This is a particularly critical concern in that neuropsychological evaluations frequently serve as the basis for establishing a particular vocational goal and often serve as the cornerstone for an individual's vocational services plan.

Looking Ahead



Continuing Study on Restraint and Seclusion

At the request of the State Legislature, the Commission has been studying the policies and practices on restraint and seclusion at state psychiatric centers and psychiatric units of general hospitals. Thus far, this study has included surveys of approximately 130 facilities and over 1,000 consumers, as well as on-site reviews at 7 state psychiatric centers, psychiatric units of 5 general hospitals, and 28 state-operated and state-certified residential programs and hospitals providing psychiatric treatment for children.

One of the most important revelations of this study has been the wide variation in the patterns of use of restraint and seclusion, unrelated to patient populations, staffing resources, funding, or overcrowding. The voices of over 1,000 consumers echoed the Commission's finding of widely variant rates of use of mechanical restraints and seclusion, and also relayed largely negative perceptions of the use of these interventions.

Although there is an enormous amount of research on the use of mechanical restraint and seclusion in psychiatric treatment facilities, the literature is not very enlightening. The Commission is planning to look at clinical and environmental characteristics in its review of the variation of the rates, but it has also decided to look at several other issues which include:

- The program opportunities for individuals on inpatient units.
- The units' assurances for basic liberties, including privacy, the right to go outdoors, and the right to participate in one's treatment decisions, which have not been well-examined in the existing research.
- Hospital and state psychiatric center policies will also be reviewed to glean whether general mission and value statements, as well as the specific procedural requirements, surrounding the use of restraint and seclusion, are different for the low-user facilities.
- Further study of children's residential programs and hospitals providing psychiatric treatment for children where rates of mechanical restraint and seclusion are equally variable, and, in some cases, higher.
- Monitoring of chemical restraint (i.e., STAT and PRN administrations of psychotropic medication) as forms of behavior management of children.

Acute Psychiatric Hospitalization of Children With Developmental Disabilities

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 and/or a developmental disability.

During the site visits to facilities, hospital staff reported having difficulties meeting some of the special needs of these children, especially with regard to behavioral management issues and appropriate placement and service provision upon discharge. Hospital staff also indicated to Commission reviewers that their psychiatric units are sometimes used inappropriately as placement of last resort for children with mental retardation.

The Commission is planning to look systemically at the care and treatment provided to children with developmental disabilities during their acute psychiatric hospitalization, as well as the issues of timely and appropriate discharge planning.

Westchester Ombudsman Program Evaluation

In response to a request by the State Legislature, the Commission has begun an evaluation of the Westchester Ombudsman Program. As part of the evaluation, the Commission has conducted a variety

of data collection activities including mail surveys to all former, current, and trained (but not currently employed) ombudsmen, interviews with program managers, reviews of programs' documents and certification histories, and site visits to community residences and Intermediate Care Facilities (ICFs).

Thus far, the Commission has received well over half of the mail surveys and has visited eight community residences/ICFs in Westchester county. Preliminary findings indicate that the community residence managers, staff, and ombudsmen are generally satisfied with the program, stating that its most outstanding benefits are the programs' agenda to bring community members into the residences and the friendships that have been established between volunteer ombudsmen and individual residents. Other responses indicate that more training for ombudsmen, more younger ombudsmen, and more frequent visits by ombudsmen would be helpful.

During the next year, the Commission will complete the evaluation of the Westchester Ombudsman Program and issue a report that will determine the effectiveness of the program in promoting the quality of life for individuals in community residences/ICFs, and the desirability of replicating the program in other counties in New York State.

Court Accessibility

The Commission, in conjunction with the New York State Bar Association and the Independent Living Centers throughout the state, and support from the office of Court Administration, conducted a survey of a representative sample of 275 courts ranging from town and village to the highest court in the state. The courts were evaluated with regard to physical accessibility and support through assisted technology for persons with disabilities in their role as plaintiff, juror, defendant or attorney. A slide presentation, developed to serve as an educational tool has been shown to court personnel in various parts of the state. The final written report which includes a "score card" for each court is in final draft and should be disseminated early 1994.

1992-93 Publications

A Review of Familial Abuse Allegations of Adults with Developmental Disabilities
July 1992

The Role of Psychotropic Medication in the Treatment of Children in NYS Mental Health Inpatient Settings
November 1992

NYS Residential Services for Children with Emotional Problems: A Call for Reform
February 1993

Discharge Planning Practices of General Hospitals: Did Incentive Payments Improve Performance?
April 1993

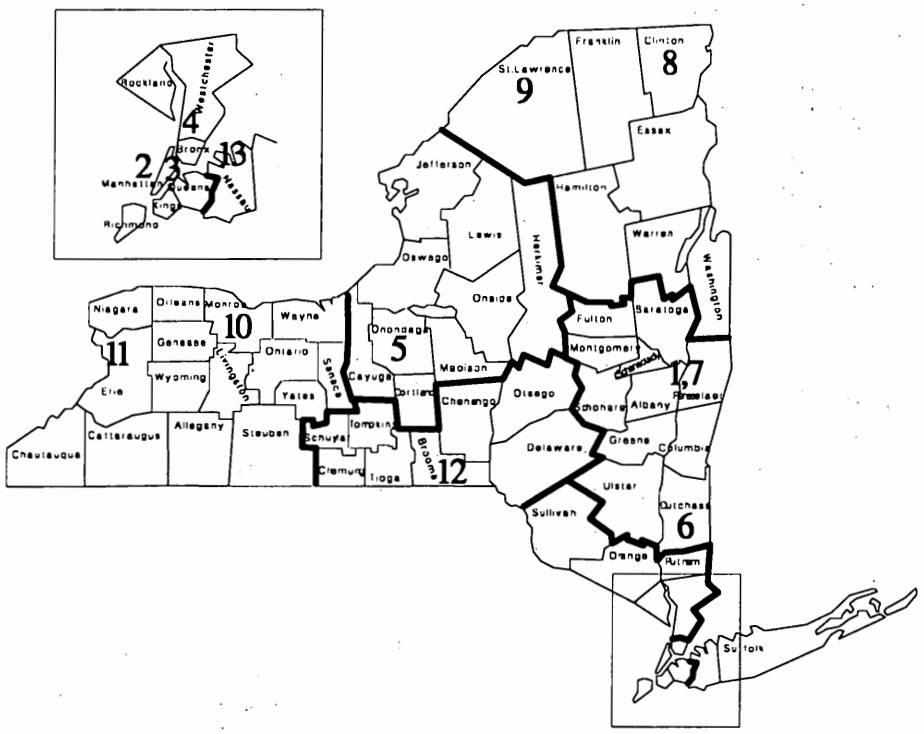
Life and Death at New Queen Esther Home for Adults
June 1993

Falling Through the Safety Net: "Community Living" in Adult Homes for Patients Discharged from Psychiatric Hospitals
August 1993

Parenting with Special Needs: Parents Who Are Mentally Retarded and Their Children
July 1993

Serving Parents Who Are Mentally Retarded: A Review of Eight Parenting Programs in New York State
July 1993

Protection and Advocacy for Developmentally Disabled Persons Regions and Offices



1. NYS Commission on Quality of Care
   Bureau of Protection and Advocacy
   Albany, NY

New York City Region

2. NYS Commission on Quality of Care
   Bureau of Protection and Advocacy
   New York, NY
3. New York Lawyers for the Public Interest, Inc.
   New York, NY

Lower Hudson Region

4. Westchester Independent Living Center, Inc.
   White Plains, NY

Central Region

5. Legal Services of Central New York, Inc.
   Syracuse, NY

Upper Hudson Region

6. Mid-Hudson Legal Services, Inc.
   Poughkeepsie, NY
7. Disabilities Law Clinic at Albany Law School
   Albany, NY

North Country Region

8. North Country Legal Services, Inc.
   Plattsburgh, NY
9. North Country Legal Services, Inc.
   Canton, NY

Western Region

10. Western New York Advocacy for the
    Developmentally Disabled, Inc.
    Rochester, NY
11. Neighborhood Legal Services, Inc.
    Buffalo, NY

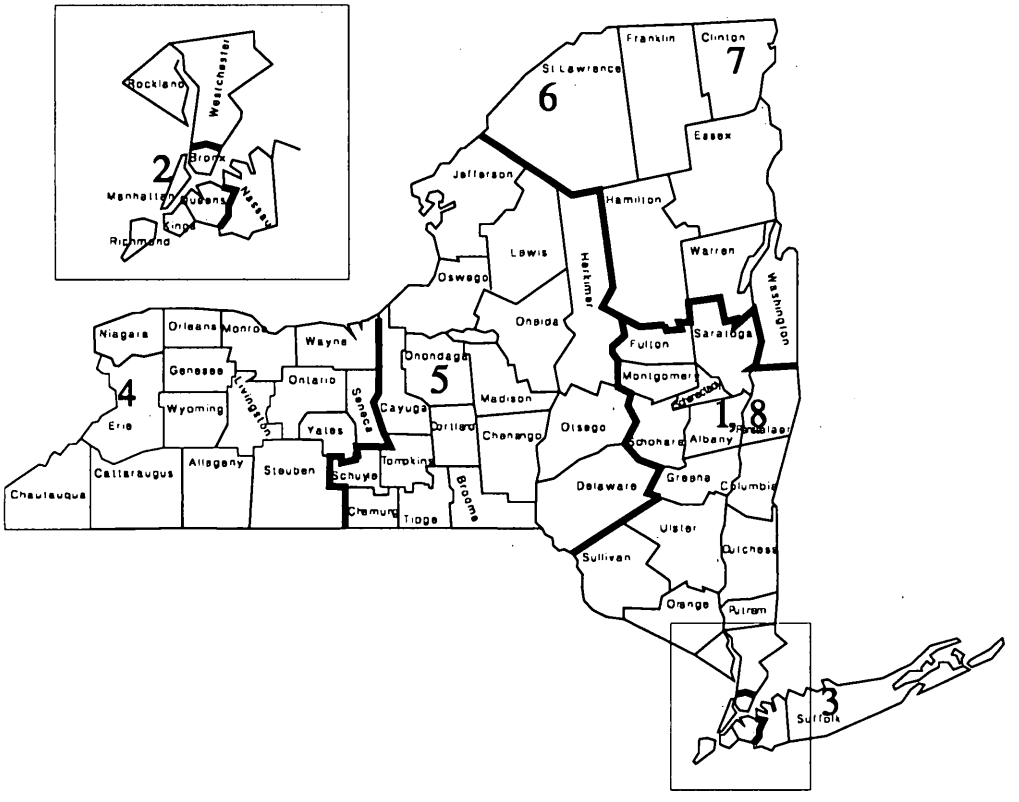
Southern Tier Region

12. Broome Legal Assistance Corporation
    Binghamton, NY

Long Island Region

13. Long Island Advocates, Inc.
    New Hyde Park, Inc.

Protection and Advocacy for Individuals with Mental Illness Regions and Offices



1. NYS Commission on Quality of Care
   Bureau of Protection and Advocacy
   Albany, NY

New York City Region

2. New York Lawyers for the Public Interest, Inc.
   New York, NY

Long Island Region

3. Touro College
   Jacob J. Fuchsberg Law Center
   Huntington, NY

Western New York Region

4. Neighborhood Legal Services, Inc.
   Syracuse, NY

Central New York Region

5. Legal Services of Central New York, Inc.
   Syracuse, NY

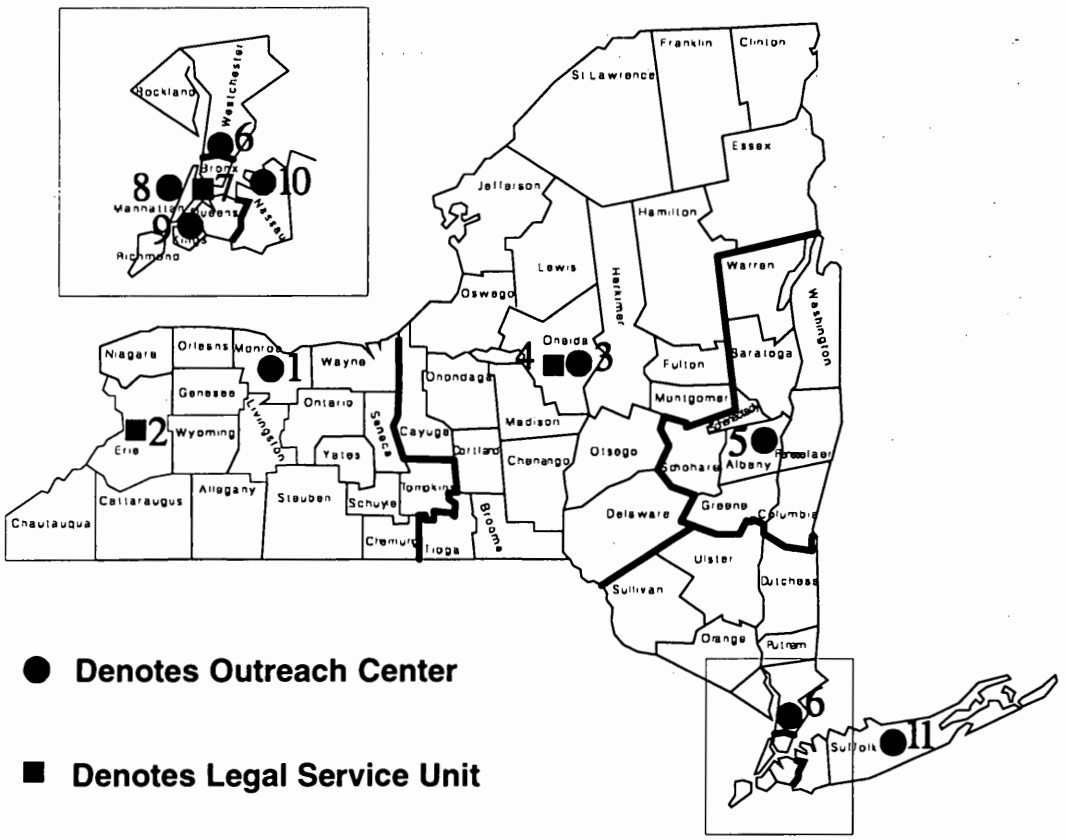
North Country Region

6. North Country Legal Services, Inc.
   Canton, NY
7. North Country Legal Services, Inc.
   Plattsburg, NY

Hudson Valley Region

8. Disability Advocates, Inc.
   Albany, NY

Client Assistance Program Regions and Offices



● **Denotes Outreach Center**

■ **Denotes Legal Service Unit**

Western New York Region

1. Rochester Center for Independent Living, Inc.
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2. Neighborhood Legal Services, Inc.
   Buffalo, NY

Central New York Region

3. Resource Center for Independent Living, Inc.
   Utica, NY
4. Legal Aid Society of Mid-York, Inc.
   Utica, NY

Hudson Valley Region

5. Capital District Center for Independence, Inc.
   Albany, NY
6. Westchester Independent Living Center, Inc.
   White Plains, NY

New York City Region

7. New York Lawyers for the Public Interest, Inc.
   New York, NY
8. Center for Independence
   of the Disabled in New York, Inc.
   New York, NY
9. Brooklyn Center for Independence
   of the Disabled, Inc.
   Brooklyn, NY

Long Island Region

10. Long Island Advocacy Center, Inc.
    New Hyde Park, NY
11. Long Island Advocacy Center, Inc.
    Hauppauge, NY (Satellite Office)

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Follow-Ups Are Key

Report notes flaws in mental-health syste

By Jim Puzzanghera
STAFF WRITER

Homeless and abusing drugs, Mike was involuntar-

of these hospitals becomes extremely [illegible] functioning of the whole mental hea[illegible]," Clarence J. Sundram, chairman o[illegible] sion on Quality of Care for the [illegible] general hospitals are doi[illegible] being available and d[illegible] stabilization . . . [illegible] doing a less tho[illegible] patient is g[illegible]

The [illegible] day

Nonprofit, but big spenders?

By JOEL SENDEROW
Daily News Albany Bureau Chief

ALBANY — State officials are launching a full-scale probe into possible misuse of state funds by not-for-profit mental-health agencies that pay excessive salaries, lease luxury cars and spend thousands on parties and travel.

Officials said that if the handful of incidents they have found are repeated systemwide, the agencies could be squandering millions of dollars. And Medicaid overcharges worth possi[illegible] as much as $12 million alread[illegible] been identified by auditors.

State Sen. Nicholas Sp[illegible] chester), chairman [illegible] Health Committee[illegible] profit agencies [illegible] had asked [illegible] Regan to [illegible] ately.

$188,000 each; spent $17,279 on a [illegible] day party and $2,000 a year for [illegible] ing garage near the home o[illegible] chiatric director.

■ Jewish Board of [illegible] dren's Services pa[illegible] an executive tri[illegible] ury cars for [illegible] ly $20,000.

■ N[illegible] of C[illegible]

Indictments expected in HI-LI scam

'HI-LI M[illegible]

By Randi Kreiss

"We are pleased to hear that indict[illegible] ments are imminent." With those words, the spokesman for a state panel that first shined a spotlight on substandard condi[illegible] at HI-LI Manor in Far Rockaway, reports of criminal charges about

[illegible], spokesman for the [illegible] mmission on Quality [illegible] Disabled, said he [illegible] urces at the [illegible] and the [illegible] ral's [illegible]

Mental care funds misused

Auditors reveal 'luxury' spending

By Jay Gallagher
Staff Writer

ALBANY — Using taxpaye[illegible] money meant for the mentally i[illegible] operators of mental-health clini[illegible] around the state have given ther[illegible] selves six-figure salaries and lux[illegible] ries like a trip to Japan, calls [illegible] telephone sex lines, and price[illegible] meals and parties, according [illegible] state documents.

Serious problems have be[illegible] found in 10 of 14 programs audite[illegible]

DECISION OF THE DAY

Appellate Division

Third Department

Medicaid

State's Recoupment for Fraud

Robert Abrams, Attorney-General (Michael S. Buskus of counsel), Albany, for appellant.

Sankel, Skurman & McCartin (Joel S. Sankel of counsel), New York City, for respondents.

MIKOLL, J.P. — Appeal from a judgment of the Supreme Court (Kenny, J.), entered Oct. 16, 1991 in Albany County, which granted petitioners' application, in a proceeding pursuant to CPLR article 78, to direct respondent to make payments to petitioners in compliance with EDPL 304.

This litigation arises out of [illegible] of parcels of domain. In July 1988 petiti[illegible] ers and the State execu[illegible] three agreements for adva[illegible] payments pursuant to ED[illegible] 304. In August 1988 petitior[illegible] brought claims in the Court[illegible] Claims for additional comp[illegible] sation for the appropriation[illegible] October 1988 respondent [illegible] proved the advance payme[illegible] On Nov. 7, 1988 the Attorn[illegible] General certified them for p[illegible] ment. On the same day the J[illegible] issued a decision in *People*[illegible] *BPRI* finding that the St[illegible] failed to meet its burden [illegible] proof. However, an order [illegible] missing the complaint in *Pec*[illegible] *v. BPRI* was not entered u[illegible] May 6, 1991. The State [illegible] pealed from that ord[illegible]

In the Matter of 3 Lafayette
Avenue Corp. et al., respon
dents, v. Comptroller of the
State of New York, appellan
Decided Sept. 17, 1992.
Before Mikoll, J.P.; Yesawich
Crew III, Casey and Harvey,

Meanwhile, petitioners co[illegible] menced this CPLR article [illegible] proceeding against respond[illegible] to compel the payment of [illegible] $4.55 million in advance p[illegible] ments due petitioners for [illegible] appropriation of the prope[illegible] Respondent, claiming tha[illegible] setoff was to be made ba[illegible] upon the State's potential [illegible] covery against Easton in *Peo*[illegible] *v. BPRI*, announced that [illegible] State did not intend to pay [illegible] advance payments. Respond[illegible] answered the petition and fi[illegible] objections in point of law. F[illegible] lowing petitioners' reply,

Commission wants child psychiatric care reform

By KRIS DOLINSKI
Gazette staff writer

Significant reform is needed to help children with emotional problems and their families, according to the State Commission on Quality of Care for the Mentally Disabled.

That reform, said Commission Chairman Clarence J. Sundram, must include more efficient use of the money spent by the Office of Mental Health each year to provide a stable environment for children in facilities.

Reform also must include assigning one caseworker per child and improved monitoring of psychotropic medication to

According to the report, about 60 percent of the children in state psychiatric centers were ready for release but remained in expensive facilities because of a lack in family-based treatment programs and community residences which only cost between $36,000-$51,500 per bed annually.

Steven Sanders, Assembly chair of the Mental Health and Developmental Disabilities Committee, said his proposal for community reinvestment of dollars saved by closing state psychiatric centers would make funding available for the development of the needed community programs.

His counterpart in the Senate, Nicholas Spano, said children do not need the institutional setting of the psychiatric cen-

through multiple child care systems because of changed diagnoses, growing up, bad behavior or even success in programs.

Sundram added that moving children from one system to another — moving them from the Department of Social Services to a mental facility to the Division of Youth — is not upholding the commission's ideal of consistency in a child's life.

"These children are often robbed of their childhood, first by the desperate conditions in their family lives that bring them to the attention of the child care system, and then by the very drugs of the service systems that keep them moving from one placement to another," the commission report said.

and family and to balance services they need from all the multiple service systems, rather than assigning different case managers from each program, for each member of the family.

Sanders said his legislation will include having a single case manager take overall responsibility for child and family.

Sundram said he is appalled that many children receive psychotropic medication without having been diagnosed as psychotic.

Psychotropic drugs are prescribed to control emotional behavior. However, parents and guardians are not told that consent forms are needed to give the drugs and in some cases, said Sundram, parents aren't aware that their children are given any drugs at all.

"In touching that psychotropic medica-

'Superhuman' image stressful

Some parents of developmentally disabled children sometimes have hard time coping with responsibility

Health: New York doesn't do enough to protect the developmentally disabled from abuse, a state commission says.

By MICHAEL J. WOODS
Observer-Dispatch

Parents who care for their developmentally disabled children at home often feel "frustrated, angry, even guilty at themselves for not being superhuman," a local advocate said yesterday.

> **"Stress can lead to abuse. Families have to be almost superhuman to provide this kind of 24-hour care."**
>
> **Donna Wax, director, Parent Advocates for the Retarded and Developmentally Disabled**

She was reacting to a report by a watchdog group that said the state should provide

of any abuse cases locally, but she said she has heard

they opened a respite care facility at Broadacres where parents could leave their children for a while. It was the first such facility in the state and one of few in the country.

Since then, the state has made strides, in part driven by its own policy of de-institutionalization, to provide more services directly to the mentally ill and developmentally disabled living with