

NEW YORK STATE COMMISSION ON

# QUALITY OF CARE

FOR THE MENTALLY DISABLED

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## ANNUAL REPORT

1997 - 1998



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# FOREWORD

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Transitions provide an opportunity for reflection and renewal. For the past twenty years, the Commission has been privileged to serve persons with disabilities and their families in our state under the leadership of Clarence Sundram. In my remarks at the luncheon honoring Clarence, I mentioned that the greatest tribute we could give to him would be to take his vision, which gave shape to the Commission, and move it forward.

Just as we review operations of programs throughout the state with an eye towards improving care, the Commission has challenged staff to look inward, to critique our own operations, and to explore ways that we could better serve the people of our state. A significant outcome of our deliberations has been an affirmation of our mission which is printed on the back cover of this report. The driving force of our agency, the vision which inspires us, is simply stated in words, but profound in its impact—"to improve the quality of life for individuals with disabilities...and to protect their rights."

For twenty years, courage, compassion, integrity, and respect have been the values that were the foundation of our activity. As an agency, we have recommitted ourselves to these principles and pledged to continue to fulfill our mission. As you review our annual report, you will see that improving the quality of life for citizens with disabilities and protecting their rights are the threads woven throughout these pages. As we move into the next millennium, we will continue to serve in the spirit that gave birth to our agency twenty years ago.

Recently, Bill Benjamin resigned as a member of the Commission and retired to Florida. For seven years he served as one of our Commissioners, providing wisdom and insight earned from a lifetime of public service. We send him and his family our best wishes for a well-deserved retirement. Florida has gained a great advocate for persons with disabilities!

I feel privileged to serve as Chair of the Commission on Quality of Care. To be inspired by such a noble mission and to work with very talented and dedicated professionals are blessings for which I am most grateful. We look forward to continuing to serve you in the years ahead.



Gary O'Brien  
CHAIR



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# PREFACE

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## YESTERDAY, TODAY AND TOMORROW

This annual report marks the twentieth anniversary of New York State's commitment to sustained professional and independent advocacy on behalf of individuals with mental disabilities. With the enactment of Chapter 655 of the Laws of 1977, the Commission on Quality of Care for the Mentally Disabled was created.

Anniversaries are time for reflection and recommitment.

Looking back over the years, it is clear that much has changed since the Commission's creation. Twenty years ago, most people with mental disabilities who relied on the state for their everyday care and treatment resided in large, often overcrowded, and sometimes scandal-riddled institutions. In 1977, nearly 50,000 individuals lived in such centers, segregated from the rich resources and opportunities New York's communities afforded its citizens.

Today, fewer than 9,000 people remain in these institutions. Community-based residential facilities, a rarity in 1977, are now found in nearly every city, town, and village across the state and serve more than 50,000 individuals with mental illness and developmental disabilities.

While the locus of care has changed over the past two decades, fundamental concepts about care, which serve as the underpinnings of the service delivery system, have also evolved. We used to speak of "programs," structured by the dictates of voluminous regulations; "treatment plans and objectives," stated in "behavioral terms that provided measurable indices of performance;" and "patients" or "clients" whose status was monitored, measured, charted and graphed for discussion at the treatment team's next "quarterly."

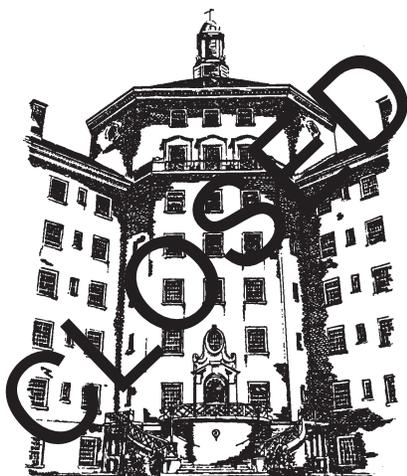
Today we focus on the "individual" or "service consumer;" engage him or her with significant others, in a more fluid process of designing a course toward recovery or attaining life goals; and develop supported housing and other opportunities, or individualized service environments, to meet the needs and desires of the individual, not the mandates of regulation.

Reflecting back on the years, however, offers a sobering realization: the more things change, the more they remain the same. Despite the progress of the past twenty years, the need for sustained advocacy on behalf of New York's most vulnerable citizens, as envisioned by Governor Carey and the State Legislature in 1977, is as alive today as it was then.

This annual report presents more than just statistics on the Commission's activities of the past year. It tells the stories of men, women and children who, in the past 12 months, relied on the Commission's services and advocacy. Their tales, of abuse, neglect, rights deprivations, thefts of funds and breaches of public trust, bear striking resemblance to situations investigated by the Commission and recounted in its first annual report, only the locus and language of care have changed. Their accounts hold a mirror to the face of New York's mental hygiene system and serve as a reminder that despite progress, the lives of vulnerable people are, and will always be, entrusted to fallible care providers: mistakes will happen, systems will break down, corrupt individuals will seize unsecured advantages, and someone must stand to speak out on the victims' behalf.

At the edge of the millennium, New York faces factors which will continue to change its mental hygiene system: the emergence of managed care, continued down-sizing and closures of state institutions, new partners in service delivery, and continued evolution in philosophies of care. Just as few in 1977 could predict how the mental hygiene system would look in 1997, few today can reliably forecast the system's configuration and operations 20 years from now. But one thing is certain, its consumers will continue to need a sustained independent voice to assure they receive quality care. On this, our 20th anniversary, the Commission commits to that tomorrow.

1977



Willowbrook



Willard P.C.

50,000 in Institutions

1997



Over 50,000 in Community Placements

Less than 9,000 in Institutions

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# MAKING A DIFFERENCE IN QUALITY OF LIFE

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## QUALITY ASSURANCE IN INDIVIDUAL CASES

As the focus of our system of health care continues to shift from the institutional delivery of services to the provision of services in the community, the same evolution is evident in the mental hygiene system. Large institutions dedicated to providing long-term inpatient services are gradually being down-sized and people are more commonly treated in short-term, acute care settings. New residential options and treatment configurations present new challenges to the agencies opening them and to those charged with the oversight of these programs. Consumers and their advocates continue to express their desires for clean, safe, and properly supervised housing, protection from abuse, appropriate treatment of mental hygiene issues, medical care that is delivered in a timely and competent manner, and freedom from the imposition of physical and chemical restraints. Consumers expect programs to seriously include them in treatment planning, and for treatment to address their wishes and choices as well as their needs. These recurring themes and the resolutions brought about by the Commission's labors are illustrated in the following case examples.

- ▶ At an upstate residence for persons with development disabilities, a complaint received from the family members of several individuals alleged that there was little food in the house, personal funds were being mismanaged, and that the house was filthy. An unannounced site visit to the home confirmed the validity of the allegations. Flammable materials were being stored next to uncovered radiators, a chain saw was found lying on a chair, broken furniture was obstructing stairways, and an old, unused stove was obstructing a portion of the kitchen. Further review also revealed that the consumers' personal funds were "borrowed" for food and recreation when petty cash was low.

In response to the Commission's request for corrective action, the staff cleaned the house, rectified the safety hazards, and the consumers' personal accounts were reimbursed for the monies staff had borrowed. To provide continued oversight, bi-monthly visits by the agency's Board of Directors were instituted.

- ▶ Family members once again alerted the Commission to untenable conditions at another community residence. CQC staff found toothpaste and toilet bowl cleaner stored side-by-side underneath the sink, insecticide, baby lotion and cooking spray stored next to one another on a kitchen shelf, and a filthy refrigerator containing outdated and spoiled food. None of the bedrooms had blinds and there was dust over two inches thick in one closet. CQC intervened and requested that the residence correct the immediate health and safety hazards.

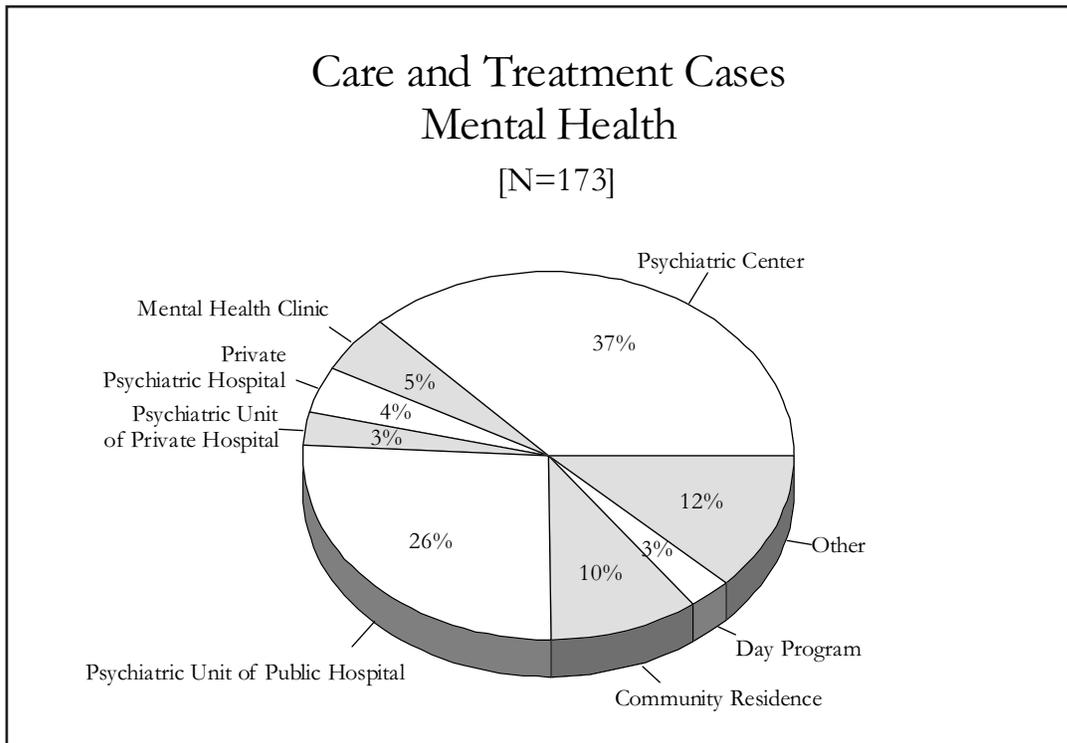
A follow-up visit conducted approximately two months later found significant improvements in the living conditions. The house was clean, contained an ample supply of food, personal hygiene products were appropriately stored, and the consumers were afforded increased privacy while in their bedrooms.

- A concerned mother asked the Commission to review conditions at the supervised apartment where her mentally ill son resided. The investigation revealed a number of deficiencies including inadequate running water, a broken stove, lack of electrical outlets, missing floor tiles, and generally, substandard living conditions. At the Commission's insistence, the agency and landlord initiated repairs. Months later, the agency relocated all of its consumers to apartments located in better neighborhoods. Mom was pleased that upon relocation, her son was moved into a clean and spacious apartment near her home.

An issue that cannot be separated from the provision of a safe environment is the supervision provided to the consumers in our mental hygiene facilities. Whether the residence is an Intermediate Care Facility (ICF), an Individualized Residential Alternative (IRA) or a hospital-based unit, the consumers depend on the staff for protection. Sometimes the threat is external — peers or program personnel— sometimes it is related to the individual's own behavior. Vigilant staff serve as the primary safeguard. However, in our evolving mental hygiene system, protection for consumers frequently demands effective communication between the residential and day programs and on the exchange of information when consumers are transferred. The subsequent series of case summaries illustrate this need.

- During her stay at a psychiatric hospital facility, a young woman was severely beaten, and possibly sodomized, by her boyfriend, a patient on another ward. The woman had off-unit privileges and had gone to the boyfriend's unit to visit him. It was determined that a male staff member on his way out of the unit had allowed the woman to enter the ward's visitor area, but failed to inform other staff members that she was there. When the woman refused to have anal sex with the boyfriend, he became incensed and began to beat her.

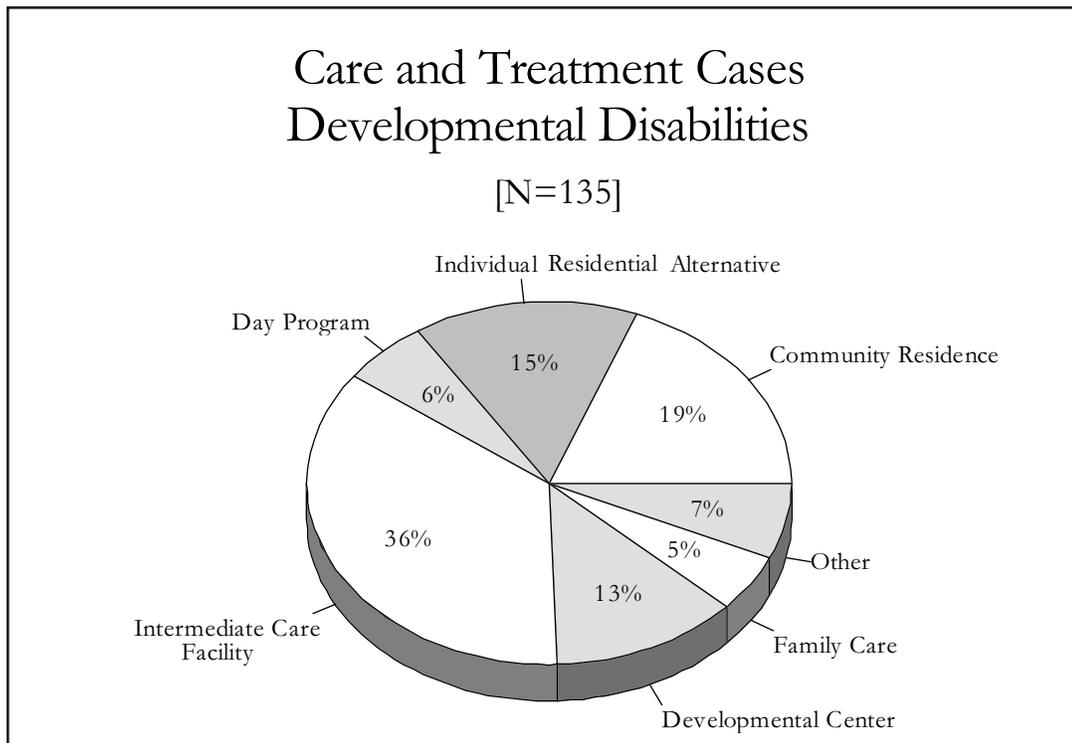
During the Commission's investigation, the woman admitted that over a two year period she and her boyfriend had engaged in sexual relations in the visitor's room a number of



times. It was also revealed that staff were not assigned to monitor patient visits (as was required by facility policy), that despite the relationship spanning over two years, neither patients' therapist was cognizant of the relationship between the patients, and that the ER physician failed to adequately document the full extent of the woman's injuries.

As a result of the Commission's review, the facility conducted a facility-wide audit of visitor procedures, and appropriate corrective measures were instituted. The ER physician was counseled about his failure to document the victim's injuries and has received additional supervision and training from his Clinical Director. A work group to address the issue of identification of relationships between clients and the signs of abuse and victimization was conducted. The facility's Quality Assurance unit is continuing to monitor the ward's logs to ensure compliance with the facility's policies to monitor visitors.

- At a community residence for persons with mental retardation, a male resident was found lying on top of a female with his genitalia exposed. It was determined that no sexual intercourse had occurred. The man had a history of inappropriate sexual behaviors involving both male and female residents. The Commission determined that communication between the community residence, the man's former ICF, and his day program was inadequate. The residence staff were unaware of the full extent of the man's sexual history prior to his transfer to the residence. Consequently, the residence was unaware of the supervision requirements needed for the resident. Although the treatment team had continued to urge increased supervision for the man to prevent sexual advances, this did not occur and he was maintained in a large residence with only one night staff person. The woman's capacity to consent to sexual activity had been evaluated, but her training needs were not.



In response to the findings of the investigation, each person was re-assessed and treatment plans were updated. Day program and residential treatment plans were integrated to ensure improved coordination, and the Developmental Disabilities Service Office (DDSO) began working on a new risk management system to identify persons who are at high risk for abuse. The male resident was transferred to a facility that could provide increased supervision.

- The school where a young man with mental retardation and a seizure disorder attended classes reported new episodes of self-injurious behavior (SIB) and assaultive behavior that required physical intervention. The Commission determined that a number of problems were occurring. The ICF and the school program did not adequately communicate and failed to recognize that similar behaviors were being displayed in both places. The school believed that the behaviors might have been related to the individual's seizure disorder, but failed to convey this information to his ICF clinicians. Relatedly, there was no integrated treatment plan between his school and his residence. Behavior encouraged in one place was discouraged in the other and vice-versa. Inadequate documentation, poor internal communication between the ICF staff and its own clinicians, and questionable evaluation by a behavior specialist further diminished effective treatment.

The Commission's intervention resulted in the ICF providing behavior tracking forms to the school, and the ICF arranged periodic meetings with school personnel and the youth's advocate. The school also implemented a physical intervention program that was designed by the ICF and approved by the Human Rights Committee. Monthly school reports are now provided to the ICF, and annual education goals are included in the ICF's record.

The provision of adequate and timely medical care is another concern frequently brought to the Commission's attention. Within this category are issues associated with medications, lack of follow-up care for existing conditions, failure to provide accurate assessments and failure to obtain adequate and timely care in emergencies. These all too common occurrences are illustrated by the following examples.

- The Commission received an allegation that a hospital-based mobile crisis unit failed to respond in a timely fashion to a request for the evaluation and hospitalization of a mentally ill family member. Upon review, CQC found that the mobile crisis unit was habitually unreachable. Incoming calls were being routed to non-operational telephones, and crisis team members used voice mail as a means of screening incoming calls. There was also no roll-over system that directed the caller to another number for immediate assistance.

As a result of CQC's findings, the facility assigned a permanent staff person to the primary crisis number. Staff were counseled on the need to provide a prompt response to voice mail messages. The crisis supervisor was issued a beeper to increase accessibility, and a roll-over line was added to the system.

- A distraught mother contacted the Commission to request that a review of her son's medical care during a recent illness be conducted. Her profoundly retarded son resided in an ICF and the mother alleged that the attending physician failed to arrive at a timely diagnosis. She also alleged that her son was prematurely discharged from the hospital and had to be re-admitted within hours after discharge.

This case was reviewed by the Commission's Medical Review Board (MRB), which concluded that the physician failed to respond aggressively when the consumer's high fever persisted for more than 24 hours. The MRB was also critical of the excessively physician-dependent stance taken by the ICF's nursing staff and indicated that the nurses should have been more aggressive in advocating for the young man.

In response to the incident, a fever protocol was established for the ICF. The protocol delineates staff responsibilities, the steps that need to occur when someone has a fever, and it removes much of the subjectivity associated with this type of medical decision.

- ▶ An allegation was received that indicated that a woman's nebulizer had not been functioning for three days. The person was medically frail and prone to pneumonia. As a precaution, the physician had ordered nebulizer treatments three times per day. The allegation was substantiated and resulted in the agency developing a new protocol for handling the repair of medical equipment and delineating staff responsibilities in this area. The primary oversight agency, an upstate DDSO, also became involved and recommended that the attending physician order an alternative treatment to be utilized in the event such a circumstance arises again. The agency concurred and this additional safeguard was also instituted.
- ▶ A private psychiatric facility was the setting for an investigation which cited multiple deficiencies in care. A few days after delivering her child, a woman became psychotic and required hospitalization. Her husband and other family members expressed deep concern that the new mother was not receiving adequate post-partum care and was being improperly restrained. CQC's investigation confirmed these allegations. It found serious violations of the consumer's rights, failure to comply with the Mental Hygiene Restraint Law, inappropriate prescription and administration of medication, poor quality nursing and medical care, and failure to document services that were reportedly rendered.

The Commission's findings provided the impetus for the facility to revise its restraint policies and to retrain staff in restraint procedures. The facility also hired an internist and nurse practitioner to ensure that complete physical assessments and follow-up care are provided to all patients. Physicians and nurses were also counseled about providing adequate and accurate documentation and that rationales for medication changes should be documented.

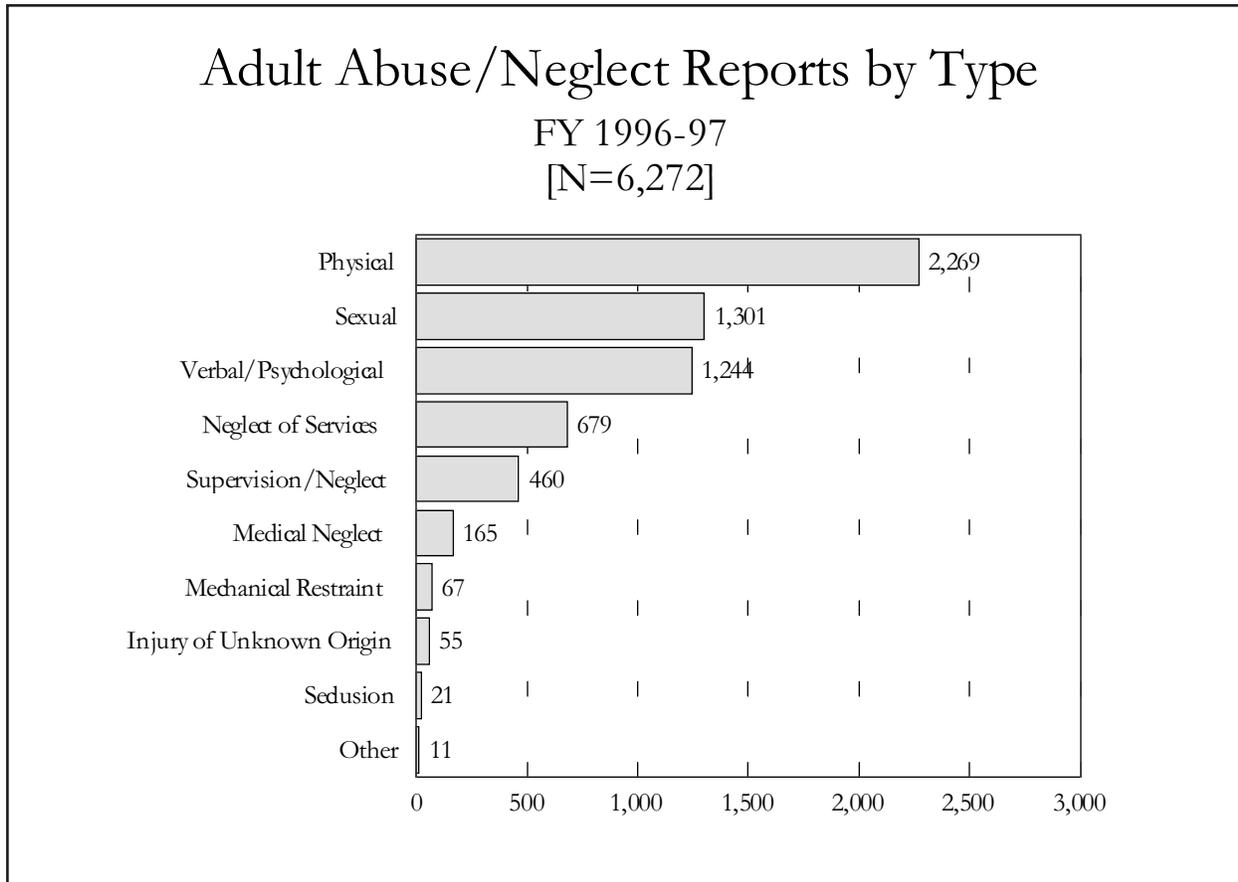
The last example provided in the above section addressed a number of deficiencies, including the issue of restraint. This remains a frequently expressed concern. The cases discussed in this section provide convincing evidence that the Commission must remain vigilant in reviewing facilities' restraint practices, even as recent Office of Mental Health policies add additional safeguards and programs work to reduce the use of restraint.

- ▶ An anonymous party requested that the Commission review the restraint practices of an upstate hospital psychiatric unit. The following cases originated from this investigation.  
  
An 18-year-old was hospitalized following a suicidal gesture. Due to his fear of losing control and harming himself or others, he requested that staff place him in restraints. Medication was administered with minimal effect. The physician was contacted by telephone, and he ordered additional medication plus 4-point restraints. The patient calmly allowed himself to be placed in restraints. Although the client was released at his request an hour later, it was noted that there was no release time specified on the restraint, and the physician did not show up to examine the patient until the next morning.

A middle-aged woman repeatedly attempted to gouge her eyes out. Over the next three and one-half days she was restrained four separate times, for a total of 51 hours (out of a possible 84 hours). The Commission's review revealed that the physician ordered 4-point restraints on a PRN (as necessary) basis, the consumer was not examined by her physician, she was in constant restraint for over 17 hours and there was no documentation indicating any release from the restraints, or that food, fluids and toileting were offered. Despite hours passing without any threats of aggression, the woman remained restrained. When finally released, she had to be transferred to a medical unit due to the prolonged periods without food or fluids.

The Commission's recommendations included revising the restraint policies to comply with current laws and regulations, and the training of staff in the requirements of restraint and seclusion. The facility brought itself into compliance by revising their policies, retrained their staff, and began an internal monitoring system to ensure continued compliance. The Commission will continue to monitor this facility.

Whether dealing with individual problems or those of a more systemic nature, continued monitoring of the care and treatment rendered to the individuals not only identifies problems, but allows the Commission to ensure that corrective actions are taken, and maintained.



## EXPANSION OF THE SURROGATE DECISION-MAKING COMMITTEE PROGRAM

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

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SDMC helps people living in programs operated or licensed by the State Office of Mental Health and State Office of Mental Retardation and Developmental Disabilities who are not capable of providing informed consent and have no parent or guardian to make consent decisions for them. The SDMC program operates through four-person volunteer panels made up of an attorney, medical professionals, consumers of services or their family members, and advocates, if a resident is seen as not capable of making an informed decision about proposed non-emergency major medical treatment. This quasi-judicial process determines whether or not a person is able to give informed consent for a proposed medical procedure, and if not, if there is a parent or guardian available and willing to provide informed consent. If not, the SDMC panel is authorized to provide surrogate consent, or to refuse the proposed treatment, utilizing a "best interests" test, including consideration of risks and benefits, alternative treatments, quality of life with and without the treatment, and consistency with the resident's previously-expressed values and beliefs. The panels always meet with the client about the proposed medical procedure before making a decision.

Previous to SDMC, major medical treatment decisions were subject to a time-consuming and costly court review, which often delayed treatment, causing pain, discomfort, or deterioration of residents' medical condition. The SDMC program is a speedy, less expensive, easily accessible, and more personalized alternative to the judicial process. Under the SDMC program, cases are heard in an average of 12-14 days, with a 5-day notice period.

The SDMC program has helped over four thousand mentally disabled individuals get timely, cost-effective and personalized consent for needed medical treatment. During the past year, the SDMC panelists heard 320 cases, resulting in decisions for 333 major medical treatments. There are 391 dedicated volunteer panelists from the ranks of attorneys, health care professionals, former patients or relatives, and advocates (see the list of panelists in the Appendix).

The budget provides funding to expand the program statewide through contracts with Community Dispute Resolution Centers, which supply local support services. The program currently is available in Bronx, Kings, New York, Queens, Columbia, Dutchess, Orange, Sullivan, Putnam, Rockland, Sullivan, Ulster, Albany, Fulton, Greene, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington, and Westchester counties.



## **REVIEWING INDIVIDUAL RESIDENTIAL ALTERNATIVES: CONGREGATE COMMUNITY LIVING WITH INDIVIDUALIZED SUPPORTS AND SERVICES**

During the 1990s, OMRDD and the provider community have been promoting a service system focused on creating individualized service environments (ISEs) for persons with mental retardation and developmental disabilities. An ISE, as a concept, promotes community living by developing an individual's self-determination and choice, self-reliance, involvement in the community, and personal achievements. Important to this effort, was the implementation in September 1991 of a federal Medicaid program called the Home and Community Based Services (HCBS) waiver, the primary funding mechanism for ISE development. Thousands of people who lived in highly regulated congregate care facilities (such as intermediate care facilities and community residences) located in communities, soon found a preponderance of their homes converted to individualized residential alternatives (IRAs), a new subclass of a community residence.

OMRDD's piloting the IRA care modality centered on the concept of creating individualized service environments for each individual and led to the dramatic expansion in 1994-1995 of IRAs to additionally capture the federal Medicaid dollar.

In late 1995, a complaint that people were not receiving appropriate services in IRAs in one DDSO district led to a Commission investigation. The Commission's findings of overall appropriate custodial care, but inadequate service planning and coordination for IRA consumers, poor staff training and oversight by clinicians, and inadequate staffing patterns and equipment, prompted the Commission to conduct a statewide review of this residential option. In total, 40 homes were visited and a sample of 82 consumers' lives were studied through interviews and record reviews across all three regions of the state.

More than half (55%) of the homes in the Commission's random sample had been converted from ICFs or community residences to IRAs, while 45% of the homes were opened as new IRAs. Of the 40 homes visited, 60% (24) were state-operated, and 40% (16) were voluntary-operated. Of the 291 consumers living in the sample 40 homes, there was a near even split between men (55%) and women (45%). The 291 consumers ranged in age, however, the largest group was between 22-45 years of age (62%). Approximately one quarter (26%) of the consumers were between the ages of 45-46 years old; only 5% were older than age 65; 3% were under 21 years of age. This information was missing for 4% of the individuals. Nearly one-half (46%) of the consumers attended day treatment programs; 32% received day habilitation services; and 14% had sheltered or competitive employment; the other 8% of the consumers engaged in a combination of these day options.

The Commission's review started with an assessment of each home's environmental conditions, such as overall cleanliness and maintenance, adequacy and appropriateness of clothing and hygiene supplies for each consumer, and fire safety. Environmental findings indicated that overall, the homes were clean, well-maintained and had adequate and clean furnishings. In addition, more than three-fourths (78%) of the homes had personal touches that reflected the interests and choices of the individuals living in the homes. In all but two of the 40 homes (95%), consumers were well-groomed and appropriately dressed. The majority of the homes (95%) were also devoid of any safety or fire hazards.

The Commission's review also assessed if service planning documents were current and available, and if these important documents, used to record a person's chosen goals for his or her own life, showed

evidence of an individualized selection of services. The study also reviewed if and how well assessments were made of consumer progress, and the quality of life afforded to consumers (i.e., promotion of choice; respect for the individual; personal development of the consumer and community integration of the individual).

Each IRA home visited received a written report of findings specific to the home, and, where required, homes needing plans of correction submitted them, had the reports accepted, and implemented the Commission's recommendations. Nevertheless, Commission staff did observe homes during the course of the statewide study that displayed best practices. One of the first IRAs to receive an unannounced visit in early December 1996 was the Peterman Road IRA in Seneca Falls, New York, sponsored by the Finger Lakes DDSO. The living conditions in the home, and the quality of life and services provided to each individual were outstanding. Every aspect of living in this home demonstrated that staff had a solid understanding of the "consumer-first" approach to serving people with severe developmental disabilities without sacrificing their additional responsibility to address consumers' needs. People received exceptional attention that promoted their health, safety and well being, and they were respected as people and helped to develop their interests, self-awareness and self-determination to the fullest extent possible.

Without a doubt, the interior of the home was beautifully appointed. Observations confirmed that staff had used their creativity and resourcefulness to make the home warm, inviting, comfortable and personal to the people who live at Peterman Road IRA. The common living areas, such as the dining room, displayed hand painted stenciled art work along the borders of the ceilings, and lattice work and wall papers on arched ceilings to give the effect of a garden patio. The two living rooms and hallways were adorned with wall arrangements of various themes, made out of antiques that had been purchased and refurbished by the staff and artistically placed to create a country living effect.

Perhaps the most impressive, were the consumers' bedrooms, not only for the tasteful selection of "designer" matching curtains, bedspreads, linens and color schemes, but because in decorating the rooms, staff had brought out the personalities of the people living in the home. Upon being escorted through the bedrooms, staff told a story of each person and some aspect of the person's life that was displayed in their bedrooms. For example, one man who is nonverbal and who has cerebral palsy, is required to do an exercise of squeezing an object in his hand; however, finding a meaningful activity for him to perform was a challenge. While at day program, staff began to notice over time that this gentleman seemed to perk up whenever a train would pass near the building in which he worked. IRA staff thought of a clever idea to install a model train track on a handmade shelf they devised to go around the perimeter of the ceiling in his bedroom. Commission staff observed the man, who was home in bed recuperating from the flu, manipulating a squeeze mechanism, which made the train go around the track, an activity he obviously enjoyed.

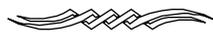
Another woman, who displays severe maladaptive behavior, has a beautiful collection of miniature horses displayed on shelves on the walls of her room. Although this woman has been known in the past to destroy items and pictures on the walls of her room, she has never destroyed her collection of horses, which are within reach. Staff observed she seems to enjoy animals, and they began to help her start a collection.

The detail and sophistication of the items displayed and used in people's bedrooms reflected that adults live in this home, and that despite severe maladaptive behaviors or physical disabilities, interests were developed and enhanced without sacrificing beauty or fine possessions.

Service planning and coordination were also exemplary in practice. Individuals chosen for the Commission’s sample, revealed that staff of the Peterman Road home, worked with individuals and/or families to establish individualized service plans, individual plans of protective oversight, and residential habilitation plans and behavior plans where needed. All staff of the home were conversant with these IRA planning documents, the purpose of each document, and the specific outcomes currently being worked on with each consumer. Additionally, although not a requirement, the Residential Program Manager also devised a useful method for collecting information on consumer progress on residential habilitation plans. Direct care staff used a “residential habilitation services recording form” indicating outcomes worked on a daily basis. The Residential Program Manager who oversees the implementation of residential habilitation plans for all consumers, then reviewed with direct care staff the contents of the recording forms, and how far the person progressed in attaining the outcome. A written summary at month’s end was used to track each person’s progress. Subsequently, consumer progress was reviewed and discussed at a monthly “quality of living review” with the individual and important people central to the individual’s life.

Perhaps most memorable was the staff’s knowledge and perspective on what they were trying to accomplish. Staff said their job was to address people’s needs by building on their strengths and interests, and developing their skills. They knew the terms and concepts used with HCBS Waiver and IRAs, but they further claimed that it made very little difference if the home located at 27 Peterman Road was known as an IRA or an ICF. The staff explained that people living in the home are most important, regardless of the regulations that govern their home and the services. Staff further stated that if something needed to be accomplished with or for a person, they assertively went after what needed to be done, without waiting to be told the importance of the item. They further said that a person’s needs and wishes “drive” what gets addressed, and that they try to observe who that person is as a human being to help create a meaningful life.

As data analysis of the Commission’s statewide study of IRAs continues, it will be interesting to discern if the story of this home, and the people who live and work there, is the mainstay of what is occurring in our communities, where people are beginning to design housing and services in congregate community living options with an eye toward more individualized services and supports.



## IMPROVING CARE AT ITTLESON CENTER RESIDENTIAL TREATMENT FACILITY

Among the valued and guiding principles in the mission of the Commission as an agency is a basic focus on ensuring corrections are made where deficiencies are found with the ultimate goal of improving the quality of life for people with disabilities. During the past year, a review of the Henry Ittleson Center residential treatment facility (RTF) was a case in point.

In 1996, the Commission conducted a review of the Henry Ittleson Center RTF, a 32-bed residential treatment facility in the Bronx. The several-day, unannounced, in-depth review focused on environmental conditions, residents' personal care, consequences and interventions for children's maladaptive behaviors; and interactions between staff and children in the residential environment.

During the review, Commission staff observed many positive features of the Center's operations, including comprehensive assessments and treatment plans which addressed many dimensions of the children's lives, cautious use of medications and careful attention to consent matters surrounding the use of medications with children, staff's provision of recreational and educational opportunities for the children, and the care with which staff supervised the children.

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*The Henry Ittleson Center responded to the Commission's review in late 1996 with a plan of correction detailing actions which would be taken to address the Commission's environmental and personal care observations and to improve the facility's response to children's negative behavior.*

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At the same time, however, Commission staff found a number of areas in need of the Center's attention including environmental problems such as broken furniture, dirty and marred walls, lack of accessible cleaning supplies, non-breakaway bars in showers and other safety hazards. Rudimentary, everyday children's needs were not well met. Many children lacked basic personal hygiene supplies (e.g., toothbrush, toothpaste, comb, etc.) and/or a sanitary place to store them. Some did not have clean bed linens, or lacked a full compliment of bedding. And all the children ate their meals on disposable plates using plastic utensils on a regular basis.

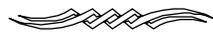
As caring as staff appeared to be in their interactions with and supervision of children, their effectiveness, particularly when children acted out negatively, was compromised by several factors. There were no formal guidelines for staff regarding a consistent approach of structured consequences for behavior problems. Nor did there appear to be vigorous clinical oversight of staff's responses to behavioral difficulties and the interventions employed and consequences issued. Consequently, the facility had no means to determine whether interventions employed – ranging from the least restrictive to the most (i.e., restraint) – were appropriate; and opportunities were lost to guide staff, reduce negative or highly restrictive interventions, and promote more proactive techniques to manage problem behaviors.

The Henry Ittleson Center responded to the Commission's review in late 1996 with a plan of correction detailing actions which would be taken to address the Commission's environmental and personal care observations and to improve the facility's response to children's negative behavior.

In 1997, Commission staff monitored the Center's plan of correction by requesting and reviewing certain documents, and by conducting another several-day, on-site, unannounced review. This 1997 review confirmed most of the corrective actions the Ittleson Center had promised to undertake. Newly installed carpeting, replaced floor tiles, repainted walls, and new furniture in bedrooms and common areas greatly enhanced the ambience of the residential units. In addition to a full complement of bedding and ample clean clothing, each child had a personal hygiene kit, and most had a full complement of hygiene supplies; where some supplies were lacking, staff explained the difficulties some of the children had, particularly the younger children, in keeping track of their own supplies. They also reported the efforts they were making to assist the children in this regard – efforts well documented in logs.

To assist direct care staff and to promote positive behaviors on children's parts, in addition to increasing the presence of clinical and/or senior staff in the residential units, the Center developed an effective privilege/consequence and level system, developed by clinicians with the input of both staff and children. The facility also developed a peer council – a body of residents elected by their peers to meet regularly with senior staff to offer advice and recommendations on various aspects of residential life, ranging from the privilege/consequence system to meal planning. Additionally, to further reduce children's length of stay in the facility and to promote reunification with natural or surrogate families, the Center stepped up its efforts to involve families in their loved one's treatment by creating a family council, increasing the frequency of home visits and more aggressively involving families in treatment planning.

The Commission's 1997 review, while verifying that corrective actions stemming from the 1996 review were completed or well on their way to completion, also indicated areas in which the Ittleson Center could take additional steps to capitalize on improvements already made, e.g., age-appropriate personalizing touches in the environment, and continued review of incident reporting and management systems to ensure that staff are clear as to what to report as incidents. Some children were repeatedly involved in events (mostly fights) which were not reported as incidents, and these repeated incidents should have triggered Special Treatment Reviews. These ongoing efforts by the Commission and the Ittleson Center certainly demonstrate that there is always room for continued improvement.



## KINGSBORO REVISITED

Kingsboro Psychiatric Center presents an example of a remarkable turnaround in conditions and treatment in a state psychiatric center.

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*Now, visiting the facility ten years later, Commission staff found a transformation of Kingsboro into a treatment facility. This all happened because of the determination, creativity, supportive collegiality, and plain hard work of hundreds of staff and administrators.*

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Approximately ten years ago, the Commission asked the Office of Mental Health to declare a state of emergency at the center. Commission monitoring during the years from 1984 to 1988 had consistently revealed seriously substandard living conditions, patients menacing each other, and staff locked away as often as possible in nursing stations and chartrooms. In response, the Office of Mental Health declared a 60-day state of emergency, placed a cap on admissions, and transferred 190 longer-term patients to other centers to relieve overcrowding. The facility was unable to meet the Joint Committee for the Accreditation of Hospitals (JCAHO) accreditation and Health Care Finance Administration (HCFA) certification standards. It appeared that Kingsboro was doomed.

Now, visiting the facility ten years later, Commission staff found a transformation of Kingsboro into a *treatment* facility. This all happened because of the determination, creativity, supportive collegiality, and plain hard work of hundreds of staff and administrators.

Kingsboro is now a much smaller center of approximately 340 culturally diverse consumers. The facility defines itself as providing intermediate care with an average length of stay of 200 days. Physical changes have been dramatic, such as the total rehab of Building 2, which now provides a well-lit, spacious, clean, and attractive environment for 160 residents. As the census has decreased, wards and programs have been consolidated. Programming for small groups of patients is facilitated by the small meeting rooms available on each ward and screened in porches provide a place for fresh air and conversation. The idleness among residents so pervasive and debilitating years ago is no longer evident. Centralized programming ranges from computer instruction in basic academic skills, to working in a quarter-acre vegetable garden, to groups meeting to discuss such topics as medication and symptom management. Men and women with alcohol and substance abuse histories are encouraged to take part in the Fresh Start program and a traditional consumer-run 12-step program.

Interactions between staff and residents, and quality assurance ensuring that the mission of the agency is being communicated to staff and, through their actions, to the residents, are taken seriously. This was evident, for example, when Commission staff observed in a tour of the wards that patients and staff know the Director of Quality Assurance by name and the Director of Quality Assurance in turn knows the residents on a first-name basis.

The surrounding community rallied to save the facility from closure in 1996, and in December of that year the institution passed not only the JCAHO extension survey, but also the HCFA and Department of Health surveys, both with perfect scores.

Kingsboro staff know, and Commission staff know the facility is not perfect. But what happened here deserves praise, recognition, and encouragement.

## WATCHING OVER THE CHILDREN

The Commission's work on behalf of children lies in two principal areas: the investigation of allegations of abuse and neglect (those involving residential programs come to the Commission from the State Central Register (SCR)), and the review of care and treatment issues either generated internally in response to serious problems identified during our SCR investigations or brought to our attention by concerned parents and other advocates.

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*As with any investigation, our ability to reach accurate conclusions during an SCR review greatly depends upon the willingness of staff and peers to candidly report what occurred during an incident, along with the judicious preservation and evaluation of physical evidence, medical records and other service documentation. . . . Commission investigations seek to hold culpable staff accountable when warranted and correct systemic deficiencies or problems in the care of a single child. . .*

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During the report period the Commission received 148 new child abuse allegations and completed the investigations of 150. Social Services Law requires that, in order to indicate a case, the Commission investigation find some credible evidence linking a named staff person's misconduct to a child's injury or substantial risk of harm. In 133 of the completed cases there was insufficient evidence to determine that the child was physically harmed (beyond minor injury), seriously emotionally harmed or placed at substantial risk of harm through the misdeeds of an identified staff person, and these cases were "unfounded."

In 17 cases (11%) sufficient credible evidence was found to "indicate" the accused staff person. Barring a reversal, the staff person's name is placed on the State Central Register of Child Abuse and Neglect, which may adversely affect his/her ability to gain certain professional licenses or future employment, and might also block the adoption or foster care placement of a child. Therefore, the involved staff person is notified of his/her due process rights at the conclusion of our investigation. This includes notification that administrative reviews of the case by State Central Register staff, or a fair hearing conducted by an administrative law judge, are considered at the legally more stringent standard of "a preponderance of the evidence."

Often, at the conclusion of an SCR investigation, agencies were also required to submit a plan of remedial action to ensure that organizational or clinical/treatment problems identified at the program were corrected or that appropriate actions were taken with respect to the "indicated" employee.

As with any investigation, our ability to reach accurate conclusions during an SCR review greatly depends upon the willingness of staff and peers to candidly report what occurred during an incident, along with the judicious preservation and evaluation of physical evidence, medical records and other service documentation. Competent investigations can untangle conflicting stories regarding a child's allegation of abuse or neglect, but cases are still sometimes "unfounded" because policy or training weaknesses at the facility prevent us from holding any individual staff person accountable for harming the child. Commission investigations seek to hold culpable staff accountable when warranted and correct systemic deficiencies or problems in the care of a single child, as noted in the following case examples.

- D The Commission recommended indicating a staff person who allegedly choked a teenage resident of a Residential Treatment Facility (RTF) until he fell unconscious. The boy was reportedly rough-housing with the staff person and acting disrespectfully, so the staff person placed him in a choke hold to show him who was in charge. When the child was released he collapsed to the ground, banging his head on the floor. The victim was not eager to pursue a complaint, believing it should be settled “man-to-man.” But other residents saw parts of the confrontation, and a staff person walked onto the scene while the child was being choked. With their witness statements, the Commission was able to determine that the child was placed at risk of serious harm by the staff member’s abusive act.
- D In a similar case, a teenage RTF resident in the acute manic phase of a bipolar disorder was offering significant problems to the staff person assigned to monitor him. The young man allegedly challenged the staff person to trade punches to the stomach in a test of “manliness,” and the staff person reportedly accepted the offer. Later, the resident attempted to push past the staff person in order to gain access to a restricted area. This quickly escalated into a fistfight after the staff person challenged the child to hit him again. Another staff person stepped between the combatants to separate them as they pummeled one another with punches. The child did not consider this incident to be more serious than other fights he’d had on the streets, but the staff person who intervened recognized the dangerous and anti-therapeutic nature of the altercation. With her candid testimony, the Commission was able to indicate the staff member who started the fight.
- D In an indicated case where staff were not helpful with the investigation, a child called his mother and told her a staff person had grabbed him by the neck and pressed it into the wooden frame of a bed. Scratches were found on the boy’s neck. The two staff who were present denied the subject had ever abused the child, and reported that the boy had scratched himself with the tines of a plastic fork. However, their reports of the incident were quite inconsistent. The Commission reviewed the child’s physical examination report, and spoke with his physician. We learned that the scratches and ecchymotic areas on the child’s neck were consistent with marks from fingers and not the tines of a fork. Petechial hemorrhages which appeared on the boy’s face also indicated that pressure had been applied to his neck. As the physical evidence supported the child’s story and contradicted the inconsistent reports offered by the two staff, the Commission recommended indicating the accused staff person for physical abuse.

Many Commission SCR investigations, whether unfounded or indicated, result in changes in agency policy or practices which create safer and more therapeutic environments for the children being served. The following are poignant examples of modifications instituted after children were involved in traumatic events.

- D One investigation at a children’s psychiatric center found sufficient credible evidence to determine that a direct care staff person had sexually abused two girls under his care. While reviewing his personnel file we found that on his application for employment he had reported an earlier criminal conviction for endangering the welfare of a minor, but the facility never adequately investigated the matter to discover that this was actually a prior sexual offense. He resigned from the children’s center, but later applied for employment at an adult state psychiatric center, where staff again failed to check into his criminal or employment history. Both psychiatric centers admitted to inadequacies in their personnel procedures and took administrative steps to ensure that this did not recur in the future.

- D In a particularly tragic case, a boy accidentally choked to death when a developmentally disabled peer loosened the leg straps of a supine stander device he had been placed in to improve his circulation. The boy had cerebral palsy and was unable to save himself when his neck slipped down between supporting straps that were intended to prevent him from falling forward. The child was supposed to be continuously monitored while using the stander, but the house supervisor directed the assigned staff person to perform another task, saying that she would ensure that constant observation was maintained. When the staff person returned from her task five minutes later, she observed a female peer playing with the stander's foot and leg straps, and the child hanging limply by his neck from the shoulder straps. He could not be revived. The house supervisor was indicated by the SCR for inappropriate custodial conduct and fired by the agency. All staff were retrained on adaptive equipment safety, and a designated safety monitor was added to the membership of the local adaptive equipment clinic. In addition, the manufacturer of the supine stander was contacted with the request that a specific warning label be placed on its adaptive equipment.
  
- D In an unfounded case from a children's psychiatric center, the Commission found insufficient evidence to confirm a young girl's report that she was punched by a staff person. Evidence suggested that a hematoma under the child's eye was most likely received when she hit her head against a picture frame while resisting staff who were attempting to restrain her. However, the restraint was conducted by staff standing with the child on her bed while trying to calm her, a method which troubled the Commission. The facility management decided to have behavior management program trainers debrief staff after each physical intervention. The facility also embarked on a 60-day trial period where seclusion and/or four-point restraint could only be initiated with the prior approval of the facility director. As a result of this initiative, the rates of seclusion and four-point intervention were significantly reduced, and there were dramatic decreases in allegations of abuse and patient-related staff injuries.

## REVIEWS OF THE CARE AND TREATMENT OF CHILDREN

The Commission also responds to concerns brought by parents and other advocates regarding the services children receive in hospitals, residences, and other community programs licensed or operated by Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities. In addition, Commission staff are increasingly initiating follow-up reviews to ensure that programmatic deficiencies discovered during the investigation of allegations of abuse/neglect are corrected.

The Commission conducted 53 reviews of care and treatment involving children during the report period. In 42% of these reviews we identified programmatic deficiencies needing corrective actions. Problems with agency policies and procedures were noted in 17% of our reviews. Somewhat less frequently, we criticized the absence of communication with children's families, inadequate supervision of children, poorly designed behavior modification programs and seriously flawed treatment planning. The case examples cited below illustrate the Commission's work to ensure the provision of quality care, and our persistence in working with facilities to resolve difficult problems.

- D The Commission received an anonymous complaint about rundown and filthy conditions at a community residence for children with developmental disabilities. Our unannounced visit confirmed substandard conditions in the home. Although the home was freshly painted and appeared quite clean, common living areas clearly needed new furniture, kitchen cabi-

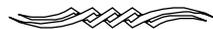
nets and floors needed replacement, potentially dangerous lighting fixtures were identified, and fire extinguishers had not been inspected. In response to our findings, the agency submitted a plan to replace carpeting and bathroom floors throughout the home and purchase furniture for common areas, and agreed to replace the kitchen floor and cabinets. The bathroom medicine cabinet was replaced, the agency replaced all potentially dangerous light fixtures and the fire extinguishers were re-inspected.

- ▶ In response to complaints we received from several parents, the Commission conducted an unannounced visit to review programming at a Residential Treatment Facility for children and adolescents. Consistent with the parents' complaints, we found that staffing was not sufficient to meet children's supervision requirements; behavior plans and token economies were not being implemented as designed; progress in treatment was not adequately evaluated; and one mother had her visitation privileges restricted without required documentation of the reasons for this restriction or proper notification of her right to appeal the decision. The facility concurred with most of our findings and implemented changes to ensure proper supervision and treatment practices in the residence. Staffing assignment protocols were modified and the agency is seeking additional funds from the Office of Mental Health to enhance direct care staffing. Several clinical staff were hired to supervise and train staff on the proper administration and documentation of treatment and behavior modification programs, and the agency demonstrated adequate knowledge of regulatory requirements related to family visitation in OMH-licensed programs.
- ▶ Another Commission review evaluated the care of an adolescent admitted to a Residential Treatment Facility to continue treatment for her history of psychotic symptoms and fire setting. Her psychotic symptoms increased after her admission; although her medication was increased, she continued to hear voices. Her social worker discovered her attempting to start a fire and she admitted she intended to "kill everyone." The social worker briefly spoke with the child but did not search the room for matches, increase the child's level of supervision, inform the physician or otherwise report the incident. Shortly afterward, the girl set a second fire and was placed on strict adult supervision. However, only two days later that level of supervision was relaxed, even though she failed to show "adequate insight into the ramifications of fire setting." One week later the child set a major fire at the facility in response to internal voices telling her to do so. She was arrested and spent the Christmas holidays in jail. Ultimately, the facility agreed with our determination that the care provided to the child before her arrest did not meet her needs and, had she received adequate services, she may have been prevented from setting a major fire. The agency took steps to ensure that, in the future, incident reports are properly completed, appropriate notifications are made, and children's supervision needs are adequately assessed and met. The social worker in question is now being more closely supervised.
- ▶ The Commission looked into a report from the mother of a consumer of residential rehabilitation services for individuals with developmental disabilities, who stated that a Res-Hab worker informed her that another child he works with had contracted viral hepatitis. The mother reported that the afflicted child received services from multiple respite programs and other agencies in the county. She also complained that respite service providers do not screen their employees through the State Central Register for Child Abuse and Neglect prior to employment. We learned that the County Health Department had been promptly notified when the child's hepatitis was diagnosed, and their staff were coordinating follow-up activities. The agency addressed the breach of client confidentiality by the Res-Hab worker who revealed the child's medical condition. However, we did confirm that

employees at this respite program are not screened through the SCR. In addition, current Social Services Law does not provide for Commission investigations of SCR allegations for children in respite care operated by voluntary agencies, nor does it require agencies offering respite services to screen employees and volunteers through the State Central Register. This is an area which merits future legislative attention.

During the report period, more than one third of the Commission's reviews of care and treatment involving children were generated internally, usually following a child abuse investigation, in order to ensure that problems identified during those investigations were reliably corrected. The two summaries which follow describe Commission follow-up reviews to prior SCR and Care and Treatment cases. Among the deficiencies noted in these cases were inadequate communication with families related to treatment and discharge planning for their children, a problem identified in 11% of our reviews.

- ▶ An SCR investigation raised enough questions to merit a follow-up review of care and treatment which identified several problems with a girl's discharge from a Children's Psychiatric Center. The 13 year-old girl had a history of suicidal ideation and medication non-compliance. The child's mother requested her discharge, even though she had been making statements like "I wish I was dead...why don't you just get a knife and stab me." The child's psychiatrist changed her medication to include a slow acting anti-hyperactivity medication, and then approved a home visit three days later, with the intention that the child would be discharged if the visit went well. However, staff were unable to reach the family during the visit to learn how the girl was doing or if she was taking her medication. She was discharged from the psychiatric center nonetheless. The visit had not gone well, and several days later the girl ran away from school. Police located her and returned her to the center. In response to our recommendations, the facility agreed to conduct a formal suicide risk assessment within one week of discharge, contact families at least every three days during home leaves, discuss medication requirements, effects and side effects with family members, and have patients return to the hospital for reassessment prior to discharge whenever it is feasible to do so.
- ▶ In a series of follow-up reviews to complaints first offered by the mother of a 10 year-old boy being treated on the adolescent psychiatry unit of a private hospital, the Commission worked to ensure that several repeated deficiencies we identified were effectively corrected. Among the problems previously noted were children being medicated without parental consent; the restraint and seclusion of children without prior approval from a physician who had personally examined the child; children who were not properly released from restraint at two hour intervals as required by state law; and improper restrictions placed on patient visitation and phone calls. Our return visits to the hospital noted gradual improvements in hospital policy and practice. With our persistent involvement, hospital staff modified hospital policies to ensure the appropriate clinical supervision of restrictive interventions; trained staff in their proper implementation; and developed a monitoring mechanism. In addition, the hospital ensured that parents give permission for the use of medications with potentially harmful side effects, and protect the rights of children to have open contact with friends and relatives absent significant clinical indications.



## MONITORING DEATHS

During the 1996-97 annual report year, the Commission reviewed the deaths of 2,009 mental hygiene recipients and, with the assistance of its Medical Review Board, investigated 260 deaths which appeared to have occurred under unusual circumstances or from other-than-natural causes.

In selecting deaths for investigation, the Commission gives priority to those individuals who were most reliant on the state or its licensees for their day-to-day care and treatment: inpatient or residents of mental hygiene facilities and individuals who recently transitioned from inpatient or residential care to live independently or with their family.

The purposes of such independent investigations are:

- to better protect the living through recommendations to facilities when the circumstances of death suggest deficiencies in care; and
- to offer families and staff of facilities comfort and reassurance when unexpected deaths did not suggest shortcomings in care.

Examples of these outcomes follow.

- The Commission's investigation into the unexpected death of a 39 year-old man who was being restrained at a Long Island hospital indicated that he died as a result of hypertensive heart disease; a contributing factor was a recent myocardial infarct.

In reviewing the hospital's restraint procedures, however, it was found that while staff restrain a patient, they snugly hold a towel over the patient's mouth as a precaution against biting or spitting. Although such wasn't done in the case under investigation, the Commission and Board were extremely critical of this practice. Individuals who are emotionally excited or physically struggling experience increased oxygen demand; compromising their airway by placing a towel over their mouths (or other means, e.g., neck or upper torso compression) places them at risk of serious harm. The facility terminated this practice in light of the Commission's and Board's comments. The Commission has also shared this information with other facilities.

- Following the Commission's findings concerning the death of a 39 year-old resident of a mental health agency in New York City, the agency revised procedures to ensure that information is shared between its clinic programs and its residential program.

Prior to his death, the man had visited the agency's medical clinic where he was diagnosed as having diabetes and a positive PPD. As this information was not communicated to the residential program, staff there were unaware of the individual's health status or the need, at least, to return to the clinic for further care and treatment. The individual never returned to the clinic for follow-up care and, several months later, died from tuberculosis.

- The Commission's investigation into the death of a 24 year-old resident of a group home in Western New York resulted in disciplinary action against several of the staff, referral of the home's LPN to state licensing authorities, retraining of all staff in emergency medical procedures, and the creation of a Medical Services supervisor for the agency.

The resident, who was profoundly retarded and had a seizure disorder, began having continuous and uncontrolled seizures at 7:00 a.m. the day of his death. By noon, staff had documented 46 seizures, yet they made no attempt to contact the individual's physician. The LPN, who was on duty and was aware of the client's continuous seizures, left the residence to take another client to a dental appointment.

After nearly four and one-half hours of being in status epilepticus, the client ceased breathing, at which time staff summoned an ambulance. He did not survive.

- In a rush to judgment following the unexpected death of a 49 year-old mildly mentally retarded woman at a sheltered workshop, the agency fired the workshop's director and suspended the client's case manager.

The Commission's investigation, however, revealed that the individual had received appropriate care. On the morning of her death, the individual complained to the director and case manager that she was not feeling well. She reported that her husband was in the hospital, that she wasn't sleeping well and that she had neck, back, and chest pains. The agency nurse who covered the workshop was on an extended leave, so the director asked the woman if she wanted to be taken to her doctor; she refused. The director took her blood pressure and pulse, which were normal.

The client claimed she would feel better if she could speak with her hospitalized husband. So the director asked the case manager to contact the family to see if arrangements could be made for the client to visit her husband in the hospital, as it was felt she was "having sympathy pains." Shortly thereafter while still at the workshop, the woman died. The cause of death was a dissecting aortic aneurism.

In the opinion of the Commission's Medical Review Board, a dissecting aortic aneurism is extraordinarily difficult to diagnose, and even with the most advanced medical attention the client may not have survived. The Board believed that in the absence of a nurse, the actions of the director and case worker were reasonable and compassionate, given the client's presentation and unwillingness to see a doctor. Rather than disciplining these individuals, it was felt that the agency's efforts would be better focused on ensuring medical coverage for the workshop.

Following the Commission's investigation the director and case manager were reinstated; the agency made arrangements for regular nursing coverage for the workshop.

While the Commission's death investigation activities help improve care at particular facilities, they also create teaching moments for all facilities. In 1997 the Commission published a compendium of 28 case studies, drawn largely from its death investigations. The studies serve as teaching tools and vehicles for facilities' critical self-evaluation. The compendium received an award for outstanding communications achievement from the National Association of Mental Health Information Officers.



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# ENSURING FISCAL ACCOUNTABILITY

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## CHALLENGES FOR REGULATORS IN THE NEW MILLENNIUM

In the last twenty years, New York's system of care has undergone dramatic changes with an increasing emphasis on developing community-based services to ensure the availability of a comprehensive service delivery system. The increasing availability of both community-based residential and non-residential services has significantly reduced the state's reliance on institutional settings to treat persons with mental disabilities. As part of the evolution of our state's system of care, voluntary agencies have come to play an increasing role in serving persons with disabilities.

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*The lack of substantive outside detection and effective and aggressive enforcement as a deterrent has permitted some unscrupulous persons to manipulate not-for-profit corporations and siphon money for their personal enrichment.*

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While unquestionably, the use of tax-exempt businesses, organized and operated exclusively for a public purpose, works very well because most operate honestly by self-regulation in the way provided for by the New York Not-For-Profit Corporation Law (vigilant boards of directors, independent audits etc.), the lack of substantive outside detection and effective and aggressive enforcement as a deterrent has permitted some unscrupulous persons to manipulate not-for-profit corporations and siphon money for their personal enrichment.

Even given the limited resources, the independent fiscal investigations conducted by the Commission have resulted in significant financial savings for the state and have hopefully served as a deterrent to future misuse of public funds. In order to maintain our vigilance over public funds and ensure that they are used for their intended purpose of providing quality care, the Commission has increasingly been working with the paying agencies and law enforcement entities to build cooperative, mutually beneficial relationships. In particular, the Commission, drawing from its experience over the past two decades, has worked to provide information on the unique problems in the state's mental hygiene system to foster the "two-way" cooperation that is needed for effective and aggressive enforcement. The evolution of the cooperative relationships between the Commission and others is evidenced by the positive outcome of complex cases handled or concluded during the 1996-97 reporting period.



## FISCAL INVESTIGATIONS AND RESULTS

### FEDERAL PRISON TERMS FOR GROUP HOME OPERATORS

A husband and wife who were the subjects of a 1994 Commission investigation were sentenced to federal prison on March 10, 1998 for turning a group home in Flushing, New York into a “squalid house of horrors” by embezzling over a half-million dollars intended to run the home.

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*The Commission’s June 1994 report, **MISSING ACCOUNTABILITY: THE CASE OF COMMUNITY LIVING ALTERNATIVE, INC.**, and subsequent court papers described how the Wrights lived a lavish and free-spending lifestyle, using misappropriated Medicaid funds to lease and operate luxury autos, gamble, and pay on their high credit card debt.*

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Leslie and Kay Wright were the executive director and chairman, respectively, of a phantom board of directors of the not-for-profit corporation, Community Living Alternative, Inc. (CLA), which was licensed to run a ten-bed intermediate care facility. Upon investigation, the Commission found roach and rat infestation; a lack of soap and toothbrushes; soiled sheets and underwear; and, improper and cheap bulk food being used as a mainstay for the nutrition of residents. The home was placed into receivership and opened under a new name as a result of the Commission’s review.

The Commission’s June 1994 report, *Missing Accountability: The Case of Community Living Alternative, Inc.*, and subsequent court papers described how the Wrights lived a lavish and free-spending lifestyle, using misappropriated Medicaid funds to lease and operate luxury autos, gamble, and pay on their high credit card debt. Meanwhile, the residents were denied the very basics of living, including: protection from harm; sanitary conditions; fresh fruits and vegetables; food that met special resident dietary requirements; toothbrushes and toothpaste; and outside recreation activities. The Commission’s report left little doubt that conditions at the home could have been substantially better had checks totaling over \$500,000 not been routinely drawn to cash and deposited into the Wright’s personal checking account.

U. S. District Court Judge Charles Sifton imposed a 37-month sentence, plus two years of probation upon Leslie Wright, and a 24-month sentence, plus two years probation, on his wife. The judge, who called the conditions at the home “pathetic and horrifying” also ordered the couple to pay \$249,692 to the state Department of Health for the substantial losses they caused and an additional \$128,125 to the United States government for the income taxes they evaded.

The stiff jail sentence for Mr. Wright took into consideration his acts in obstructing the Commission’s investigation, as evidenced by his destruction of CLA’s business records just prior to the abrupt closure of the facility which left the residents stranded at their day programs. Both of the Wrights’ sentences also reflected the presence of “vulnerable victims” in the crime who were deprived of the money the Wrights were diverting.

CLA’s certified public accountant (CPA), who conspired with the Wrights and completed fraudulent acts to conceal the thefts from OMRDD, was also indicted, arrested, and has pled guilty to the charges. In April 1998, he was sentenced to four months in federal prison, two years of probation, and \$25,000 restitution. He previously agreed to surrender his CPA license for five years. Judge Sifton noted that but for the special circumstances of illness in his family, the CPA might have received as much as two to two and one-half years in federal prison.

The investigation leading to the convictions was jointly conducted by the U.S. Attorney, Eastern District of New York; the Federal Bureau of Investigation; the Internal Revenue Service; and, was assisted by the staff of the Commission's legal, fiscal, and quality assurance bureaus.

## **RECOUPMENT OF IMPROPER MEDICAID BILLINGS**

For the first time in its history, the Department of Social Services (DSS) successfully utilized the illegibility of a facility's Medicaid records as the basis for a substantial disallowance.

Pursuant to a Stipulation Agreement executed on July 16, 1997, the Queens County Neuropsychiatric Institute, Inc. (QCNI) agreed to remit \$404,448 in Medicaid overpayments because it failed to meet Medicaid record keeping requirements for legibility and documentation. In order to participate in the Medicaid program, providers must maintain "complete, legible records" which disclose the extent of service rendered to patients and to make such records available to both state and federal governments. QCNI waived its right to challenge these findings at an administrative hearing seeking recoupment for improper billings for psychiatric clinic services.

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DSS' actions were taken based upon the Commission's investigation and report on QCNI, a not-for-profit clinic serving primarily low income clients with Medicaid, which was found to be "subordinating its avowed beneficent purpose to become an engine for the personal enrichment of the agency's founder/medical director who misappropriated close to a half-million dollars [see, *Profit Making in Not-For-Profit Care: Part III, The Case of Queens County Neuropsychiatric Institute, Inc.*, October 1996]. The report discusses the Commission's findings on the questionable quality of services, conversion of corporate assets, concealment of financial wrongdoing by the agency's CPA, and failure of the board of directors to carry out its fiduciary responsibilities.

The Commission has made referrals to the United States Attorney, Eastern District of New York, the Federal Bureau of Investigation, and the Internal Revenue Service for possible criminal prosecution related to the misappropriation of medical assistance monies. The reconstituted QCNI board of directors has also expressed an interest in pursuing civil recovery of these funds to help it pay the Medicaid disallowance which it agreed to reimburse the state.

## **CONVERSION OF MEDICAID FUNDS BY INDEPENDENT LIVING CENTER**

The Commission's review of the Independent Living Center of Amsterdam, Inc. (ILC/A) began in the summer of 1997 after the Commission received a referral from the Department of Law, Medicaid Fraud Control Unit (MFCU), which had received a complaint alleging program and fiscal abuse at this agency. Because of the Commission's knowledge and expertise in program and fiscal oversight of not-for-profit corporations and its knowledge of how the OMRDD system operates, the MFCU referred several of the allegations to the Commission while retaining responsibility for review of the agency's Medicaid billing practices. Accordingly, the Commission looked at the conditions of ILC/A-sponsored family care homes and issues concerning possible financial abuse against the not-for-profit corporation and state funding agencies.

The Commission's study found that, while visits to five of the ten agency-sponsored family care homes resulted in many positive findings, only about 50 percent of the monies went to family care providers and the other 50 percent to ILC/A for administrative and program support of the family care program. The ILC/A generated a substantial surplus from its portion of the revenue from this program which was diverted to an affiliate not-for-profit corporation to develop a multi-million dollar apartment community for middle and upper income seniors. Notwithstanding that the establishment or operation of residential facilities by an independent living center is barred under the NY Education Law §1121(iii), use of Medicaid monies for what might even be an otherwise legitimate purpose (i.e., the retirement complex) are prohibited under federal law [18 USC 666(a)(1)(A)]. The manifest purpose of the federal statute is to prohibit misapplications from programs receiving federal funds in order to safeguard finite federal resources and to police those with control over these federal funds.

At the same time that funds were being converted to the unrelated corporate purpose, ILC/A, in apparent violation of federal and state statutes, was soliciting donations from many of the consumers who were being transported in its vehicles. These solicitations took place even though the agency was already being paid by the state to purchase vans and reimburse their operating costs. Other irregularities noted include the misuse of OMRDD Family Support Services monies for other purposes and the improper allocation of ILC/A overhead to the OMRDD and Office of Vocational and Educational Services for Individuals with Disabilities (VESID) which are the prime funding sources for ILC/A.\*

#### **SHAM NOT-FOR-PROFIT SHIELDS SCHEME TO DEFRAUD**

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*The executive director, who would have earned a salary of almost \$190,000 had he not abruptly departed in mid-1997, was rarely seen at the facility even though he reported to government agencies that he regularly worked 60 hours a week.*

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As a result of a complaint, the Commission commenced an investigation into the financial practices of a ten-bed group home and small transportation program in an upstate community. The Commission conducted an on-site fiscal audit and found that the husband and wife team operating the program were skimming substantial monies through exorbitant salaries; preferential fringe benefits; leased vehicles; nonmarket sale of personal vehicles to the agency; and use of agency funds for private business purposes. The principals were able to exact personal gain from the not-for-profit corporation because the board of directors that should have been approving their compensation and monitoring their performance did not exist even though there were board minutes representing that there was an active board. Instead, the Commission found that the board minutes had been fabricated to shield from public scrutiny the fact that the agency was operating without a legitimate board of directors. The executive director, who would have earned a salary of almost \$190,000 had he not abruptly departed in mid-1997, was rarely seen at the facility even though he reported to government agencies that he regularly worked 60 hours a week. The Commission, the FBI and the U.S. Attorney, Northern District of New York, are investigating the apparent conspiracy to defraud the medical assistance program. Also being investigated is whether fraud was committed in the filing of financial reports to OMRDD, which reimbursed the agency \$100,000 yearly for each individual residing in the intermediate care facility.

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\* Subsequent to the report period, the Commission, in cooperation with OMRDD and VESID, developed a cooperative action plan which has resulted in the termination of contracts with ILC/A and assignment of its functions to other agencies.

## **SELF-DEALING FOUND AT GROUP HOME WITH POOR CONDITIONS**

The Commission commenced a review of an OMRDD-licensed not-for-profit corporation in Queens when a complainant contacted the Commission about the lack of appropriate care and treatment that the residents of two four-bed individualized residential alternatives (IRAs) were receiving and wide-scale nepotism at the agency. The complainant reported that the facility was not supplying the residents with important services and supplies. There were charges of inadequate food; failure to provide medically-necessary specialized diets; a need for proper nursing supervision; irregularities in resident fund accounts; use of agency funds for trips out of the country; many relatives of the executive director on the payroll; and a general failure in upkeep of the physical environment.

Commission site visits during December 1997 which confirmed the complainant's allegations found significant environmental deficiencies including roach infestation, odor of urine, lack of personal hygiene items, lack of hot water for bathing, and an inadequate fire alarm system. The food supply consisted mainly of government surplus items, including ground meat, pasta and beans. Habilitation and behavior plans were not being implemented and serious questions arose about the medical management of one resident's diabetes.

Simultaneously, given the gravity of the situation, the Commission's fiscal bureau became involved because the executive director attributed many of the agency's shortcomings to insufficient funding. When the fiscal staff arrived at the agency, it became obvious that very little money was being spent on food and other household items. Conversely, the executive was being generously compensated, receiving some \$115,000 in 1997, undocumented withdrawals of agency funds, trips unrelated to the agency's public purpose, and had 16 of her relatives on the payroll. These and other questionable expenditures, although difficult to quantify because of missing invoices and very poor record keeping, seem to account for a major portion of funds that should be going to program services.

The Commission has recommended corrective actions to address these serious deficiencies and is monitoring the conditions at this agency.



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## PROTECTING FROM HARM, ADVOCATING FOR QUALITY OF LIFE

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Mindful that citizens with disabilities are often vulnerable to abuse and neglect, the United States Congress passed the various protection and advocacy programs to ensure that the legal and human rights of individuals with disabilities would be promoted and protected. Because of its reputation and proven history in investigating abuse, protecting from harm, and advocating for quality of life, the Commission was entrusted with administering these federal programs. The Commission is responsible for administering four such advocacy programs: the Protection and Advocacy for Developmental Disabilities program, the Protection and Advocacy for Individuals with Mental Illness Program, the Client Assistance Program, and the Protection and Advocacy for Individual Rights Program.

The Commission's Advocacy Services Bureau is responsible for administering these federal advocacy programs, each serving a special population of individuals with disabilities. In order to ensure that the advocacy services funded under these programs are reasonably accessible to New Yorkers with disabilities, the Commission has established an extensive network of privately contracted regional offices.

In addition, to these federally-funded programs, the Commission also receives state funding to administer an advocacy program on behalf of mentally disabled residents of adult homes.

Listed below are examples of individual case assistance, technical assistance, and legal representation which summarize the accomplishments of the protection and advocacy programs over the past year.



### PROTECTION AND ADVOCACY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

The Developmental Disabilities Assistance and Bill of Rights Act of 1975 (Public Law 103-230) requires states to establish a protection and advocacy system for persons with developmental disabilities (PADD) which is capable of providing a full range of advocacy services including the ability to pursue legal, administrative, and other appropriate remedies.

Approximately 28,000 New York State citizens with developmental disabilities were served by the New York State PADD program this past year. These services included legal assistance and non-legal individual advocacy and encompassed a variety of educational and training programs and special efforts fostering community integration of persons with disabilities. The Commission also has been actively involved in advocacy for systems reform of services and programs for persons with developmental disabilities, as well as the investigation of alleged abuse and neglect of institutionalized children and adults with developmental disabilities.

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

## **NYC PADD OFFICE WINS FULL INCLUSION IN KINDERGARTEN**

The parents of a five year-old child with Down Syndrome wanted to have their child placed in the regular kindergarten after she had success in an integrated pre-school. Since it was recommended that she needed a 1:1 aide in the classroom to facilitate the full inclusion, the Committee on Special Education (CSE) recommended instead that she attend a program called Kindergarten Plus which had a special education teacher and a paraprofessional in 50/50 mix of special education and typical students. However, this program was only in a few sites throughout the city and the parent's evaluative material indicated that their child could do just fine in a class with a majority of non-disabled peers. Negotiations broke down and the parents and the New York City PADD advocate asked for an Impartial Hearing. New York Lawyers for the Public Interest (NYLPI) offered assistance and arranged for a *pro bono* attorney to represent the parents at the hearing. However, at the last minute, the District convened a new team and placement was made in a regular kindergarten with a 1:1 aide.

## **NEIGHBORHOOD LEGAL SERVICES (NLS) CONVINCES MAJOR INSURANCE COMPANY OF ITS MAJOR ADA RESPONSIBILITIES**

Nationwide Insurance refused to reimburse certain expenses for an individual with developmental disabilities who was injured in a motor vehicle accident while walking home from his job as a bus maintenance aide. The company claimed that the young man missed the filing deadline. The NLS attorney filed an administrative complaint with the New York State Insurance Department alleging that due to the client's pre-existing impairments of cerebral palsy and a learning disability, combined with his marked memory loss resulting from the accident, he was unable to meet the deadline and as such he should be granted a reasonable accommodation of an extended deadline. Soon after the filing of the complaint, Nationwide acknowledged its mistake and sent the client a check for the balance which was due.

## **NEW YORK LAWYERS FOR THE PUBLIC INTEREST (NYLPI) GAINS BI-LINGUAL BI-CULTURAL CLASS FOR DEAF STUDENT**

NYLPI was successful in gaining appropriate service for a six year-old child who is deaf. NYLPI has an agreement with over forty private law firms to take special education cases on a *pro bono* basis. In this case, the firm of Morgan and Finnegan agreed to represent the child before a Committee on Special Education (CSE) to argue that she needed a "bilingual-bicultural" class in the public school. Traditionally, deaf children needing to be immersed in a American Sign Language (ASL) class with other deaf students would be placed privately in schools like the Lexington School for the Deaf. The CSE agreed, rather quickly, that it was best to create a class in the public school and then to invite the parents of other deaf students to have their children participate in the program. Such a class would allow the children to have their full day instruction communicated through ASL and, by being with other deaf students, a culture would be reinforced with all students reaching maximum communication and increased academic success. The theory, within the deaf community, is that deaf children in a non-deaf class with an individual sign language interpreter miss many subtleties in the class and become isolated because of the non-deaf children's inability to communicate with them. This class will help create the appropriate "culture" without removing the child from his/her own neighborhood school.

## **NORTH COUNTRY LEGAL SERVICES (NCLS) SAVES CLIENTS' HOMES**

Two NCLS attorneys assisted individuals with developmental disabilities with a serious financing problem with their trailer homes. The referral came as an emergency request from the State Office of Mental Retardation and Developmental Disabilities local Developmental Disabilities Services Office (DDSO).

The owner of the trailer park had controlled the financing for the homes and the individuals had made six months of payments. Then, the owner sold the note to a bank. The bank wanted payments for the full amount; not counting what had been paid to date or else the homes would be repossessed. The NCLS attorneys negotiated a refund from the trailer park owner of the six months payment so that there was no loss to the individuals. This case reflects the priority from comments expressed in a recent Consumer Survey which identified the need to protect individuals with developmental disabilities from exploitation as one of the top priorities for the PADD program.

### **ALBANY LAW SCHOOL (ALS) WINS FIRST EARLY INTERVENTION COMPENSATORY EDUCATION CASE**

The ALS Disabilities Law Clinic came to the aid of a family which had Early Intervention (EI) services summarily discontinued without any due process or prior notice. As a result of PADD services, the child was able to continue to receive needed services with compensatory services also being provided because of the Early Intervention official's failure to ensure the due process rights of families under the program. The Early Intervention Program under Part H of the Individuals with Disabilities Act (IDEA) is administered by the State Department of Health with local management often by county Departments of Health.

In this instance, the Albany County EI official told the parents that they could no longer send their child to a previously approved center-based program because a "mistake" had been made and the child did not need the service. The parents removed their child "under order" but fortunately sought advice about their rights. ALS advised the family to ask for mediation and that the law provided that the child remain in "stay put" during the pendency of mediation and any further appeal. Since the child was out of the program the "stay put" was up for question. The mediation produced an agreement whereby the child returned to the center-based program and an independent evaluation was ordered to help resolve the level of need for service. The evaluation verified the need for center-based services, and, further, the Albany Law School made a request for compensatory education.

Under the Federal Individuals with Disabilities Education Act (IDEA), an individual may be entitled to compensatory education, if it has been determined at hearing, that the educational agency failed to provide special education services during a defined time period. It has been established, in past cases for school-aged children, that compensation would occur by extending their education beyond age twenty-one by using a formula of one year of compensatory education for each year of lost service. Albany County agreed to make up for the time the child was out of her center-based program by adding an extra day per week to her present program. This case makes very clear the fact that the Early Intervention Program must be administered by the counties in the same way as the school-age part (ages 3-21), Part B. The rights and due process protections remain constant throughout IDEA.

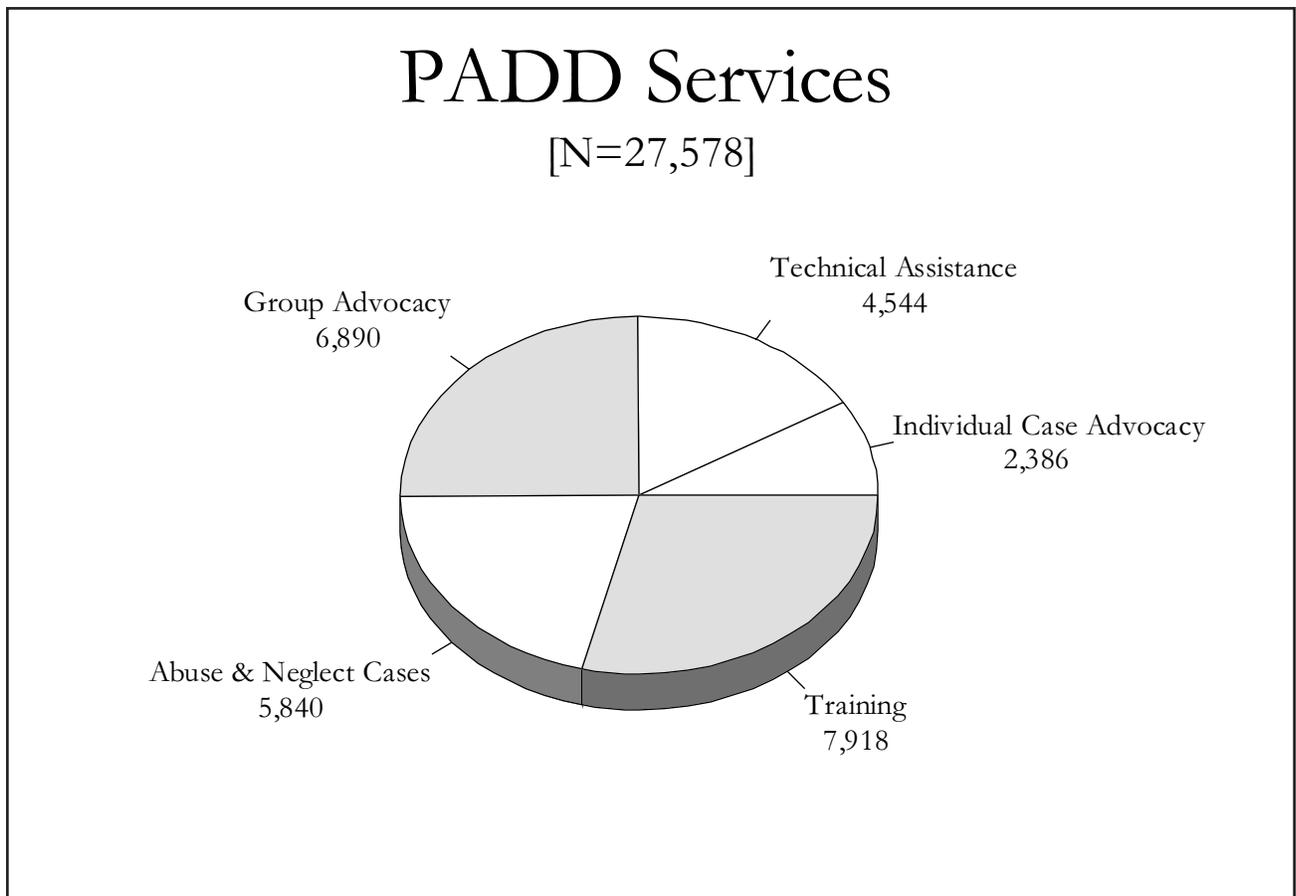
### **NYLPI HELPS LEGAL ALIEN TO BECOME A CITIZEN**

New York City New York Lawyers for the Public Interest (NYLPI) came to the aid of a legal alien who was denied citizenship by the Immigration and Naturalization Service (INS). At issue was that the INS determined that the client, Chin Soo C., did not have the mental capacity to take the Oath of Allegiance to the United States. Such decisions are made by INS officers who have no medical training, and the appeal process for such a decision is a review by another INS agent. NYLPI placed the case with the private law firm of Davis, Polk and Wardwell, which is part of the NYLPI *pro bono* network. The attorneys from Davis, Polk and Wardwell brought out medical evidence which indicated that although Mr. Chin Soo C. had received a waiver from the language and civics part of the citizenship process, he did have an understanding of the oath and he could indicate such acknowledgment. Mr. Chin Soo C. attended a formal citizenship swearing in ceremony at 26 Federal Plaza in Manhattan.

## ALBANY LAW SCHOOL SOLVES COMPLICATED EARLY INTERVENTION CASE

The ALS Disabilities Law Clinic came to the aid of a young couple with a severely disabled one year-old child with Mobia Syndrome and thus helped to avoid possible protracted litigation. Mobia syndrome is manifested by severe brain injury, epilepsy, and cerebral palsy. The child is cared for at home with the aid of nursing services, respirator, apnea monitor and oxygen. Her 22 year-old mother is consumed with the child's care and she has literally saved her child's life on a couple of occasions through suctioning her lungs. At issue was the fact that this family needed expert case management service to help them negotiate the labyrinth of services necessary for the survival of their child. There were outstanding concerns regarding a need for an orphan drug not yet approved by the Federal Drug Administration (FDA) but available in Canada, a need for Medicaid approval for more nursing hours, and Medicaid permission to visit the Boston Children's Hospital. All these issues were appealable under Medicaid regulations, but a good case manger, knowledgeable in the regulations, might secure those benefits without appeal.

Such expert case management was available through SKIP of New York Inc., which is recognized statewide through licensure by the NYS Department of Health (DOH) and the State Office of Mental Retardation and Developmental Disabilities (OMRDD). However, the family's home county, Ulster, did not have a contract with SKIP, but, rather it used another agency which did not have the same level of experience or expertise. ALS contacted DOH and, through a series of phone calls and faxes, arranged for SKIP to be placed on the Dutchess County provider list. Then, with the help of a DOH Public Health nurse, ALS convinced the Ulster County officials that this child's health and welfare would be best protected by the intervention of the SKIP case manager. No further legal intervention was necessary, and the case was resolved in a matter of two days.



## **PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS**

The Protection and Advocacy for Individuals with Mental Illness Amendments Act of 1991 (Public Law 100-509) provides a resource for individuals who have been diagnosed as mentally ill and who reside in any residential facility which provides care and treatment, or who are in the process of being admitted to or recently discharged from such a facility.

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*During the past year, New York State's PAIMI program served a total of 1,724 individuals with mental illness in New York State who have been abused or neglected in residential treatment settings, or who have contacted us regarding problems they identified related to their care and treatment or the violation of their legal rights.*

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The New York State PAIMI system, through both the Commission and a network of regional offices around the state, investigates complaints about abuse, neglect, and violation of rights, and provides both legal and non-legal advocacy services on behalf of such individuals.

During the past year, New York State's PAIMI program served a total of 1,724 individuals with mental illness in New York State who have been abused or neglected in residential treatment settings, or who have contacted us regarding problems they identified related to their care and treatment or the violation of their legal rights. In addition, the PAIMI program worked to benefit thousands other persons throughout the state by advocating for systemic changes in the delivery of mental health services. Systemic advocacy takes many forms, from participating on local and statewide task forces related to specific issues, to meeting with providers of New York State-licensed and operated programs as well as the state provider agencies regarding topics of concern, to pursuing litigation to resolve problems which cannot be solved by other means.

The PAIMI program has also provided 2,000 information and referral services for persons who contacted PAIMI and who could not be helped directly or who would be better served by another agency. The PAIMI program also provided training regarding the rights of individuals in the mental health system and on specific related topics for approximately 2,800 persons.

The following are some examples of specific PAIMI cases.

### **ASSISTANCE TO EMOTIONALLY DISTURBED CHILDREN AND ADOLESCENTS**

- ▶ North Country Legal Services, Inc. (NCLS) successfully assisted a 16 year-old special education student who was classified as emotionally disturbed in obtaining an appropriate residential educational placement. The special education provider for this young man had initiated a Person in Need of Supervision (PINS) petition against him in Family Court through the local Department of Social Services, attempting to have him placed in a NYS Division for Youth facility. The NCLS PAIMI attorney, together with the law guardian for the youth, represented the young man in Family Court and succeeded in persuading the Judge that the residential educational placement was a more appropriate plan. The client has been in his residential educational placement for more than six months at this time and is reportedly doing well there.

- ▶ Neighborhood Legal Services, Inc. was successful in assisting two adolescents and their families in preventing unnecessary residential treatment placements after the PAIMI attorney became involved in assisting them during the course of Persons In Need of Supervision (PINS) proceedings in Family Court:

**K.H.** is school-phobic and had a number of absences from her school program. Residential placement was averted in this case through advocacy with the Committee on Special Education, as well as with the school district, which agreed not to pursue placement as part of the PINS petition. The Family Court gave K.H. a conditional discharge, thus allowing her to stay with her mother and to pursue her individual needs through the local CSE. The education issues continue to be monitored through the PAIMI program's involvement.

**J.D.** had an extensive psychiatric history and had been placed in a juvenile detention facility by the Family Court. As a result of NLS intervention, J.D. was released from the detention facility to parental custody with community mental health and support services to be provided to J.D.

- ▶ Disability Advocates, Inc. (DAI) was contacted by the mother of a minor daughter who had recently been discharged home from a private psychiatric hospital, even though a residential placement was indicated. An appropriate placement had been identified but the hospital did not appear to be following through with the necessary application. Time was of the essence because there was a chance that the placement would be lost if action was not taken immediately. DAI intervened and ensured that the hospital took the necessary actions to obtain the appropriate placement for the child.

## **ASSISTANCE TO PERSONS WHO RESIDE IN ADULT HOMES**

Neighborhood Legal Services, Inc. has assisted two individuals in issues related to services from adult homes (which provide room, board, and aids in daily living). These programs, which are regulated by the NYS Department of Health, are a significant source of housing for individuals being discharged from psychiatric hospitals:

- ▶ *P.P. v. Connelly*, and a related administrative complaint involved the denial of admission to an adult home based on the client's diagnosis of mental illness. Ultimately, the client was admitted to the adult home, but was then rehospitalized. Administrative remedies against the adult home were pursued based on poor quality of care and financial abuse. Although the specific administrative remedies did not prove to be successful, the client did obtain her funds and move to another adult home where she is living comfortably and happily.
- ▶ *Bridgewell v. B.W.* in Buffalo City Court was an illegal eviction proceeding against a client who is both mentally ill and physically disabled. During the course of an interim settlement stipulation, the client was evicted without a court order and hospitalized in a psychiatric ward. The client decided not to pursue court action, preferring to move to a more acceptable living arrangement when he was discharged.

## TREATMENT IN AN APPROPRIATE LANGUAGE

- New York Lawyers for the Public Interest, Inc. is working with Mental Hygiene Legal Service, First and Second Departments, to encourage the NYS Office of Mental Health (OMH) to provide proper treatment for patients who speak neither English nor Spanish. OMH operates wards staffed completely by caregivers who speak English and wards staffed completely by people who speak Spanish; these wards are filled by individuals who speak those languages. However, OMH has often neglected to provide for the communication needs of significant numbers of patients from east Asia and the former USSR who do not speak English, although the agency presently employs many treatment professionals who speak the relevant languages. Consequently, individuals of certain races and national origins receive vastly different levels of care as compared to those of other races and national origins.

Negotiations, in the forms of both meetings and correspondence, between the advocates and the Office of Mental Health have been ongoing for more than a year. OMH recently has opened two “clusters” – special units for treatment of non-English-speaking patients of Asian ancestry. Monitoring of the specific needs of non-English-speaking Asian patients in the metropolitan New York City region will continue. This group’s primary task is to work on an improved OMH policy on the provision of interpreter services. In addition, a core group of psychiatric center administrators has been developed whose responsibility it is to deal with language issues.

- Legal Services of Central New York, Inc. (LSCNY) represents a Spanish-speaking client who was transported to a medical center in an upstate rural county for an emergency psychiatric evaluation. The hospital failed to provide an interpreter during the evaluation, and then had the client transported to another hospital in a neighboring county for further evaluation. The second evaluation, which included a Spanish language interpreter, revealed that the client actually did not need involuntary hospitalization and resulted in her release. If the initial evaluation had included an interpreter, the transportation and second evaluation would not have been necessary. This case remains under investigation for possible litigation.
- LSCNY is also representing a young deaf man who was brought to an emergency room due to exacerbation of his mental illness. No interpreter service was provided at the emergency room, despite repeated requests by the young man and his family. He was then admitted involuntarily to a psychiatric unit for one week, during which he was provided with an interpreter only on two occasions. After his release from the hospital, the client contacted the PAIMI unit to pursue his complaint about this lack of accessible treatment.



## CLIENT ASSISTANCE PROGRAM

The Client Assistance Program (CAP) is authorized by the Federal Rehabilitation Act, a program which provides for many services for persons with disabilities, especially vocational rehabilitation, employment, and independent living services. Each state is required to have a CAP program to provide legal and advocacy services to persons receiving services in order to receive Rehabilitation Act funds. New York's CAP program serves individuals with disabilities who are applying for, or in the process of receiving services from the NYS Department of Education's Office of Vocational and Educational Services for Individuals with Disabilities (VESID) and the NYS Office of Children and Family Services' Commission for the Blind and Visually Handicapped (CBVH).

The Commission's statewide network of dedicated CAP advocates provides advocacy services and information to New Yorkers with disabilities that is often critical to accessing state-sponsored vocational and related services. CAP advocates rely on a range of alternative dispute mediation strategies for resolving consumer complaints. In those instances where these approaches prove unsuccessful, CAP is available to pursue formal administrative procedures and litigation to protect the rights of New York State consumers of vocational rehabilitation, independent living, and related services.

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*The Commission's statewide network of dedicated CAP advocates provides advocacy services and information to New Yorkers with disabilities that is often critical to accessing state-sponsored vocational and related services.*

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More than 6,600 persons with disabilities were served by CAP during the past year. CAP professionals provided 809 individualized intensive case advocacy services. Nearly 2,000 more individuals were provided with information and referral services, linking them to a vast array of vocational and related services. The CAP program also trained nearly 3,000 persons on their rights in the rehabilitation process.

The following are some typical CAP cases.

### **SMALL BUSINESS DEVELOPMENT**

The Central New York CAP office assisted Mr. D. in securing VESID services to expand his fledgling lawn care and groundskeeping business. Mr. D. has a significant learning disability and was assigned a VESID counselor who had no previous experience with self-employment ventures.

Mr. D. had developed a business plan in full compliance with VESID's self-employment requirements. The VESID counselor denied the plan based on his assessment that the plan was not viable, even after Mr. D. produced a list of clients who had committed to utilizing his services. The VESID counselor also found Mr. D's planned use of a job coach to assist with accounting and promotional activities problematic.

CAP assisted Mr. D. with refining his business plan to include specific price quotes for necessary equipment and negotiated with the VESID counselor's supervisor to achieve a successful case closure with job coaching service. Mr. D. presently has his own thriving lawncare and groundskeeping business.

### **RESOLVING INTER-AGENCY COORDINATION**

The Western New York CAP office assisted Mr. T. in overcoming a lack of coordination between VESID and CBVH. Mr. T. has a visual impairment and had been receiving services from CBVH while his vision improved to the extent that driving an automobile was possible with low vision devices. In order for Mr. T. to secure his driving license he would need a driving evaluation and special training. According to Mr. T., CBVH had informed him that he was no longer legally blind and that he should seek VESID

sponsorship for driving related services. VESID denied Mr. T.'s request for services on the basis that Mr. T. was still legally blind and should be receiving services from CBVH.

Complicating Mr. T.'s case was a request he had made to CBVH for home modification services prior to his vision improving. CBVH had hired an architect to conduct an accessibility survey when the case was transferred to VESID. The transfer was viewed by VESID personnel as premature and, as a result, the VESID district manager was unwilling to even meet with CBVH to resolve the question of which agency should take the lead in serving Mr. T.

At the suggestion of the VESID district office manager, CAP contacted Mr. T.'s eye doctor to secure a definitive determination on the status of Mr. T.'s eyesight. CAP was ultimately successful in persuading VESID to meet with CBVH. VESID agreed to accept the case transfer and to provide Mr. T. with driver training on the condition that CBVH complete the home modifications. CBVH agreed to the conditions of the transfer.

## **TRANSITION FROM SHELTERED TO SUPPORTED EMPLOYMENT**

The Western New York CAP office assisted Ms. D. in her interest to secure employment opportunities outside of the sheltered workshop where she had been employed for several years. Ms. D. experiences mental retardation and was receiving case management services from the regional Developmental Disabilities Services Office (DDSO). The DDSO case manager referred Ms. D. to CAP indicating that she was high functioning and could master more complex tasks than those she was engaged in at the workshop. Packing boxes had represented the bulk of Ms. D.'s work activity at the workshop.

The case was complicated by Ms. D.'s criminal record which included a serious assault on an elderly neighbor with whom Ms. D. had maintained cordial relations for years. The Association of Retarded Citizens (ARC) was reluctant to consider alternative employment placements despite the DDSO case manager's belief that Ms. D. should be working in the community. CAP facilitated a meeting during which all parties agreed to place Ms. D. in supported employment for six months to assess and improve her social interaction in a more integrated work environment and consider prospects for competitive employment.

## **POST-EMPLOYMENT SERVICES**

The Western New York CAP office assisted Mr. A. in securing VESID post-employment services. Mr. A. has a pronounced learning disability and was employed full-time as a truck driver when he applied and was denied eligibility for VESID services. Mr. A. applied for VESID services seeking sponsorship for developmental reading classes at a local reading development center.

As a result of Mr. A.'s learning disability he had never learned to read. He had managed to obtain and maintain employment by being an extremely reliable employee with an excellent work ethic. He also compensated for not being able to read by having his wife complete his job applications and she assisted him in memorizing his daily delivery routes. VESID acknowledged that Mr. A. had a disability, but failed to see how it was affecting his ability to obtain or maintain employment.

Undaunted, CAP secured documentation from the learning development center which linked Mr. A.'s inability to read with compromised job performance. This compromised performance placed him at risk of losing his current employment. CAP also documented the fact that Mr. A.'s current employer did not know that he could not read and in all likelihood would fire him if he was aware of Mr. A.'s deficits. With this documentation, VESID agreed to provide the developmental reading instruction requested by Mr. A.



## **PROTECTION AND ADVOCACY FOR INDIVIDUAL RIGHTS PROGRAM**

The Protection and Advocacy for Individual Rights (PAIR) program is another protection and advocacy program authorized by the Federal Rehabilitation Act which provides authority to states to represent in legal and nonlegal actions individuals with disabilities who do not qualify for other existing protection and advocacy programs. Individuals with mental illness living independently in the community and persons with onset of disabilities in their adult age are typically the persons served in this program.

The New York State PAIR program served nearly 4,000 persons with disabilities, their families, and advocates during the past year. Intensive case advocacy services or legal representation were provided to 389 persons. Another 1,515 persons received information and referral services and 1,886 persons were trained in 59 training sessions.

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*Individuals with mental illness living independently in the community and persons with onset of disabilities in their adult age are typically the persons served in this program.*

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Following are examples of some typical PAIR cases.

### **PROTECTION OF HUMAN SUBJECTS OF EXPERIMENTATION**

Disability Advocates, Inc. (DAI), with New York Lawyers for the Public Interest, and the New York Civil Liberties Union, wrote to the Commissioner of the Office of Mental Retardation and Developmental Disabilities (OMRDD) to ensure that it comply with state and federal law when conducting human experiments in its facilities.

On December 5, 1995, the Appellate Division decided *T.D. v. New York State Office of Mental Health*, 650 N.Y.S. 2d 173 (1<sup>st</sup> Dept., 1996). The decision declared that OMH human experimentation regulations were invalid and unenforceable and that numerous experimental practices involving incapable adults and children were unlawful. Although the decision addressed OMH experiments, the legal holdings are equally applicable to OMRDD. OMRDD has human experimentation regulations which are almost identical to the unlawful OMH regulations. The letter demanded that OMRDD comply with the *T.D.* decision.

DAI met twice with OMRDD officials regarding the demand that OMRDD implement the *T.D. v. New York State Office of Mental Health* decision in its operated and licensed facilities. Negotiations continue and a resolution of this issue without litigation is anticipated.

### **ACCESSIBLE TAXICABS**

New York Lawyers for the Public Interest (NYLPI) and Disabled in Action (DIA) continue to devote substantial time and effort to make taxicabs accessible to people who use wheelchairs available in New York City. Because of the difficulty of using public transportation, taxicabs play an important role in the transportation of individuals with mobility impairments. NYLPI and DIA have worked with a number of city and state agencies to forge a coalition to support a workable proposal. Because taxis are much less expensive than ambulettes, accessible taxicabs would not only benefit many individuals but could save money for Medicaid and the State Office of Vocational and Educational Services for Individuals with Disabilities, which now pay for ambulettes.

## ACCESSIBILITY ISSUES IN VOCATIONAL AND HIGHER EDUCATION

Nassau/Suffolk Legal Services is assisting clients in several cases involving Americans with Disabilities Act accessibility issues in vocational and higher education. Clients have been assisted with requests for reasonable accommodations for their learning disabilities and, in one case, for readmission to a program following discharge related to a mental disability.

In still another case, a client was successfully assisted in obtaining a reasonable accommodation for her orthopedic disability while sitting for the New York State Bar examination.

## NATURALIZATION FOR PEOPLE WITH DISABILITIES

Beginning last year, New York Lawyers for the Public Interest (NYLPI) began an education and training campaign and increased advocacy for people with disabilities seeking United States citizenship. As various government programs began to restrict eligibility to those who are citizens, there was an increase in the number of people who sought to naturalize, including many persons with disabilities. NYLPI responded to the emergence of this problem through education, individual advocacy, and litigation.

NYLPI prepared a memorandum describing the possible problems confronted by people with disabilities who are denied citizenship, either because of the oath requirement or because local Immigration and Naturalization Services (INS) offices are not implementing the recent amendment to the Immigration and Naturalization Act granting waivers of the English history and government requirements to people whose disabilities make them unable to comply. As part of this effort, NYLPI reached out to work with some immigrant communities with which NYLPI has not worked to any substantial degree in the past.

NYLPI distributed the memo to the New York City Immigrants Coalition, the Asian American Legal Defense Fund, the New York City Department of Aging, Victims Services, the Korean American Association for Rehabilitation of the Disabled, Association for the Help of Retarded Children (AHRC), Westchester ARC, and the New York City Mayor's Office of Immigrants' Affairs. The memo informs advocates and others that NYLPI will seek *pro bono* counsel for individuals with disabilities who experience these problems. The following is a typical case problem encountered:

A 55-year-old woman from Ecuador suffered a stroke which left her unable to speak, read, or write. When she applied for citizenship, the INS assumed that her inability to speak indicated mental incompetence and denied her application. NYLPI, the Disability Rights Education and Defense Fund, and NYLPI member firm Patterson, Belknap, Webb & Tyler worked together to represent her on appeal and obtain reversal of the initial decision to deny her citizenship. She was sworn in as a United States citizen in September.



## ADULT HOME ADVOCACY PROGRAM

Created and funded by the State legislature, the Commission's adult home advocacy project has been operating since October, 1995. The project, which at this writing provides services in New York City and on Long Island, provides mentally disabled residents of adult homes with legal and non-legal advocacy services as well as training in a number of important topics which include the rights of adult home residents, rights of persons receiving services from mental health agencies, and self-advocacy.

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*Although the project has assisted adult home residents in a wide variety of problem areas, two major complaint areas have become apparent. They are: (1) Illegal evictions from adult homes, especially when a resident has been hospitalized and is ready for discharge back to the adult home or when a resident is believed to have "difficult" behaviors; and (2) Financial questions. . .*

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Services are provided under contract with the Commission by Nassau/Suffolk Law Services Committee, Inc. on Long Island and by MFY Legal Services and the Coalition for Institutionalized Aged and Disabled in the five boroughs of New York City. Since the project began, more than 600 individuals have received advocacy services from the project, and approximately 2,500 individuals have participated in training events developed by the project. In addition to these direct services, project staff have successfully developed relationships with other providers of services and advocates who work with adult home residents. Important cooperative work has been done with Long Term Care Ombudsmen in both project regions, and meetings are held regularly with both ombudsmen and with representatives of mental health service agencies, adult home operators, and local advocacy organizations to exchange information and identify issues which the project should address.

Although the project has assisted adult home residents in a wide variety of problem areas, two major complaint areas have become apparent. They are: (1) Illegal evictions from adult homes, especially when a resident has been hospitalized and is ready for discharge back to the adult home or when a resident is believed to have "difficult" behaviors; and (2) Financial questions related to residents' control of and access to his/her personal needs allowance accounts, additional charges made by adult homes, and lack of information regarding rights related to Medicaid co-payments for prescription drugs. Advocacy assistance provided for clients of the project can range from support for residents to address problem areas themselves through the Resident Council at their adult home, to representing residents in litigation.



## **LEGAL INTERVENTIONS**

Federal statutes governing these advocacy programs provide the authority to use legal interventions to protect and enforce constitutional rights for people with disabilities. Litigation remains a tool of last resort in the federal protection and advocacy programs administered by the Commission. While mediation and negotiation are by far the dominant mechanisms for case resolution, legal representation is a critical vehicle for individual recourse and systemic impact. The following are examples of legal actions pursued by the protection and advocacy programs during the past year.

### **PADD LEGAL ACTION**

#### **HOME AND COMMUNITY BASED SERVICES**

*Caffrey v. Wing*

This action was brought in the Federal District Court for the Northern District and it followed a very favorable Part 633 Hearing Officer decision which affirmed that proper notice is due when an agency plans to terminate a service under the Home and Community Based Services (HCBS) waiver of the State Office of Mental Retardation and Developmental Disabilities. However there still remained the issue of whether aid was to be continued during the pendency of an appeal and thus the need for a Federal Court action against the State Commissioner of Social Services, who was at that time the administrator of the State's Medicaid program. The Albany Law School (ALS) PADD office argued that the HCBS waiver was a Medicaid program and subject to all rules and regulations pursuant to that program. The case was settled with a clearly defined route of appeal which will become part of the 633 regulations and aid will continue during the pendency of appeals.

#### **DISCRIMINATION AGAINST INDIVIDUALS WITH VISUAL IMPAIRMENTS**

*Vernon Grist, Disabled in Action and Greater New York Council of the Blind  
v. New York Commission on Human Rights*

At issue was that the very Commission responsible for educating the public to reduce prejudice and discrimination was, in fact, discriminating against individuals with visual impairments. The Commission on Human Rights has numerous educational publications in standard print as well as rules of practice for administrative hearings held by the Commission to remedy individual human rights violations. However, when a person with a visual impairment asks for these materials on audiotape, the Commission requires justification before it will record a publication. The Commission may refuse taped copies of documents, even to someone who asks for them to pursue an administrative complaint before the Commission. When New York Lawyers for the Public Interest (NYLPI) brought this policy discrepancy to the Commission's attention, there was no response by its administration, and the instant action was brought in the U.S. District Court for the Southern District. The petition alleged that the Commission on Human Rights violated the Americans with Disabilities Act. It appears that a settlement acceptable to the parties is likely to be agreed upon in the near future.

## **NURSING SERVICE**

*Martin v. Wing*

This action was brought in the Federal District Court for the Northern District by Legal Services of Central New York (LSCNY), challenging a provider's discontinuance of nursing service because it claimed that the agency had no available nurses. Subsequently, it placed the individual in a hospital. Federal Judge Frederick J. Scullin in granting LSCNY's plea for a preliminary injunction, ordered that the nursing agency as an agent of the state Department of Social Services and the Office of Mental Retardation and Developmental Disabilities, had an obligation to give proper notice to the family advising them of the discontinuation of service and the right of appeal. He ruled that the nursing agency must provide aid continuing during the pendency of that appeal.



## **PAIMI LEGAL ACTION**

### **RIGHT TO COUNSEL IN GUARDIANSHIP PROCEEDINGS**

*St. Luke's—Roosevelt Hospital v. Marie H.*

On December 20, 1996, the State Court of Appeals decided that there is a constitutional right to counsel in guardianship proceedings which seek to place an allegedly incompetent individual in a nursing home or to make medical decisions without the individual's consent. Few civil proceedings have greater potential for loss of freedom than do such guardianship proceedings – and it is now finally established that no one can be involuntarily placed in a nursing home or lose the right to make medical decisions without having an attorney to advocate for their liberty.

Disability Advocates, Inc. represented the defendant, an allegedly incapacitated and indigent woman, in this case. For the first time, a state's highest court has declared that there is a constitutional right to counsel when a guardianship petition seeks to institutionalize or make major medical decisions. The case also resolves a dispute between the State and City of New York about which branch of government is responsible for the expense of counsel. The New York high court's decision requires the county (or in New York City, the City) to pay for the constitutionally required counsel for indigents. The issue was contested by the City of New York, which had refused to pay for counsel for an indigent person in a guardianship proceeding.

### **REPRESENTATIVE PAYEES**

*Balzi v. Stone* (85 Civ. 8706) and *Brogan v. Apfel* (90 Civ. 7805), United States District Court, Southern District of New York.

This lawsuit (which began as two separate class actions filed by two PAIMI offices, Touro College Mental Disability Law Clinic and Neighborhood Legal Services, Inc.) challenged both the policies and practices of the New York State Office of Mental Health and the Social Security Administration in appointing state psychiatric centers as representative payees for inpatients who have Social Security benefits. The Social Security Administration provided inadequate notice to individuals in the appointment of representative payees. Additionally, the Office of Mental Health consistently violated its fiduciary responsibilities to plaintiffs by placing its own financial interests ahead of those of the plaintiffs, with the effect that plaintiffs face inordinate hardship in obtaining housing and meeting their living expenses upon leaving a state psychiatric facility.

A settlement agreement was reached during which will benefit thousands of current and future patients in New York State psychiatric centers and provides relief for two subclasses of the lawsuits, the “representative payee” subclass and the “endorser” subclass, and defines specific rights and protections to be afforded to each subclass. Members of the endorser subclass will be advised that there is an option for the patient to refuse to pay the charges assessed for his/her care and treatment. Members of the representative payee subclass are protected both by the need for the Social Security Administration to follow a certain order of preference list in making appointments as well as the clarification of advance notice to both the patient and to Mental Hygiene Legal Service. Additionally, the Social Security Administration will publish posters to be prominently displayed in State psychiatric facilities explaining the patient-beneficiary appeal rights as well as acceptable uses of benefits by payees. This information will also be provided to SSA staff who work in New York State. The settlement agreement will be monitored by the Court for three years.



## CAP LEGAL ACTION

### MEANINGFUL CAREER DEVELOPMENT

#### • *Murphy v. VESID*

This case asserts that the Office of Vocational and Educational Services for Individuals with Disabilities (VESID) failed to comply with a fundamental tenet of the Rehabilitation Act by not supporting Ms. Murphy in an employment objective consistent with her interests and abilities.

Ms. Murphy is an eligible VESID consumer who was denied VESID sponsorship for law school. The Central New York CAP legal unit at Legal Aid Society of Mid-New York (LASMNY) filed an Article 78 complaint on behalf of Ms. Murphy who had an individualized written rehabilitation plan that identified her vocational goal as a career in “legal services and related fields.” After supporting Ms. Murphy in earning a B.A. degree, VESID refused to provide supports associated with her enrollment in law school.

A decision dismissing the petition was rendered and LASMNY has appealed to the Appellate Division, Third Department.

#### • *Tourville v. VESID*

This is another case in which the Legal Aid Society of Mid-New York (LASMNY) is challenging VESID’s propensity for focusing on entry level employment as opposed to meaningful careers. The plaintiff is an eligible VESID consumer with epilepsy who could not reach agreement with her VESID counselor on an appropriate goal, and, as a result, no plan for service was established. She has a B.A. degree and is interested in pursuing a career as an attorney. VESID suggested that she pursue a career as a tour guide or a county welfare clerk. LASMNY initiated an Article 78 proceeding in January 1996. The case was heard and the court dismissed the petition. A notice of appeal was filed by LASMNY.

*Murphy v. VESID* and *Tourville v. VESID* were briefed and argued before the Appellate Division, Third Department. Several prominent New York State disability service and advocacy organizations collaborated and filed *amici curiae* briefs. These *amici* briefs speak to broad-based support for CAP’s longstanding posi-

tion that vocational rehabilitation services should focus service delivery on meaningful career development.

## **TUITION ASSISTANCE**

*Baranes v. VESID*

This action involves a woman with a learning disability whom VESID deemed eligible for sponsorship in a masters program in rehabilitation counseling. However, she was denied tuition assistance to study at a university located out-of-state.

The New York City CAP legal unit at New York Lawyers for the Public Interest, Inc. (NYLPI) represented Ms. Baranes at a fair hearing, arguing that the Boston University program she attends is unique and offers special services for students with learning disabilities. The hearing decision ruled against Ms. Baranes and was affirmed by the VESID deputy commissioner.

NYLPI then filed an Article 78 petition in the Albany County Supreme Court alleging that VESID's refusal to sponsor Ms. Baranes at an out-of-state university was arbitrary and capricious, violating the Rehabilitation Act as well as federal regulations. In addition, Ms. Baranes alleged that the VESID denial, while sponsoring other similarly situated consumers to other out-of-state programs, violated her right to equal protection as guaranteed by both the New York and the United States constitutions. A violation of Ms. Baranes' civil rights pursuant to 42 U.S.C. Section 1983 was also advanced. NYLPI is awaiting a decision from the Supreme Court.



## **PAIR LEGAL ACTION**

### **DISABILITY INSURANCE PLANS**

*Leonard F. v. Israel Discount Bank of New York*, No. 95 Civ. 6964(S.D.N.Y.)

This New York Lawyers for the Public Interest case challenges a two-year limit on coverage for psychiatric disabilities in a long-term disability insurance plan that offers full coverage to the age of 65 for all other disabilities. The case was filed in August 1965 and since that time has been actively litigated. Initially, the bank filed a motion to dismiss the case on the grounds that the plaintiff, who is too disabled to work, is not covered by the Americans with Disabilities Act (ADA), the employment provisions of which protect only "qualified" individuals with disabilities from discrimination. The trial court dismissed the case on the grounds that, since Mr. F's benefits had not yet run out, the case was not ripe for review by the federal courts. On appeal, the United States Court of Appeals for the Second Circuit reversed the trial court, holding that plaintiff's action was ripe for review and that he did not need to wait for his benefits to expire to challenge the provision.

The case then returned to the trial court where the defendant renewed its motion to dismiss on the grounds that Mr. F. is not a qualified individual with a disability for the purposes of Title I of the ADA. This time the trial court denied the motion, recognizing that a broad reading of the ADA in conformity with other civil rights statutes would lead to the conclusion that the plaintiff is protected by the ADA, but the trial court reserved a final ruling until a full factual record could be developed. The last year has seen three significant developments in this case. First, the trial court granted plaintiff's motion to amend the complaint to add a claim under Title III of the ADA and to add the Metropolitan Life Insurance Co. ("MetLife") as a defendant. The trial court then granted a motion to dismiss the claims under Title III and

dismissed MetLife as a defendant. Second, the United States Equal Employment Opportunity Commission joined the case as a plaintiff along with Leonard F. Third, the bank defendant moved for summary judgment asserting that, based upon the undisputed material facts, judgment should be granted to it. In a decision after the closing date of this report, the trial court denied the bank's motion and moved toward setting a trial date.

The case has now made far more progress than a number of other cases around the country which raise similar issues concerning discrimination between mental and physical disabilities in insurance and the nature of the defenses which may be raised to justify such distinctions in insurance policies.

## **DISCRIMINATION AGAINST LIVING IN THE COMMUNITY**

### *Janin v. Village of Patchogue*

Federal District Court Judge Jacob Mishler ordered a stipulation of settlement which provides for the continuation of an unlicensed "family-like" group home for persons with mental illness in a single family residential zone in the village of Patchogue and marks the end of an 8-year effort by the village of Patchogue to ban the group home and evict its residents.

The village argued that the home violated the village's definition of "family" in its zoning ordinance. After a request by the plaintiffs for a "reasonable accommodation" under the 1988 Fair Housing Act amendments, the village attempted to argue that, requiring the home to operate as a licensed community residence was a reasonable accommodation under the Fair Housing Act.

In obtaining a settlement of the case, plaintiffs demonstrated that their needs could be met in a more informally structured and supportive living arrangement, rather than in more restrictive licensed settings, with the provision of mental health community support services.

During the course of the litigation with Patchogue, four other homes run by the same provider were protected from similar attempts to close them made by a neighboring municipality, which municipality agreed in a federal court stipulation of discontinuance to abide by the court's decision in the Patchogue case. Several hundred clients with mental disabilities were protected from eviction and assisted with their recovery by Nassau/Suffolk Legal Services, Inc., the PAIR agency in this case.



## EDUCATION AND TRAINING

The scope of protection and advocacy extends beyond individual case representation, and even litigation. A broad range of activities including trainings, technical assistance, outreach, and special projects provide assistance to countless individuals with disabilities, their family members, advocates, and others. In many instances, the change accomplished by these activities comes to fruition in a more timely fashion than protracted litigation. The following are some examples of these activities during the past year.

- ▶ **PADD Continues Collaboration With The State Advocate for the Disabled In Implementing the Technology Assistance Act:** The State Advocate for the Disabled contracts with the Commission to provide a Technology Assistance Advocacy program according to the Federal Technology Assistance Act. The Commission, in turn, has contracted with Neighborhood Legal Services of Buffalo to provide technology assistance and back-up to advocacy agencies throughout the state. In addition to the limited number of cases it is able to represent, NLS has established a network of *pro bono* attorneys who are willing to take on technology appeals.
- ▶ **Western New York Advocacy for the Developmentally Disabled (WNYADD) Conducts Successful Training:** WNYADD, a PADD outreach office coordinates multi-cultural trainings in the city of Rochester for minority service coordinators and parents of individuals with developmental disabilities. The workshops addressed strategies for parents and service coordinators to team up and advocate for an individual with a disability. The training was duplicated in Batavia, Buffalo, and Jamestown, New York. These workshops generated further interest in special education training.
- ▶ **Albany Law School Joins Educational Advocacy Training in Successful Educational Advocacy Conference:** The June 6, 1997 conference was a culmination point of the years of training conducted by the Educational Advocacy Training (EAT) program. The conference included a mock Committee on Special Education meeting, joint session lecture on "How to Communicate with Your District," and, finally, a joint parent/professional panel discussion completed the conference. A 750-page binder of materials was distributed to each participant. The entire conference was videotaped for future trainings.
- ▶ **Disability Network Newsletter, Impact and WWW.NLS.ORG Are Valuable Resources:** New York Lawyer's for the Public Interest's publication *Disability Network Newsletter* has been providing valuable information on NYLPI cases as well as a synopsis of U.S. Supreme Court decisions. Neighborhood Legal Services serves as the national back-up center for technology-related cases and through its newsletter *Impact* has been providing informative articles on accessing durable medical equipment through Medicaid and other available resources like the Physically Handicapped Children's Program through the New York State Department of Health and local school districts via IDEA. *Impact* and Medicaid Fair hearing Decisions can be accessed further through the NLS web site at [www.nls.org](http://www.nls.org).

- PAIMI Trainings:** The Protection and Advocacy for Individuals with Mental Illness program provided staff attorneys for trainings on all aspects of the legal rights of psychiatric consumers, their family members, advocates, and providers of services on topics such as:

  - Health Care Proxy Law
  - Employment Discrimination
  - Discrimination on the basis of disability in post-secondary education
  - Medicaid waiver programs
  - Right to refuse treatment
  - Confidentiality
  - Sealing of mental health records
  - Rights in psychiatric facilities
  - Statutes prohibiting discrimination against people with disabilities
  
- CAP Statewide Transition Services Trainings:** Transition from school to adult life represents a challenging process for youth with disabilities, parents, schools, and the vocational service system. The Client Assistance Program conducted statewide trainings to acquaint parents and students with the complex array of options and challenges inherent in successful transition. CAP's extensive experience with adult services ideally complemented the Commission's Protection and Advocacy Programs' special education advocacy experience. In a joint effort, the CAP coordinator and the Commission's parent training coordinator conducted a series of trainings throughout the state for over 300 individuals on this topic. CAP also produced a comprehensive transition resource packet that was distributed to over 600 parents and students statewide.
  
- Educational Advocacy Training:** An important continuing statewide training program is the provision of specially designed workshops focusing on special education issues for parents. During the past year sessions were conducted throughout the state focusing on advocacy skills for parents, including how to understand evaluations and assessments, how to write Individualized Education Plans, and how to monitor a child's special education program. Many of the workshops were co-sponsored with other disabilities organizations such as the Learning Disabilities Association, the Parent Network, the Mental Health Association, the SUNYA TRIAD Program, and the Taconic Resources for Independence, Inc.
  
- Minority Outreach:** The Commission's statewide Minority Outreach Project continues its primary mission of assisting the Commission and its related advocacy partners effectively serve the state's minority groups. Among the project's specific activities:

  - to serve as a liaison with minority organizations to ensure that these organizations are aware of Commission resources and services;
  - to provide education to professionals on more effective ways of delivering minority advocacy services;
  - to assist minority parents, groups, and associations to better utilize existing advocacy programs; and
  - to encourage persons of color to serve in the field of disability as professionals and as members of advisory councils, planning committees, task forces, and other relevant areas.

- ▶ **Disabilities and the Law:** Disability and the Law is a continuing video series which deals with relevant issues in disability law. This award-winning series is co-produced by the Commission and the New York State Bar Association, and broadcast on local cable television stations throughout New York. Videos are also available for purchase. During the past year two shows were produced and distributed. One deals with supported employment, while the other highlights the importance of the Individuals with Disabilities Education Act, the Rehabilitation Act, and the Americans with Disabilities Act in the everyday lives of persons with disabilities.
  
- ▶ **Disabilities Awareness:** As in past years, the Commission, along with nine other co-sponsors, conducted a statewide disability awareness program. This program is designed to provide information to students to help promote positive attitudes towards persons with disabilities. Over the years, a variety of school presentations and activities for students have been conducted, including essay, art, and photography contests. Judging from the more than 2,000 entries annually, the program has been a success in helping to focus attention on the many similarities among persons with disabilities and those without disabilities.





# Appendices

# Timeline of CQC 20-Year Highlights

CQC created Chapter 655 Laws of 1977	Chairman Clarence J. Sundram, Commissioners Mildred B. Shapiro, I. Joseph Harris Appointed and Confirmed June 1978	Establishment of Priorities: Public Hearings	Beginning of Investigation of Care and Treatment Complaints 50 Initially Investigated
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1977

1978

Gov. Carey names CQC Statewide PADD Agency Sept. 30, 1980	1st Issue CQC Newsletter: "Quality of Care"	Report: Cautionary Notes on Converting CRs into ICFs	Profit v. Care: A Review of Greenwood Rehabilitation Center, Inc.	Gov. Carey signs bill on Receivership	The Endless Quest The Autistic and Their Families
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1981

CQC designated to administer CAP Program	Living Conditions of Nine Psychiatric Centers Reviewed	Restraint and Seclusion Studies	SDMC Program Initiated as Two-Year Demonstration	Review of Living Conditions in Developmental Centers Begun	PAIM Initiated CQC NYS
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1985

Study on Admission and Discharge Practices of Psychiatric Hospitals	Study on Discharge Practices of Inpatient Psychiatric Facilities	Study on Outpatient Suicides	Review of 32 OMH Community Residences	Interagency Symposium on Abuse and Neglect Prevention and Intervention	Minority Outreach Program Begun
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1988

Case Study on Supervision and Care of Seriously MI Children	SDMC Award: National Council of State Government Innovations Program	Study on Parents' Perspective on Special Ed in New York State	Study on Oversight of Transportation Services for Persons with Mental Disabilities	Study on Adult Homes: Conditions, Services, Regulation	National Symposium on the Prevention of Abuse and Neglect
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1990

1991

Psychotropic Medication and Children in NYS MI Inpatient Settings	Call for Reform: Residential Services for Children with Emotional Problems	Life and Death at New Queen Esther Home for Adults	Falling Through the Safety Net: "Community Living" in Adult Homes for MI Discharged Patients	MR Parents and Their Children	Wi L
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1993

Review of Spending Practices in OMRDD Rate Appeals	Patient Safety and Services at Kingsboro, P.C.	Governance of Restraint and Seclusion Practices	"Could This Happen" Series Receives National Recognition and Awards	Adult Homes Advocacy Project Begins Downstate	Study o Comp Case M Pr
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1995

First Facility Reviews: Broome D.C. O.D. Heck D.C. Syracuse D.C. Bronx P.C.	First Deaths Investigated: Joel G., Robert K. John D., Louis F. Allen S.	Family Care Reviews	Review of MHIS	1st Professional Conference: Needs of Emotionally Disturbed/ Developmentally Disabled Individuals; Boards of Visitors: Making Advocacy Work
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1979

1980

CR Study: "Willowbrook: From Institution to the Community"	Managing Resources Studies: Incident Reporting Staff Deployment Discrete MR Units	Family Advocacy Projects	Commissioners Irene L. Platt James A. Cashen Appointed and Confirmed	Review of Outpatient Services for Developmentally Disabled People
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1982-1983

1984

Program by Congress; Administrator	"Profit Making in Not-For-Profit Care:" BPRI Review	"The Multiple Dilemmas of the Multiply Disabled" MICA Study	Study of Medication Practices at Five DCs	Study on Misuse of Aversive Behavior Modification Techniques	Studies on Institutional Child Abuse and Neglect
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1986

1987

Investigation into Allegations of Child Abuse at Western NYCPC	Study on Preventing Inpatient Suicides by Hanging	Study on Psychiatric Emergency Room Overcrowding	Study on Outpatient Mental Health Services	Study on Patient Leaves Without Consent	"Profit Making in Not-For-Profit Corporations:" NYPCC
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1989

Study on Inmates with Developmental Disabilities in New York State	Elizabeth W. Stack and William P. Benjamin Appointed and Confirmed Commissioners	Investigation of Sexual Incidents at Bernard Fineson, D.C.	PAIR Program	Exploiting the Vulnerable: The Case of HI-LI Manor	CQC Required to Conduct Investigations of Institutional Child Abuse	Review of Familial Abuse Allegations of Adults with DD
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1992

End of Willowbrook Litigation	Survey of Access to NYS Courts for Individuals with Disabilities	Investigation into Community Living Alternative, Inc.	Investigation into Project L.I.F.E.	Symposium and Monograph on Choice and Responsibility	Progress Report on Care and Treatment for Persons with Multiple Disabilities
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1994

on Financing prehensive Management Program	Study on Private Psychiatric Hospitals	Study on Psychiatric Clinic Costs	Report on Active Programming in State Psychiatric Centers	Investigation of Queens County Neuropsychiatric Institute, Inc.	CQC Website Online	Review of Individual Residential Alternatives	Kingsboro Revisited
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1996

1997



STATE  
OF  
NEW YORK

# STANDARD VOUCHER

Voucher No.

1 PAY TO:	
Payee Name (Limit to 31 spaces) <b>Commission on Quality of Care for the Mentally Disabled</b>	
Address (Limit to 29 spaces) <b>99 Washington Avenue</b>	
City & State (Limit to 24 spaces) <b>Albany, New York</b>	Zip Code <b>12210</b>

## ANNUAL REPORT 1997-98

QUANTITY	DESCRIPTION OF SERVICES-July 1, 1996 to June 30, 1997	Amount
45,108	Persons Served Through PADD, CAP, PAIMI & PAIR Networks	
50,000	Website Hits/Month	
16,747	1-800 Calls Received	
6,272	Reports of Suspected Adult Abuse Reviewed	
2,711	Recommendations Made	
511	Site Visits	
320	Surrogate Decision-Making Cases Reviewed	
308	Individual Quality Assurance Complaints Acted Upon	
260	Deaths Investigated	
148	Reports of Suspected Child Abuse Responded To	
3	Published Reports	
TOTAL EXPENDITURES FOR SERVICES		
State Operations		
General Fund		\$2,794,772
Special Revenue Fund - Federal		3,422,167
Special Revenue Fund - Other		1,486,246
Aid to Localities		
General Fund		\$ 188,156

<input type="checkbox"/> <b>PAYEE CERTIFICATION:</b> I certify that the above bill is just, true and correct; that no part thereof has been paid except as stated and that the balance is actually due and owing, and that taxes from which the State is exempt are excluded.	<b>TOTAL</b>	<b>\$7,891,341</b>
	Discount %	
	<b>NET</b>	<b>\$7,891,341</b>

→ <u><i>Mary O'Brien</i></u> PAYEE'S SIGNATURE IN INK 1997-98 Date	Chairman Title Commission on Quality of Care for the Mentally Disabled Name of Company
---	--

## 1996-97 PUBLICATIONS

*Watching Over the Children: A Review of 1996 Commission Activities on Behalf of Children with Mental Disabilities*, February 1997

*Incident Reporting and Management Practices at Five NYS Psychiatric Centers*, March 1997

*Could This Happen in Your Program? A Collection of Case Studies Provoking Reflection, Discussion, and Action*, April 1997

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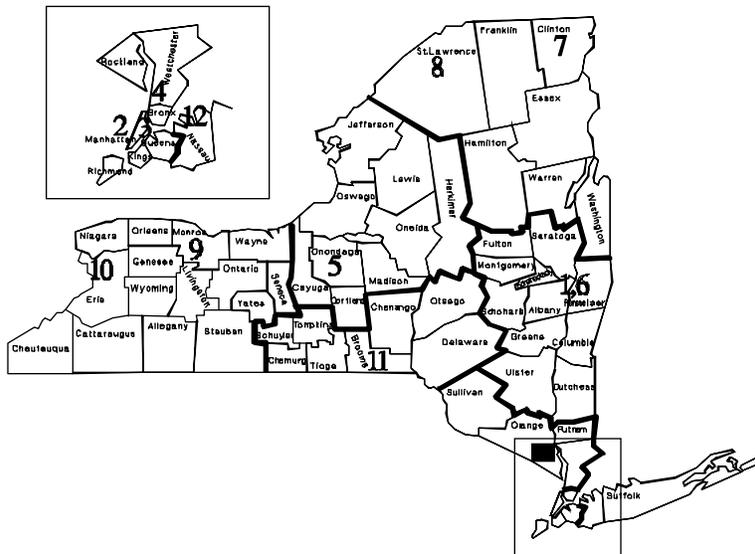
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1. NYS Commission on Quality of Care  
Bureau of Protection and Advocacy  
99 Washington Avenue, Suite 1002  
Albany, NY 12210  
(518) 473-7378

**NEW YORK CITY REGION**

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2. NYS Commission on Quality of Care  
Bureau of Protection and Advocacy  
270 Broadway, Room 2808  
New York, NY 1007-2372  
(212) 417-5096
3. New York Lawyers for the Public Interest, Inc.  
30 West 21st Street, 9th Floor  
New York, NY 10010  
(212) 727-2270

**LOWER HUDSON REGION**

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

**CENTRAL REGION**

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

**UPPER HUDSON REGION**

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

**NORTH COUNTRY REGION**

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7. North Country Legal Services, Inc.  
100 Court Street  
Plattsburgh, NY 12901  
(518) 563-4022
8. North Country Legal Services, Inc.  
P.O. Box 648  
Canton, NY 13617  
(315) 386-4586

**WESTERN REGION**

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9. Western New York Advocacy for the  
Developmentally Disabled, Inc.  
Medical Arts Building  
277 Alexander Street, Suite 500  
Rochester, NY 14607  
(716) 546-1700
10. Neighborhood Legal Services, Inc.  
295 Main Street  
Ellicott Square Building, Rm 495  
Buffalo, NY 14203  
(716) 847-0650

**SOUTHERN TIER REGION**

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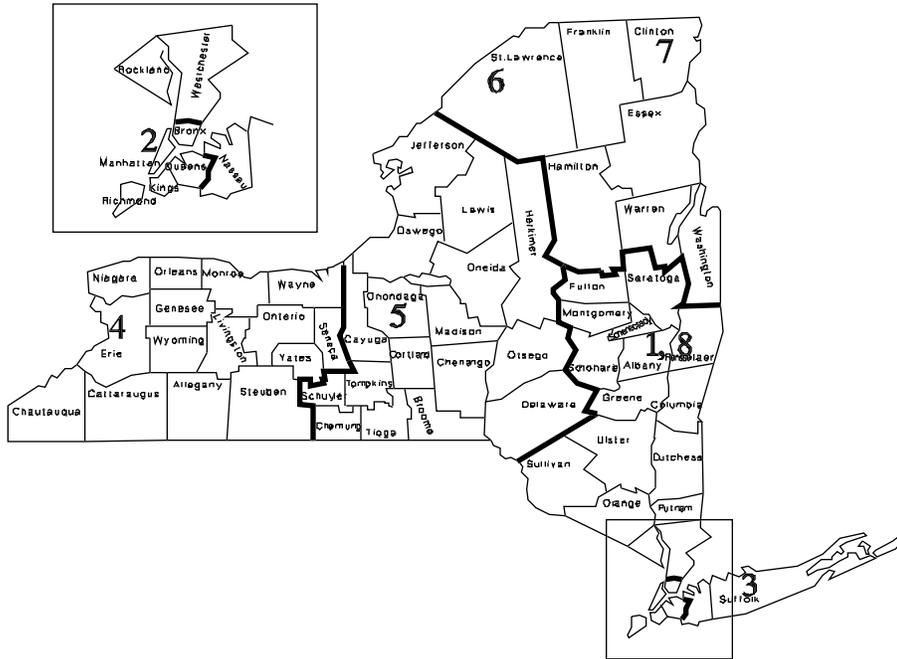
11. Legal Aid for Broome/Chenango Cos., Inc.  
30 Fayette Street  
P.O. Box 2011  
Binghamton, NY 13902  
(607) 723-7966

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12. Long Island Advocates, Inc.  
4250 Hempstead Turnpike, Suite B  
Bethpage, NY 11714  
(516) 735-5466

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FOR INDIVIDUALS WITH MENTAL ILLNESS  
REGIONS AND OFFICES



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

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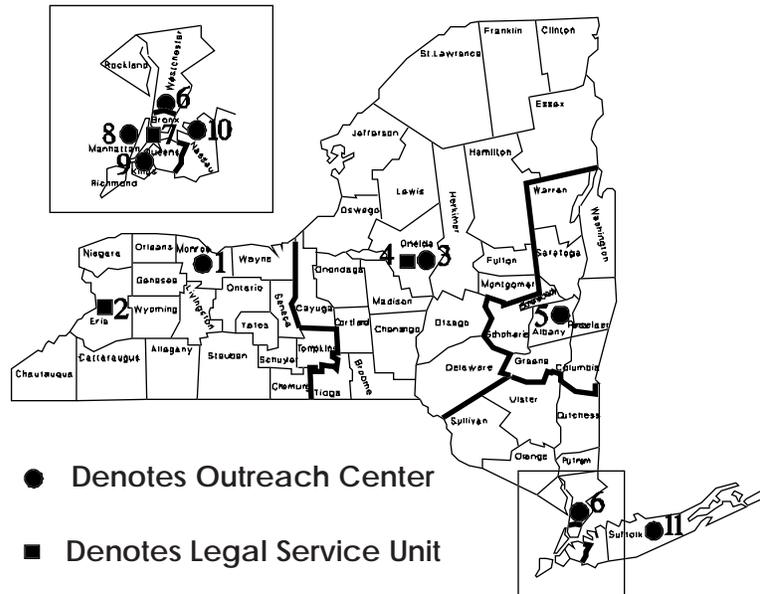
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7. North Country Legal Services, Inc.  
100 Court Street, POB 989  
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(518) 563-4022      1-800-722-7380

**HUDSON VALLEY REGION**

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

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1. Rochester Center for Independent Living, Inc.  
758 South Avenue  
Rochester, NY 14620  
(716) 442-6470 (Voice and TTY)
2. Neighborhood Legal Services, Inc.  
295 Main Street  
Ellicott Square Building, Rm 495  
Buffalo, NY 14203  
(716) 847-0650 (716) 847-1322 (TTY)

## CENTRAL NEW YORK REGION

3. Resource Center for Independent Living, Inc.  
409 Columbia Street  
Utica, NY 13502  
(315) 797-4642 (315) 797-5837 (TTY)
4. Legal Aid Society of Mid-York, Inc.  
255 Genesee Street  
Utica, NY 13501  
(315) 732-2131 (Voice and TTY)

## HUDSON VALLEY REGION

5. Capital District Center for Independence, Inc.  
855 Central Avenue, Suite 110  
Albany, NY 12206  
(518) 459-6422 (Voice and TTY)
6. Westchester Independent Living Center, Inc.  
200 Hamilton Avenue  
White Plains, NY 10601  
(914) 682-3926 (914) 682-0926 (TTY)

## NEW YORK CITY REGION

7. New York Lawyers for the Public Interest, Inc.  
30 West 21st Street, 9th Floor  
New York, NY 10010  
(212) 727-2270 (212) 727-2997 (TTY)
8. Center for Independence of the Disabled in New York, Inc.  
841 Broadway, Suite 205  
New York, NY 10003  
(212) 674-2300 (Voice or TTY)
9. Brooklyn Center for Independence of the Disabled, Inc.  
2044 Ocean Avenue, Suite B-3  
Brooklyn, NY 11230  
(718) 998-3000 (718) 998-7406 (TTY)

## LONG ISLAND REGION

10. Long Island Advocacy Center, Inc.  
Herricks Community Center  
999 Herricks Road  
New Hyde Park, NY 11040  
(516) 248-2222 (516) 877-2627 (TTY)
11. Long Island Advocacy Center, Inc. (Satellite Office)  
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Hauppauge, NY 11788  
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Bonnie Ivey  
Paula Jackson  
Darlene Mayo  
Brenda Traynham  
Pamela Williams

NEW YORK STATE COMMISSION ON

# Quality of Care

FOR THE MENTALLY DISABLED

## MISSION STATEMENT

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

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

## VALUED AND GUIDING PRINCIPLES

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

### ▶ Committed and Courageous Independence

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

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

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

### ▶ Compassion

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

### ▶ Integrity

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

### ▶ Respect

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