Improving Lives, Protecting Rights

Keeping the Dream Alive

NYS Commission on Quality of Care
For the Mentally Disabled
2002 - 2003 Activities
Foreword

This report coincides with the 25th Anniversary of a dream - that of providing the highest quality services to New Yorkers with mental disabilities.

Spurred by the scandalous conditions of the Willowbrook State School in the 1970s, conditions which then newly elected Governor Hugh Carey called unworthy of New York State, and abuses at other facilities, New York embarked on a major overhaul of its mental hygiene system. Shepherded by Governor Carey, Senator Frank Padavan, Chair of the Senate Mental Hygiene and Addiction Control Committee, and Assemblywoman Elizabeth Connelly, Chair of the Assembly Mental Hygiene, Mental Retardation/Developmental Disabilities and Alcoholism and Substance Abuse Services Committee, and supported by advocates and service providers in the public and private sectors, legislation was enacted in 1977 dismantling the often-criticized and overly bureaucratic structure of the Department of Mental Hygiene. The legislation created three autonomous offices, each with its own dedicated mission, leadership and budget to serve the uniquely different needs of people with mental disabilities:

- The Office of Mental Health (OMH);
- The Office of Mental Retardation and Developmental Disabilities (OMRDD); and
- The Office of Alcoholism and Substance Abuse Services (OASAS).

The 1977 reform package also created the Commission on Quality of Care for the Mentally Disabled, which commenced operations in 1978. The Commission was charged with providing independent oversight of the three offices for the purpose of offering the Governor and the Legislature, Commissioners of the Offices and program operators informed, yet impartial, advice and recommendations to ensure that service recipients receive the highest quality of care in a cost effective and responsible manner.

The reorganization of the Department of Mental Hygiene paved the way for advances in service delivery, including the downsizing of large institutions; the development of small, community-based residential and non-residential programs; the inclusion of more partners, especially consumers and family members, in mission-driven service planning; and the evolution of philosophies concerning care and what constitutes quality care. Twenty-five to thirty years ago the system struggled, often unsuccessfully, to provide basic custodial care for the masses as a benchmark of quality. Today, the caliper increasingly used for assessing quality is the degree
to which services and supports are designed to meet the needs and wishes, hopes and desires of the individual recipient.

The service system of today looks much different from that of yesteryear. But that wasn’t simply the result of reorganization. The transformation was achieved through the continued hard work of Governors Cuomo and Pataki, legislative leaders and members, agency commissioners and countless public and private sector staff, consumers and advocates who shared in the dream of Governor Carey, Senator Padavan and Assemblywoman Connelly. These men and women seized every opportunity offered in the reorganization and subsequent years to further that dream.

The literally hundreds of staff and volunteers who have worked for the Commission over the past 25 years also labored to further that dream, specifically through their participation in investigations of complaints, deaths and reports of abuse; systemic studies of policy, program and fiscal issues; the Surrogate Decision Making Program; and the provision of educational and advocacy services.

Is the dream fulfilled? No, but it is being pursued aggressively. Quality is an ever-evolving ideal. And when fallible humans care for each other, providing the highest quality of service is, naturally, a formidable challenge. But the beauty of certain dreams is that they call for pursuit, regardless of the challenges.

With this report on activities during the 25th Anniversary of its genesis, the Commission recommits to the dream which gave rise to its birth, and pledges to continue, with its partners in that dream, the pursuit of the highest quality of care for New Yorkers with disabilities.
# Contents

**Introduction** ................................................................. 1

**Maintaining Traditional Oversight Activities**  
& Monitoring New Service Trends and Modalities .................. 3

- Case Activities
- Watching Over the Children
- Electroconvulsive Therapy for Individuals with  
  Developmental Disabilities
- Medical Care for Individuals with Disabilities
- Monitoring New Service Trends & Modalities

**Assisting People with Mental Disabilities**  
Outside the Traditional Mental Hygiene System .................... 9

- Monitoring Conditions in Adult Homes
- Adult Home Workgroup
- A Study on the Layering of Services
- Other Adult Home Studies
- Prior Adult Home Work Revisited
- Criminal Justice System
- Alternatives to Incarceration
- Mental Health Services in State Correctional Facilities

**Advocating For and Empowering People with Disabilities** .......... 15

- Surrogate Decision Making Committee Program
- Maintaining a Statewide Advocacy Network
- Knowledge is Power

**Promoting Excellence and Fostering Awareness of Commission Services** ....... 21

- Case Studies
- Newsletter
- Speakers Bureau
- NYSDEAL

**Looking Ahead** ................................................................. 23

**Appendices:** ........................................................................ 24

- **Appendix A** – Medical Review Board & Advisory Council Members
- **Appendix B** – Surrogate Decision-Making Panel Members
- **Appendix C** – Advocacy Services Network Offices
- **Appendix D** – Speakers Bureau Topics
Introduction

Much like the system it oversees, the Commission has changed over the past 25 years, embracing new challenges and opportunities to serve people with disabilities.

While the Commission’s enabling legislation focused its activities on programs operated or certified by the Office of Mental Health (OMH), the Office of Mental Retardation and Developmental Disabilities (OMRDD), and the Office of Alcoholism and Substance Abuse Services (OASAS), over the years that focus has expanded.

Beginning in 1980, with the designation of the Commission as New York State’s administering agency for the federal government’s Protection and Advocacy (P&A) system, the Commission’s purview broadened as the P&A system evolved to represent and support people outside “traditional” mental hygiene programs as well as people with physical disabilities or other disabling conditions.

In 1986, the Commission took on a quasi-judicial task – administering the Surrogate Decision Making Committee (SDMC) program which, as an alternative to courts, facilitates informed decision-making on behalf of certain people with disabilities who require non-emergency medical care but lack the capacity to consent to such and have no legally authorized surrogate available or willing to do so.

And, in the 1990s, the Commission’s investigative jurisdiction was expanded to include adult homes, certified by the Department of Health, which serve significant numbers of people with mental disabilities.

Despite these and other changes which have shaped the Commission’s current scope of operation, its mission has remained the same: to improve lives and protect the rights of people with disabilities.

To further advance that mission as it approached its 25th Anniversary of operation, the Commission engaged in a strategic planning process to guide future activities. Representatives of consumer, family, advocacy and provider groups, commissioners and senior staff of operating and regulatory agencies, as well as officials from the Governor’s Office, Division of the Budget and Legislature were invited to share their perspectives on Commission operations, issues impacting people with disabilities, and priorities for Commission action.

The ensuing dialogue resulted in a plan, published in June 2000, to guide Commission oversight and advocacy activities through the year 2003, its 25th Anniversary.

Four overarching goals were identified in the plan:
• Maintaining the Commission’s traditional oversight activities, and monitoring new and emerging service trends and modalities within the mental hygiene system;
• Endeavoring to ensure that persons with mental disabilities served primarily by non-mental hygiene agencies receive services which effectively meet their needs;
• Advocating for and empowering persons with disabilities in exercising their rights; and
• Promoting excellence and fostering public awareness of the Commission’s mission and services.

This report provides an accounting of the Commission’s major activities and accomplishments for the period January 1, 2002 through December 31, 2003 in pursuit of these goals.
Maintaining Traditional Oversight Activities & Monitoring New Service Trends and Modalities

Case Activities

As the cornerstone of the mental hygiene system should be the individual it was designed and built to serve, it is only natural that responding to individuals’ complaints and concerns, investigating allegations and untoward events, and conducting program reviews form the heart of the Commission’s oversight functions. Such activities:

- Present opportunities to provide program operators, regulators and policy makers unbiased assessments of the quality of services and suggestions for improvement, assessments and suggestions rooted in the experiences of service consumers;
- Assure consumers, families, advocates and providers as well that concerns about care will receive a fair and objective review;
- Deter further abuse, neglect and unscrupulous practices through the reporting of findings and the referral of individuals and programs for appropriate administrative or legal sanctions; and
- Enable the Commission to keep tabs on the pulse of the system.

To achieve these ends, the Commission staffs a toll-free telephone line for people who have concerns about their care, or that of a loved one, or who are in need of assistance in navigating the system; reviews all allegations of abuse and deaths occurring within the system, conducting direct investigations into those where facility investigations seem lacking or the nature of the event warrants independent scrutiny; maintains investigative staff on call 24 hours-a-day, seven days-a-week; and conducts hundreds of announced and unannounced site visits and program reviews yearly.

In 2002 and 2003, the level of these activities reached heights unprecedented in the Commission’s history. Nearly 60,000 calls for assistance were received and responded to, over 25,000 reports of death and alleged abuse were reviewed, and over 2,000 direct investigations and program reviews were conducted.
Examples of Individual Case Activities: 2002 - 2003

A family member contacted the Commission on behalf of his brother who lived in a group home and frequently sustained bruises of unknown origin, raising suspicions of possible abuse. The Commission investigation revealed that the likely cause of the injuries was the individual’s difficult-to-control seizure disorder; however, information about the seizures and their treatment was not being adequately communicated between the group home and the individual’s private neurologist. At the Commission’s suggestion, better lines of communication were established enabling the neurologist to know more about the nature, frequency and duration of seizures, and residence staff to better implement the neurologist’s recommendations.

An investigation into a suicide on a psychiatric unit of a general hospital prompted revision in policies on supervision levels. The case involved a young man admitted to the hospital for suicidal ideation. Upon admission, the gentleman would give no information to assist staff in their assessment of his mental status or potential lethality. He was placed on a level of supervision requiring 15-minute checks, the facility’s standard level for those patients whose psychiatrists have not ordered a more intensive level of supervision. That night, in between 15-minute checks, the patient killed himself. In response to the Commission’s findings, the hospital now requires that patients, who do not provide sufficient information to allow a thorough mental status examination, be placed on a constant observation status, for their safety and that of others, until such an examination can be conducted.

Watching Over the Children

Watching over children receiving residential care in New York’s mental hygiene system is an everyday activity for Commission staff. Under Social Services Law, allegations reported to the State Central Register’s hotline for child abuse and maltreatment (1-800-342-3720) involving children in OMH or OMRDD residential facilities are routed to the Commission for

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<th>Individual Case Activities and Changes: 2000 - 2003</th>
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<td>Toll-Free Calls for Assistance</td>
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<td>Child Abuse Investigations</td>
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<td>Adult Abuse Reports Reviewed</td>
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<td>Adult Abuse Reports Assigned for Further Inquiry</td>
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<td>Death Reports Reviewed</td>
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<td>Death Reports Assigned for Further Inquiry</td>
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On call 24 hours-a-day, seven days-a-week, Commission investigators respond to these reports within 24 hours to assure the safety of the children involved and to determine whether the report is “indicated” – i.e., there is some credible evidence that abuse or maltreatment, as defined in social Services Law, occurred – or “unfounded.”

### Definitions of Child Abuse and Maltreatment

Social Services Law, Article 6, Title 6, defines an abused child in residential care as one whose custodian:
- inflicts or, with knowledge or deliberate indifference, allows to be inflicted any injury with causes death, serious or protracted disfigurement or protracted impairment of physical health, protracted impairment or loss of the function of any organ, or a serious emotional injury;
- creates a substantial risk of such injury; or
- commits, promotes, or knowingly permits the commission of a sex offense against such child.

A maltreated, or neglected, child in residential care is defined as one whose custodian:
- inflicts by act or omission physical injury, excluding minor injury, by other than accidental means;
- creates a substantial risk of physical injury, excluding minor injury, by other than accidental means;
- intentionally administers any prescription drug other than in substantial compliance with the physician’s prescription; or
- fails to comply with state regulations involving the care and treatment of children, resulting in foreseeable and serious emotional injury, or in physical injury, excluding minor injury.

In 2002 and 2003, the Commission conducted over 500 child abuse and maltreatment investigations. Most of the investigations (63%) pertained to allegations of physical abuse by staff, including the inappropriate use of, or excessive force during, restraint (6%). Lax supervision and staff negligence were the focus of 14% of the cases. Inappropriate sexual contact between staff and children or between children was alleged in 12% of the cases, with psychological abuse or other forms of mistreatment constituting the remaining 11% of cases investigated.

In 14% of the cases investigated, the care provided or the conduct of staff was found to be substandard, warranting recommendations and remedial action. In 6% of the cases, the level of harm, or risk of harm, to children was sufficient to warrant “indicating” the case under Social Services Law, which has serious implications for the custodian’s future work with children.
During the same period, pursuant to its authority under Mental Hygiene Law, the Commission conducted over 80 clinical or programmatic reviews in facilities serving children, with more than half resulting in recommendations for improved care and treatment.

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<th>Children’s Activities</th>
<th>2002 – 2003</th>
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<td>Total Cases</td>
<td>Indicated Cases</td>
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<td>OMH Operated Facilities</td>
<td>68</td>
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<tr>
<td>OMH Licensed Facilities</td>
<td>145</td>
</tr>
<tr>
<td>OMRDD Operated Facilities</td>
<td>46</td>
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<tr>
<td>OMRDD Licensed Facilities</td>
<td>256</td>
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</tbody>
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| **Clinical/Programmatic Reviews: N = 85 Cases** |             |
| Total Cases | Cases Resulting in Recommendations |
| OMH Operated Facilities | 3 | 2 |
| OMH Licensed Facilities | 37 | 20 |
| OMRDD Operated Facilities | 5 | 4 |
| OMRDD Licensed Facilities | 40 | 22 |

**Examples of Children’s Activities: 2002 - 2003**

In the course of child abuse investigations at a center serving individuals with developmental disabilities, the Commission became concerned over the center’s use and role of “substitute” workers. These per-diem staff were not provided the same level of training as other direct care staff, did not have access to individuals’ histories, and were not trained in clients’ individual service and/or behavior management plans. While such workers can appropriately be used for general supervision purposes, at this center, it was found that they were being assigned to provide one-to-one coverage for clients whose unique needs posed heightened supervision challenges. Unaware of these unique needs and not trained in appropriate interventions, the substitute staff were at a loss to protect the clients from self- or other-injurious behaviors. At the Commission’s request, the OMRDD provided the center guidance and technical assistance in developing policies on the training and proper use of substitute staff.

An investigation into the alleged sexual abuse of an adolescent girl by a staff member on an inpatient psychiatric unit yielded sufficient credible evidence to indicate the report and involve local police. It also resulted in revisions to the hospital’s policies on reporting allegations of abuse to external parties for appropriate administrative and criminal investigation.
Electroconvulsive Therapy for Individuals with Developmental Disabilities

Following its 2001 survey of Electroconvulsive Therapy (ECT) practices in State psychiatric centers, in 2002 the Commission was requested by the Assembly Committee on Mental Health to undertake a review of ECT use with people who have developmental disabilities. As no program operated or certified by OMRDD performs ECT, the Commission secured hospital-based diagnostic and procedure data from the Department of Health for the year 2000. These data indicated that 15 individuals with a diagnosis of mental retardation or developmental disability underwent ECT in eight hospitals statewide in 2000. Through site visits, record reviews and staff interviews, the Commission examined the diagnostic profiles of these individuals and the hospitals’ compliance with standards governing the use of the procedure.

It was found that all 15 individuals carried additional psychiatric diagnoses (major depressive disorders, schizophrenia, etc.) and, in one case, a medical diagnosis (neuroleptic malignant syndrome) for which ECT, according to scientific literature, has been proven to be an effective form of treatment. (A diagnosis of mental retardation or developmental disability alone is not sufficient reason for ECT.) It was also found that, for the most part, facilities had adequate policies and procedures in place for securing informed consent for the procedure, privileging physicians in the use of ECT, and the actual administration of the therapy. At a couple of hospitals, however, it was felt that procedures for securing informed consent could be strengthened. The facilities responded positively to the Commission’s suggestions on this issue.
Medical Care for People with Developmental Disabilities

A family member’s complaint, not about the quality of her loved one’s medical care, but about the need and cost for such, led to a programmatic and fiscal review of a not-for-profit agency providing outpatient medical services to over 10,000 people with developmental disabilities residing in 13 counties. The Commission’s review of the agency’s operations and a sample of claims for reimbursement submitted between 2000 and 2002 raised serious concerns about the medical necessity of some services rendered, reimbursement rate-setting methods which inflated revenues far above costs, and the inter-locking relationships among this agency and other providers who referred individuals for services. More fundamentally, the review raised the question of the appropriateness of agencies, such as this one, being certified to provide clinic services under the jurisdiction of the Department of Health (DOH), as opposed to being under the jurisdiction of OMRDD, which certifies clinic programs designed to provide cost-effective health and habilitative services specifically geared toward people with developmental disabilities.

The Commission referred its findings and recommendations to DOH, OMRDD and the Attorney General’s Office for further review and appropriate action. The matter was ultimately settled with the facility discontinuing the services questioned by the Commission and agreeing to repay $2.5 million inappropriately billed to Medicaid.

Monitoring New Service Trends and Modalities

Conducting case investigations and program reviews is one way to ensure that services are responsive to the needs of individuals. But, despite its value in improving care, it is also a reactive intervention. During the report period, the Commission continued to proactively promote quality services as an active participant in various committees and task forces working on new service trends and modalities, bringing to these forums and discussions information and experience gleaned from its retrospective reviews.

Among the groups the Commission worked with are the NYS Developmental Disabilities Planning Council, NYS Council on Children and Families, various committees for OMRDD’s residential and forensic initiatives, and the NYS Division of Probation and Community Alternatives’ Shared Services Committee.
Assisting People with Mental Disabilities
Outside the Traditional Mental Hygiene System

During its strategic planning process, the Commission was urged to devote attention to two groups of individuals with mental disabilities being served outside the “traditional” mental hygiene system: those in adult homes certified by the Department of Health (DOH); and those within the criminal justice system.

Monitoring Conditions in Adult Homes

During the report period, the Commission conducted 82 site visits to 56 adult homes serving over 8,500 people, most of whom have mental disabilities. Each home underwent a comprehensive review by a two-three person team which visited unannounced. During the two-day reviews, through observations, record reviews and staff, and resident interviews, teams assessed:

- Basic living conditions, including housekeeping, furnishings and maintenance;
- Fire, safety and food service/nutritional issues;
- Personal care and medication management;
- Resident activities; and
- Protection of resident rights.

Reports of findings, with recommendations or requests for plans of corrective action, were issued to the adult homes visited. Copies of the reports were also provided to DOH, which ensured that facilities responded to the Commission’s findings.

Nineteen (19) of these facilities, serving nearly 3,000 people, underwent at least one, and in several cases, many follow-up visits as the Commission monitored conditions and the implementation of corrective action plans.

Inside One Adult Home, And Out

During their two-day visit to a 30-bed adult home on Long Island, Commission staff found significantly deficient conditions. The home reeked of urine and body odor; some residents wore the same dirty clothes for both days and were poorly groomed; although there was ample food in storage, residents were served a peanut butter and jelly sandwich, two cookies and tea for dinner. While juice was on the menu, it was not served. Checking cupboards it was found that there were not enough glasses to serve everyone a cool beverage. Bedrooms, common areas and bathrooms were filthy and had broken furniture/appliances; most bathrooms lacked toilet paper, soap, and towels; some rooms lacked smoke detectors and the fire alarm system was not audible.
in all areas of the facility. A review of medication records revealed many medication errors; and the posted activity schedule, which announced the offering of only eight hours of activities during the week, was not being followed.

Following the Commission’s visit and report of findings, DOH cited the home for various violations and threatened civil penalties. Shortly thereafter, the operator announced plans to close the home. The Commission visited several more times to monitor conditions during the closure process until all the residents were relocated.

Recently, the Commission had the opportunity to visit one of the former residents who is now living in a clean and well-appointed community residence which is supervised by an obviously caring staff. He reported that he really enjoys his new home, where he is learning to cook, take his own medications and care for his everyday needs. He looks forward to living independently someday - a goal not envisioned in his prior placement.

**Adult Home Workgroup**

With DOH, the Office of Mental Health and the State Office for the Aging, the Commission provided staff support to a workgroup established by DOH Commissioner Antonia Novello, M.D., Dr.P.H., and charged with examining issues relating to adult homes and offering recommendations to improve care and the quality of life for adult home residents.

The workgroup included advocates and adult home residents, adult home operators and representatives of agencies providing health, mental health and other services to residents of adult homes.

As a result of the workgroup’s activities, in late 2002, DOH announced several initiatives to improve the lives of adult home residents which were reflected in the Executive Budget Proposal for fiscal year 2003-2004. These included:

- independent clinical, psychiatric and functional assessments of adult home residents to determine their needs and preferences;
- enhanced medication management systems;
- improved social and recreational services;
- increased advocacy and legal support to protect residents’ rights; and
- improved case management and coordination to assure that appropriate care and services are delivered.

**A Study on the Layering of Services**

The workgroup’s recommendations concerning improved case management and service coordination were supported in part by a report completed by the Commission in 2002: *Adult Homes Serving Residents with Mental Illness: A Study on Layering of Services.*
The study, which focused on the 11 largest adult homes in the greater New York City area serving over 2,600 residents, found that many residents received multiple layers of services from different service providers. These services were often costly, fragmented, and sometimes unnecessary. Also, they often appeared to be revenue-driven, rather than based on need.

While it is commonly claimed that the $28 per day in public funds expended to support a resident in adult homes is insufficient, the study showed that almost three and one-half times that amount is really being spent, but in a disjointed, patch-work fashion with little assurance that the needs of the residents are being met.

The Commission released the study to the workgroup and key state agencies, as they considered structural changes or alternatives to the adult home modality, with the fundamental question: Are there ways in which the funds currently being spent each year to support an adult home resident could be better utilized on his or her behalf?

Other Adult Home Studies

In 2003, the Commission commenced two studies pertaining to adult homes. The first focused on health needs and medical services provided to adult home residents. The second is a fiscal and programmatic review of adult homes with assisted living components. Findings will be described in a subsequent report.
Prior Adult Home Work Revisited

Prior Commission reviews in adult homes were revisited in 2002 and 2003 in the form of criminal, civil and administrative actions.

In 2002, the operators of Ocean House, a 125 bed adult home, were indicted by the Manhattan District Attorney’s Office. They were charged with Grand Larceny, First and Second Degree, Scheme to Defraud in the First Degree, multiple counts of Falsifying Business Records in the First Degree and Offering a False Instrument for Filing in the First Degree. The charges stemmed from financial transactions detailed in the Commission’s 2001 report: *Exploiting Not-for-Profit Care in an Adult Home: The Story Behind Ocean House Center, Inc.*

Also as a result of that report, DOH moved to recoup nearly $750,000 in improper Medicaid billings from entities serving Ocean House residents: $15,934 from Ocean House Transportation, Inc.; $261,930 from St. John’s Episcopal Hospital; $388,818 from First to Care, Inc.; and $68,281 from two physicians in the employ of St. John’s Episcopal Hospital.

A Certified Public Account (CPA) pled “no contest” to multiple charges of negligence in his duties as a CPA for the former HI-LI Manor Home for the Aged, the operator of which was sentenced to 30 months in prison for bank fraud and embezzlement following a Commission investigation. Charged by the State Education Department’s (SED) Office of Professional Discipline, the CPA agreed to a penalty of a one-year stayed suspension, a concurrent one-year probation and a fine of $2,500.

In 2003, another CPA surrendered his license after being charged with professional misconduct by the SED’s Office of Professional Discipline. This followed a Commission investigation into Bayview Manor Home for Adults.

Criminal Justice System Activities

Under state law, the Commission has no authority to oversee the criminal justice system. However, the Commission’s strategic planning process reinforced its sense of moral obligation to individuals with mental disabilities who interface with that system. As such, in 2001, the Commission met with state agencies involved in the criminal justice and mental hygiene fields to discuss ways in which the Commission might be of assistance in a shared mission: quality services for people with mental disabilities. The resulting dialogue led to partnerships with agencies on several projects.
Alternatives to Incarceration

In 2002, the Division of Probation and Correctional Alternatives (DPCA), under its Services for a Shared Population initiative, began awarding grants for model Alternatives-to-Incarceration programs specifically designed for individuals with serious mental illness. To ensure the success of these programs, DPCA requested assistance from other agencies and a committee, Services for a Shared Population: Defendants and Offenders with Mental Illness, was formed involving representatives from state and local government. The Commission was invited to serve on the committee.

By 2003, seven of these programs were in operation in various parts of the state; each was unique and served a distinct target population (children vs. adults, males vs. female, etc.). As such, it was felt that each had valuable stories to tell about “starting from scratch” and bringing mental health and correctional systems together. To facilitate this exchange of information, the Commission provided funding through the DPCA for an independent study of the programs, to identify factors that facilitate or inhibit the appropriate diversion of individuals with mental illness from incarceration. The study, *Closing the Gap: Clarifying the Parameters*, identifies elements that promote the success of programs delivering community forensic mental health services, as well as strategies to be used in implementing model programs in other jurisdictions of the state.

Additional information on this topic is available at [www.dpca.state.ny.us](http://www.dpca.state.ny.us) under Specialized Projects.

Mental Health Services in State Correctional Facilities

With the cooperation of the Department of Correctional Services (DOCS), the Commission conducted a review of mental health services in state correctional facilities. The retrospective review, which included site visits, record reviews and interviews with staff and inmates, followed 40 inmates who, in 2000 and 2001, had received inpatient psychiatric care at OMH’s Central New York Psychiatric Center and outpatient services offered by satellite clinics operated by the center in various prisons.

The review identified positive aspects of care, such as specialized treatment units and the expansion of treatment options for inmates. Opportunities for improvement, however, were noted in the areas of medication administration/management, strengthening treatment planning and treatment strategies, ensuring that mental health issues are consistently considered in DOCS’
disciplinary process, monitoring and treating inmates with mental health needs in disciplinary housing units, and maximizing the therapeutic value of other special units.

In late 2003, the Commission briefed OMH, DOCS and the Governor’s Office on its findings – findings which offered independent support and underscored the importance of initiatives they were planning on undertaking. DOCS adopted regulations addressing the mental health needs of inmates in the disciplinary process and the Executive Budget proposal for fiscal year 2004-2005 supported the development of additional and enhanced mental health services in prisons, including special treatment units.
The Commission’s efforts to improve lives and protect rights through case investigations and program, policy and fiscal reviews are complemented by the work of a network of programs administered by the Commission and designed to assist and empower people with disabilities in the exercise of their rights.

In 2002 and 2003, these programs were very successful in their aims.

**Surrogate Decision Making Committee Program**

Accessing appropriate medical care in a timely fashion is a fundamental need of all people. But for some it is difficult, particularly when their capacity to consent is compromised and they have no legally authorized surrogate willing or able to consent on their behalf. Assisting these individuals is the goal of the Surrogate Decision Making Committee (SDMC) program.

Historically, authorization for non-emergency medical care for people who lacked the capacity to consent for such, and had no legal guardian or surrogate decision maker to do so, had to be secured from the courts. This involved a protracted process which could delay needed medical attention for weeks, if not months in some cases. The SDMC program was created as an alternative to the courts. Individuals residing in facilities certified or licensed by OMH or OMRDD who require medical care, but lack the capacity to consent to or refuse treatment, can have their cases determined by an SDMC panel.

The four-member volunteer panels - consisting of an attorney, medical professional, family member and advocate - review documentary evidence, interview the individual, receive testimony from care providers and make three determinations:

- Does the individual have the capacity to make this decision for him/herself?
- If not, is there a legally authorized surrogate to make the decision on the person’s behalf? And,
- If not, is the proposed medical intervention in the person’s best interest?

On average, the panels’ determinations are issued within two weeks from the date of application for SDMC assistance. If requested, cases can be resolved on an expedited basis within a couple of days.
Initially started as a pilot program in several counties in 1986, the program was made permanent in 1990, and began county-by-county expansion during the late 1990s, becoming operational statewide in 2001. With over 1,300 volunteer panel members, the SDMC Program resolved 2,849 cases in 2002 and 2003, 67% more than the number of cases heard in the prior two years. The cases ranged from routine dental care under general anesthesia to complex surgical procedures.

SDMC in Action

A resident of a facility in Central New York was admitted to a hospital where his condition rapidly deteriorated and he was placed on a ventilator. On April 4th, hospital staff contacted the SDMC program with an urgent request for permission to treat. The patient required placement of a peripherally inserted central catheter (PICC line) and insertion of a feeding tube (PEG tube). SDMC staff educated hospital staff about the SDMC process, and the forms necessary to proceed with the case were received late in the afternoon of April 4th. SDMC staff contacted panelists and other interested parties, generated the necessary hearing documents and scheduled a hearing for April 5th. SDMC staff traveled to Syracuse on April 5th to provide administrative support during the hearing. Panelists visited with the patient on the ventilator unit before determining that the patient lacked the capacity to make his own decision regarding the proposed medical treatments. They took testimony and determined that no legally authorized surrogate was available or willing determination. The panel voted that the proposed major medical treatment was in the best interest of the patient and authorized the insertion of a PICC line and PEG tube. Less than one full day had passed from the time of the initial request from the hospital to the time the panel rendered a decision providing consent for the procedures.

The Citizens Budget Commission awarded the SDMC program an honorable mention in its 2002 Prize for Public Service Innovation stating that the program “has attained commendable results in providing timely, professionally-appropriate health care for the mentally disabled.”

Maintaining a Statewide Network of Advocacy Services

A woman in the North Country missed three mortgage payments while hospitalized and was at risk of losing her house. A man confined to a wheelchair could not attend village board meetings in Central New York because they were held on an inaccessible floor of a principal building. A person was denied access to an independent apartment in a subsidized housing program in the Hudson Region because he resided in an adult home. A 50-year-old woman who had recently become blind needed independent skills training, but her request for services was denied. And in the downstate area, a woman on a psychiatric ward was strip searched, as were
all the other female patients, when it was found that she had a glass bottle of perfume which staff considered contraband.

Miles apart and facing different challenges and problems in their lives, these five individuals had one thing in common in 2002 and 2003: the assistance of a statewide network of agencies administered and funded by the Commission. These agencies provide administrative and legal advocacy for individuals with disabilities. Through their intervention, the woman’s mortgage difficulties were resolved and she kept her house; the village changed the location of its board meetings; the subsidized housing program amended its admission standards; the visually impaired woman received her training; the psychiatric facility replaced search policies with ones more respectful and protective of individuals’ privacy and rights; and over 100,000 other people with disabilities received assistance in protecting their rights.

Under federal and state statutes, the Commission administers the following advocacy programs:

- The Protection and Advocacy for Persons with Developmental Disabilities (PADD) program and the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program which, as their names imply, respectively serve people with developmental disabilities and mental illness;
- The Client Assistance Program (CAP), which assists individuals with a wide variety of disabilities secure training and services leading to employment and independent living;
- The Protection and Advocacy for Individual Rights (PAIR) program, which serves people with disabilities not covered by the federally authorized PADD, PAIMI or CAP programs;
- The Protection and Advocacy for Assistive Technology program, which aids individuals with disabilities who require assistive devices (e.g., wheelchairs, special communication equipment, etc.) in their every day lives;
- The Protection and Advocacy for Beneficiaries of Social Security (PABSS) program, which provides advocacy services to assist recipients of Social Security Disability
Insurance (SSDI) and Supplemental Security Income (SSI) obtain, maintain or regain employment;

- The Protection and Advocacy for Persons with Traumatic Brain Injury program which provides legal and non-legal advocacy services for individuals with traumatic brain injury; and

- The Adult Home Advocacy program, established by New York State law in 1995, to provide advocacy services on behalf of people with mental disabilities residing in adult homes.

The Commission contracts with not-for-profit agencies in various regions of the state to carry out advocacy activities consistent with the federal and state mandates. This contractual/regional model allows for timely, efficient and locally-responsive advocacy services.

In 2002 and 2003, the Commission’s network of advocacy agencies provided information and referral services - i.e., brief written or oral information about rights, services and resources - to over 25,000 people. Nearly 9,000 individuals received direct, one-on-one advocacy services through the network. These services included counseling and advice, mediation and negotiation services, assistance in administrative appeals and representation in litigation.

Additionally, 100,000 people were represented in the network’s systemic advocacy efforts, which included non-litigation advocacy, court-ordered monitoring and class action litigation.

**Examples of Group & Systemic Advocacy Efforts**

Disability Advocates, Inc. partnered with other rights organizations and a private law firm to bring suit in federal court alleging that NYS Office of Mental Health and NYS Department of Correctional Services have failed to respond to the serious mental health needs of state prisoners with mental illness.

Statewide regulations and policies concerning the availability of motorized wheelchairs in nursing homes and the provision of appropriate access and reasonable accommodations for homeless persons with disabilities in the Temporary Housing Assistance Program were favorably revised as a result of settlements reached in litigation brought by Nassau/Suffolk Law Services Committee, Inc.
MFY Legal Services, Inc., joined by Disability Advocates, Inc. and a private firm, represented 17 residents of an adult home who were subject to unnecessary and invasive surgical procedures, winning $7.5 million on the individuals’ behalf in a settlement with most of the parties.

New York Lawyers for the Public Interest, Inc. reached a settlement in the Brad H. V. City of New York lawsuit compelling New York City to provide discharge planning services for inmates with mental illness within the city’s jail system.

In the Hudson Valley, Disability Advocates, Inc. advocated for and continued to monitor transportation companies’ services for visually impaired persons and their compliance with the US Department of Transportation’s ADA regulations.

Issues with which the advocacy network assists people, on either an individual or group basis, include: architectural accessibility, assistive technology, education, employment, entitlements, guardianship/conservatorship, health care, housing, transportation and the exercise of any civil rights. A complete listing of agencies within the Commission’s advocacy network is in Appendix C.

**Knowledge is Power**

Empowering people to protect and exercise their rights by providing them with needed information through education and training is an everyday activity for the Commission and its advocacy network. In 2002 and 2003, the Commission and its contract agencies provided training to nearly 31,000 consumers, advocates, family members and interested parties on matters relating to disability services and rights. Topics included:

- Special Education and Educational Advocacy
- Transition from School to Work and Adult Life
- Guardianship and Future Planning
- Self-Advocacy
- Mediation
- SSI/SSDI Benefits
- Assisted Outpatient Treatment (Kendra’s Law)
- Americans with Disabilities Act
- Ticket to Work and Work Incentives Improvement Act
- Age Discrimination in Employment Act

In each year, the Commission also offered its Disabilities Awareness Program to thousands of school children from around the state. The program is designed to dispel myths
about disabilities and people who live with disabilities, through classroom lectures and essay and art contests. In June of 2002 and 2003, award luncheons were held at the Executive Mansion to celebrate each academic year’s contest winners. Their works were also presented in the annual edition of *Disabilities Awareness*, a newsletter supported by the Commission and written and edited by high school students with and without disabilities, for students with and without disabilities. As its name implies, the newsletter is intended to raise awareness about disability issues.

With the New York State Bar Association Committee on Issues Affecting People with Disabilities, the Commission co-produced three new installments of the award winning video series *Disability and the Law*, shown on local cable television stations throughout New York. The first, *Leveling the Playing Field*, explores the importance and growth of sports and recreational activities for people with disabilities and features important legal actions involving athletes with disabilities and reasonable accommodations. *Supplemental Needs Trusts* explains the basics in establishing supplemental needs trusts, which allows a family or friend to set aside funds for a loved one with disabilities to meet everyday expenses without jeopardizing governmental financial supports. In *Parent to Parent: Negotiating the Special Education Years* experienced parents offer practical advice to newer parents of children with disabilities who are entering school and encountering the dizzying array of federal and state laws.

A catalogue of all the videos in the *Disability and the Law* series is posted on the Commission’s website. Videos can be purchased at a nominal fee.
**Promoting Excellence**

&

**Fostering Awareness of Commission Services**

The Commission has been fortunate to have recruited a highly skilled workforce, most of whose members have spent many years working in related fields before joining the Commission. In the course of their statewide work with the Commission, these men and women encounter and examine situations and practices, gaining a wealth of information that few administrators, managers, clinicians or staff of any one agency have the opportunity to glean.

Often, given the nature of the Commission’s work, these situations and practices are problematic - few people call the Commission to register a compliment about a program. But in the resolution of problems, better or best practices are found from which others can learn. And, sometimes in their journeys, Commission staff find excellent programs worthy of replication elsewhere.

As such, in its strategic planning process, the Commission made sharing information, from which others could learn in their quest for quality and excellence, a priority. As the information shared arises from its everyday work, the process of sharing fosters awareness of the Commission’s services so that others may avail themselves of such when needed.

**Case Studies**

During the report period, the Commission published four case studies. The studies, intended for use as quality assurance and training tools, are part of an ongoing series of case studies, drawn from Commission investigations, entitled *Could This Happen in Your Program?*

The studies published in 2002 and 2003 addressed issues relating to: Diabetes Management, Physical Restraint and Interventions, Bathing Safety, and Vacation Planning. These, and all the studies in the series, are available on the Commission’s website.

**Newsletter**

Like most agencies, the Commission publishes a newsletter. Four issues of *Quality of Care* were published in 2002 and 2003. In addition to providing updates on Commission activities and news germane to the field, the newsletters featured articles aimed at promoting quality and excellence in serving people with disabilities. Among these articles were:
• **Selecting an Independent CPA** which described the important role played by independent certified public accountants and offered advice for not-for-profit agencies on the selection process.

• **The Ethical Way** which offered advice for not-for-profit agencies on developing and implementing an organizational code of ethics.

• **Parents, Please Heed!** which suggested tips on first steps in planning for future residential placement of a child.

• **Living with Spina Bifida** which shared the author’s experiences on how he and others with disabilities want to be perceived and treated.

• **Inclusion Does Work!** which described scenes from a local school district.

Recent issues of the Commission’s newsletters are available on the Commission’s website.

### Speakers Bureau

The Speakers Bureau was created as a vehicle for interested parties to gain the Commission’s perspective on certain topics or issues ranging from sexuality to end-of-life decision making. A complete list of topics is presented in Appendix D. As part of this program, in 2002 and 2003, Commission staff made over 90 presentations to agencies across the state. Agencies interested in this free service can schedule a Commission presentation by contacting Bill Combes at 518-388-2887 or Bill.Combes@cqcapd.state.ny.us.

### NYSDEAL

During the report period, Commission staff offered their advice and assistance to the OMRDD in its development of a New York State Distance Education and Learning project (NYSDEAL). NYSDEAL provides on-line, standardized training for employees within the developmental disabilities service system. The first course, **Home and Community-Based Waiver Services**, will be followed by others on topics such as medication administration, and incident management and investigation which the Commission helped develop.
Looking Ahead

Nearing the end of its three-year strategic plan, in Fall 2003, the Commission re-engaged in a planning process to guide its activities over the next three years: 2004 through 2006.

As in 2000, partners in the mission of improving lives and protecting rights of people with disabilities were invited to share their thoughts on the Commission’s role in this shared endeavor and issues the Commission should examine or activities it should undertake in the coming years. The Commission met with and listened to representatives from the Governor’s Office, Legislature, Division of the Budget and other state agencies. Similar meetings were held with service recipients, family members, advocates and service providers.

Participants re-affirmed the Commission’s four major goals: maintaining traditional oversight; assisting people outside the traditional mental hygiene system; advocating for and empowering people with disabilities; and promoting excellence and fostering awareness of Commission services. The Commission was also encouraged to continue its work in adult homes and the criminal justice system.

Based on the dialogue, the Commission was able to identify a number of new issues or projects that would receive the Commission’s attention in the coming years. These included:

- Devoting increased attention to the operations of the Office of Alcoholism and Substance Abuse Services;
- Conducting programmatic and fiscal reviews of the continuing day treatment program and the Medicaid case management program;
- Exploring issues relating to children’s services; and
- Examining the feasibility of expanding the SDMC program and the Commission’s advocacy programs;

The Commission looks forward to reporting on its activities in these areas in the future.
Appendices
Appendix A

Mental Hygiene Medical Review Board Members

Michael Baden, M.D
Harvey Bluestone, M.D.
Jerry Broman, M.D.
Peter Fisher, M.D.
Irwin Hassenfeld, M.D.
Arnold Merriam, M.D.
Saul Moroff, M.D.
Moritza Molina, M.D.
Sophia Socaris, M.D.
H. David Stein, M.D.
Dan Thompso, M.D.
Edward Timm, Pharm. D.
Heidi Van Bellingham, M.D.

Advisory Council Members

Dale R. Angstadt
James Bopp
Grace E. Clench
Mary H. Derby
Judy Eisman
Shirley Flowers
Richard P. Johnson
Joan E. Klink
Deborah S. Lee
Jeffry Luria, Ph.D.
Anna Marie Lusins
E. Regis Obijiski
Milo I. Tomanovich, Esq.
Elizabeth Wickerman
Appendix B: Surrogate Decision-Making Panel Members

Nan Abbott  Marilyn Baxter
Margaret Abbott  Patricia Bayack
Judy Abbott  Annabel Bazante
Neva Ahboush  Bruce Becker
H. James Abdella  Daria Becker
Sarah Abeles  Suzanne Beddoe
Lenore Beth Abend  Lea Bedore
Karen Alterman  Maria DeMarco Begley
Ezra Aboudi  Joseph Belevich
Sharon Aboulafia Oken  Martin Bekowski
Mary Abraham  Rosemary Bell
Theo Abraham  Carl Bellavia
Joseph Abraham  Nancy Bellinger
Penny Abulencia  Marian Bellucci
Janice Acar  Stephen Bellus
Elizabeth Ackerman  Horace Belton
Patricia Adams  Amanda Bement
Cynthia Stewart Adamo  Howard Benavitch
Carl Adamec  Carmen Benitez
Stephen Acquario  Ginger Benifier
Elizabeth Ackerman  Lisa Bennice
Janice Acar  Mary Bennis
Patricia Adams  John Bensen
Cynthia Stewart Adamo  Charles Benton
Carl Adamec  Cynthia Berger
Stephen Acquario  Diane Berger
Elizabeth Ackerman  Lynn Berger
Janice Acar  Sam Berger
Patricia Adams  Victor Berger
Cynthia Stewart Adamo  Vivian Berger
Carl Adamec  Deborah Berger
Janice Adar  Sara Berger
Anthony Adorante  Marc Berk
Raymond Baker  Allan Berkowitz
Marie Bakharia-Ifill  Sheila Berman
Abiola Agboola  Eric Berman
Laurel Baker  Elizabeth Berman
Raymond Baker  Barry Berman
Betty Alpert  Maria Bernal-Rabasco
Leah Almeleh  Conrado Bernardo
Norman Alterman  Anthony Bemini
Robert Alpert  Diane Bernstein
Ruth Alterman  Jeff Bernstein
Karen Alterman  Patrick Berginan
Arthur Alterman  Robert Beshay
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Karen Alterman  Maria Bernal-Rabasco
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## Appendix C: Advocacy Services Network

### Service Codes

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<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>AH</td>
<td>Adult Home Advocacy</td>
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<tr>
<td>AT</td>
<td>Protection &amp; Advocacy for Assistive Technology</td>
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<tr>
<td>BSS</td>
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<tr>
<td>CAP</td>
<td>Client Assistance Program</td>
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<tr>
<td>DD</td>
<td>Protection &amp; Advocacy for Individuals with Developmental Disabilities</td>
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### REGION/AGENCY

#### Statewide

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<thead>
<tr>
<th>Agency</th>
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<tbody>
<tr>
<td>New York State Commission on Quality of Care Advocacy Services Bureau</td>
<td>401 State Street, Schenectady, NY 12305</td>
<td>Statewide coordination of all contract offices for AH, AT, BSS, CAP, DD, IR, MI and TBI</td>
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<tr>
<td>Legal Services of Central New York, Inc.</td>
<td>The Empire Building, 472 Salina Street, Suite 300, Syracuse, NY 13202</td>
<td>Statewide TBI</td>
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<tr>
<td>Neighborhood Legal Services, Inc.</td>
<td>295 Main Street, Ellicott Square Building, Room 495, Buffalo, NY 14203</td>
<td>Statewide AT</td>
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#### New York City

<table>
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<th>Agency</th>
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<tr>
<td>Brooklyn Center for Independence of the Disabled, Inc.</td>
<td>2044 Ocean Avenue, Suite B-3, Brooklyn, NY 11230</td>
<td>CAP</td>
</tr>
<tr>
<td>Center for Independence of the Disabled in New York, Inc.</td>
<td>841 Broadway, Suite 205, New York, NY 10003</td>
<td>CAP</td>
</tr>
<tr>
<td>MFY Legal Services, Inc.</td>
<td>Mental Health Law Project, 299 Broadway, 4th Fl., New York, NY 10007</td>
<td>AH</td>
</tr>
<tr>
<td>New York Lawyers for the Public Interest</td>
<td>151 West 30th Street, 11th Floor, New York, NY 10001-4007</td>
<td>BBS, CAP, DD, IR and MI</td>
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## Long Island Region

<table>
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<tr>
<th>Organization</th>
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<tr>
<td>Long Island Advocacy Center, Inc.</td>
<td>Herricks Community Center, 999 Herricks Road</td>
<td>CAP</td>
</tr>
<tr>
<td></td>
<td>New Hyde Park, NY 11040</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(516) 248-2222 (516) 877-2627 (TTY)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Services: DD</td>
<td></td>
</tr>
<tr>
<td>Long Island Advocates, Inc.</td>
<td>4250 Hempstead Turnpike, East Building, Suite 19</td>
<td></td>
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<tr>
<td></td>
<td>Bethpage, NY 11714</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(516) 735-5466</td>
<td></td>
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<td></td>
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<td></td>
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<tr>
<td>Nassau/Suffolk Law Services Committee, Inc.</td>
<td>1757 Veterans Highway, Suite 50</td>
<td></td>
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<tr>
<td></td>
<td>Islandia, NY 11749</td>
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<tr>
<td></td>
<td>(631) 232-2400</td>
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<tr>
<td></td>
<td>Services: AH and IR</td>
<td></td>
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<tr>
<td>Touro College</td>
<td>Jacob J. Fuchsberg Law Center</td>
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<tr>
<td></td>
<td>300 Nassau Road</td>
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<tr>
<td></td>
<td>Huntington, NY 11743</td>
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<tr>
<td></td>
<td>(516) 421-2244 Ext. 331</td>
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<td>Services: MI</td>
<td></td>
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## Hudson River Region

<table>
<thead>
<tr>
<th>Organization</th>
<th>Address</th>
<th>Services</th>
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<tbody>
<tr>
<td>Capital District Center for Independence, Inc.</td>
<td>855 Central Avenue, Suite 110</td>
<td>CAP</td>
</tr>
<tr>
<td></td>
<td>Albany, NY 12206</td>
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<tr>
<td></td>
<td>(518) 459-6422 (Voice and TTY)</td>
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<tr>
<td></td>
<td>Services: DD</td>
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<tr>
<td>Disabilities Law Clinic at Albany Law School</td>
<td>80 New Scotland Avenue</td>
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<tr>
<td></td>
<td>Albany, NY 12208</td>
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<tr>
<td></td>
<td>(518) 445-2328</td>
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<tr>
<td>Disability Advocates, Inc.</td>
<td>5 Clinton Square</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Albany, NY 12207</td>
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<tr>
<td></td>
<td>(518) 432-7861</td>
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<tr>
<td>Legal Services of the Hudson Valley</td>
<td>4 Cromwell Place</td>
<td></td>
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<tr>
<td></td>
<td>White Plains, NY 10601</td>
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<td></td>
<td>(914) 949-1305</td>
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<tr>
<td></td>
<td>Services: DD and IR</td>
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<tr>
<td>Westchester Independent Living Center, Inc.</td>
<td>200 Hamilton Avenue</td>
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<td></td>
<td>White Plains, NY 10601</td>
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<td></td>
<td>(914) 682-3926 (914) 682-0926 (TTY)</td>
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<td>Services: CAP</td>
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## North Country, Central & Southern Tier Region

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<tr>
<th>Organization</th>
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<tbody>
<tr>
<td>Legal Aid Society of Northeastern New York, Inc.</td>
<td>100 Court Street</td>
<td>DD and MI</td>
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<tr>
<td></td>
<td>Plattsburgh, NY 12901</td>
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<tr>
<td></td>
<td>(518) 563-4022 1-800-722-7380</td>
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</tr>
<tr>
<td>Legal Services of Central New York, Inc.</td>
<td>The Empire Building</td>
<td></td>
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<tr>
<td></td>
<td>472 Salina Street, Suite 300</td>
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<tr>
<td></td>
<td>Syracuse, NY 13202</td>
<td></td>
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<tr>
<td></td>
<td>(315) 475-3127 1-866-475-9967</td>
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</tr>
<tr>
<td></td>
<td>Services: BSS, DD, IR, MI and TBI</td>
<td></td>
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<tr>
<td>Resource Center for Independent Living</td>
<td>409 Columbia Street</td>
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<td></td>
<td>Utica, NY 13502</td>
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<tr>
<td></td>
<td>(315) 797-4642 (315) 797-5837 (TTY)</td>
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<td>Services: CAP</td>
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### Western Region

| **Neighborhood Legal Services, Inc.**  
295 Main Street  
Ellicott Square Building, Room 495  
Buffalo, NY 14203  
(716) 847-0650  
(718) 847-1322 (TTY)  
**Services:** BSS, CAP, DD, IR, MI and TBI  
Rochester Center for Independent Living, Inc.  
1641 East Avenue  
Rochester, NY 14610-1616  
(585) 442-6470 (Voice and TTY)  
**Services:** CAP | **Western New York Advocacy for the Developmentally Disabled, Inc.**  
590 South Avenue  
Rochester, NY 14620  
(585) 546-1700  
**Services:** DD |
Appendix D: Speakers Bureau Topics

Legal Issues:

Rights of Minors in Decision-Making: The speaker will address the issue of individuals with developmental or other disabilities participating in decisions which may ultimately change their lives. Individuals below the age of 18 are still considered minors and under the decision-making capacity of their parents unless emancipated. Procedures are available to review questions regarding protection from mistreatment.

Ethical Issues in Representing People with Disabilities: The discussion centers on capacity to give consent and balancing best interests with personal autonomy.

General Rights of People with Disabilities: The attorney presenter discusses the rights of individuals with disabilities under the various civil rights laws and reviews the general rights of all citizens.

Legislative Process: The main focus of this presentation is how a bill gets passed and how the State Legislature conducts its business.

Americans with Disabilities Act & Section 504 of the Rehabilitation Act: Both pieces of legislation provide for the civil rights of individuals with disabilities and require “reasonable accommodations” in employment and public facilities. The presenter will provide an overview of what a person with a disability should expect for “reasonable accommodation” and the obligations on the part of the public to provide them.

Human Rights Law & Public Policy: This topic concentrates on New York State Laws which establish rights for persons with developmental disabilities and how public policy either incorporates those rights or makes changes to accommodate them.

Legal Ramifications of Child Abuse Reporting: The attorney presenter discusses the mandates for professionals to make a child abuse report and the importance of avoiding frivolous claims.

Commission on Quality of Care and Advocacy for Persons with Disabilities’ Overview: The Commission has been an oversight agency over the Office of Mental Retardation and Developmental Disabilities and the Office of Mental Health since 1978. The presenter will discuss the various powers and responsibilities of the Commission along with many of the lessons learned over the past twenty-four years.

Investigations:

Child Abuse in Facilities: The Commission investigator will discuss the appropriate ways to conduct an investigation, including information gleaned from Commission institutional abuse cases which are reported to the Child Abuse Registry.
Adult Abuse & Death Investigations: Similar to the presentation on child abuse investigation, the presenter will discuss proper abuse investigation techniques in addition to various Commission findings.

Sexuality & Consent: Ways to determine capacity to give consent utilizing the clinical team is the main focus of the presentation. Also, there is a discussion regarding the criminal issues which arise when one person is unable to give consent.

Restraint & Seclusion: There will be a discussion of the Commission findings which were given in evidence to Congress with regard to a need for monitoring of these practices in facilities.

Could This Happen in Your Facility: The Commission has published a very instructive compendium of lessons learned from its investigations. Yes, such problems could happen in your facility and it is important to learn from the mistakes of others.

Less Adversarial Advocacy: The speaker addresses ways to be less confrontational and more conciliatory, but assertive, when advocating on behalf of individuals with disabilities.

Abuse/Neglect: What is It and How to Stop It: The presenter will draw upon her twenty years of experience at the Commission to discuss ways of preventing abuse in facilities through staff development techniques and internal monitoring systems.

Fiscal:

Board of Directors Training: The speaker concentrates on the fiduciary responsibilities of Board members. Members must know what is happening in an agency, beyond merely attending quarterly meetings.

Current Legislation on Intermediate Sanctions: The speaker will discuss the sanctions which can be levied against agencies which do not have strict accounting of their funds.

Diversion of Funds: The speaker will discuss recent Commission investigation findings with regard to executive directors siphoning funds from non-profit agencies.

Personal Allowance Fund Issues: It is extremely important that agencies have discrete accounts for the personal allowance portion of the individual's Supplemental Security Income (SSI). The speaker will discuss the best way to insure financial protection.

Not-For-Profit Pitfalls: Could This Happen to You? Similar to the care and treatment pitfalls from “Could This Happen......,” there are many lessons learned with regard to accounting pitfalls which have befallen non-profit agencies.
Life Planning:

Advance Directives: The attorney presenter will cover the essential elements of a living will, health care proxy, and, power of attorney, particularly with regard to judging the individual’s capacity to sign such documents.

End of Life Decisions: Who has the authority to make decisions on behalf of an individual with developmental disabilities with regard to the termination of life support? The attorney presenter will help provide the answer.

Guardianship: Why & How To: The discussion will center on the “pros” and “cons” of an Article 17A guardianship with a review of the petition process. Subsequent “hands on” training with all of the necessary forms for filing a 17A petition may be scheduled as well.