Commission on Quality of Care

and Advocacy for Persons with Disabilities

2008 Annual Report

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EXECUTIVE SUMMARY

The Commission on Quality of Care and Advocacy for Persons with Disabilities (the Commission) is charged with protecting and improving the quality of life for New Yorkers with disabilities. The Commission provides independent oversight of the quality and cost-effectiveness of services provided by mental hygiene programs in New York State and is also designated by the Governor to serve as the federally mandated "Protection and Advocacy" agency for New York State. This ***2008 Annual Report*** describes the Commission's activities in each of these critical mission areas.

During 2008, the Commission responded to over 43,000 requests for assistance, screened or reviewed over 12,000 allegations of abuse or deaths reported by mental hygiene facilities and conducted over 1,100 program reviews and independent investigations into those allegations and deaths.

Additional highlights included:

- Completed 363 residential child abuse investigations, a 12% increase from 2007. The overall rate of indication for child abuse investigations was 14%.
- Commission staff trained 6,700 individuals on issues of concern to people with disabilities, including the Americans with Disabilities Act; accessibility; special education; assistive technology and disability; and diversity awareness.
- The Commission's Technology-Related Assistance for Individuals with Disabilities (TRAID) program made over 10,000 loans of adaptive equipment and saved over half a million dollars through recycling of assistive technology devices.
- As the State's protection and advocacy agency, the Commission contracted with over 30 not-for-profit community-based agencies to serve approximately 44,000 people by providing information and referral services, training, direct representation in legal and administrative matters, and systemic advocacy, including class action litigation.

In 2008, the Commission assumed new or expanded responsibilities under State law. These responsibilities are:

- Oversight of the quality of mental health care provided to inmates with serious mental illness in New York State prisons.
- Convening and supporting the Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-blind or Hard of Hearing to promote the availability of a comprehensive service system for this constituency.
- Authorizing Surrogate Decision Making Committee (SDMC) panels to make a decision to withhold or withdraw life-sustaining treatment for persons with mental retardation or developmental disabilities if no guardian or authorized family member is available.

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OVERVIEW OF CASE ACTIVITIES

In 2008, the Commission responded to over 43,000 requests for assistance, screened or reviewed over 12,000 allegations of abuse or deaths reported by mental hygiene facilities, and conducted over 1,100 program reviews and independent investigations into those allegations and deaths.

The Commission screens all allegations of abuse and deaths of people receiving mental hygiene services and conducts direct investigations when the nature of the event warrants independent scrutiny. Investigative staff conduct hundreds of announced and unannounced site visits and program reviews each year. The Commission is assisted in its clinical investigations by the Mental Hygiene Medical Review Board (MHMRB), a panel of volunteer medical professionals appointed by the Governor.[1]

The Commission staffs a toll-free telephone line for people who have concerns about their care, or that of a family member or friend, or who have questions or are in need of assistance in navigating the system.

Requests for Assistance through Toll Free Line	43,679
Allegations of Adult Abuse Screened by the Commission for Further Action	9,232
Adult Abuse Reviews*	263
Death Reports Screened	2,745
Death Reports Assigned for Further Review or Investigation	199
Child Abuse Investigations (including Non-State Central Register Allegations)*	437
Care and Treatment Reviews for Children and Adults	181

*details on adult and children's case activities follow in the next sections

[1] Under the State Mental Hygiene Law, the MHMRB consists of up to 15 voluntary and unsalaried physicians (including specialists in forensic pathology, psychiatry, surgery, and internal medicine) appointed by the Governor. The MHMRB identifies problems in the care provided to individuals and makes recommendations for improving medical and psychiatric care services in facilities.

Improving Care in Hospital Psychiatric Units

During 2008, the following improvements in patient care in hospitals in New York State occurred as a result of Commission investigations and reviews:

- A protocol was implemented with the New York City Police Department to ensure that hospital staff are aware of court hearings and can accompany a patient when necessary.
- Training was improved for physicians and residents on discharge planning and documentation.
- Policies and procedures were implemented to ensure family notification with consent when a person is evaluated in a Comprehensive Psychiatric Emergency Program (CPEP).
- Health screening and patient supervision in a CPEP were improved.
- A new suicide assessment policy was implemented that requires staff to help reduce patient access to any lethal means of self-harm post-discharge by working with the patient and family to identify and limit access to those means.

ADULT ABUSE INVESTIGATIONS

The NYS Mental Hygiene Law requires that facilities operated or licensed by the Office of Mental Health (OMH) and the Office of Mental Retardation and Developmental Disabilities (OMRDD) report all allegations of abuse or mistreatment to the Commission to ensure effective investigation of complaints of patients, residents and employees of mental hygiene facilities.

Adult Abuse Investigations

Commission staff screen each allegation of abuse or mistreatment reported and make a determination on how to handle the matter. The reporting facility must investigate each allegation in accordance with the requirements of Part 524 (OMH) or Part 624 (OMRDD) of Volume 14 of the New York Code of Rules and Regulations. In addition, OMH and OMRDD central offices may also conduct investigations into allegations. Depending upon the nature of the allegation, the Commission, as the oversight entity, may review the quality of the facility investigation and seek corrective actions or re-investigation by the facility. In some cases, the Commission may choose to complete an independent on-site care and treatment review when:

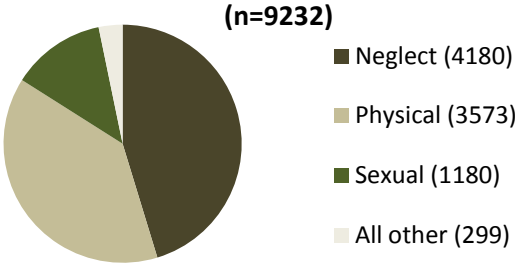
- severe abuse is alleged;
- the Commission has concerns about the quality of care at the facility in question;
- the allegation raises systemic concerns;
- the facility review of the incident is inadequate; or
- further review is requested by the individual alleged to have been abused or mistreated, by their family or by another concerned party.

In 2008, the Commission screened for further action 9,232 allegations of adult abuse or mistreatment of individuals in the OMH and OMRDD systems. The Commission conducted reviews into 263 of these allegations. A breakdown by agency auspice is presented in the following chart.

Adult Abuse Allegations from OMH and OMRDD Facilities Screened for Further Action 2008 (n=9232)

Adults 2008	Allegations Screened	CQCAPD Reviews
OMRDD - Licensed	6442	143
OMRDD - State Operated	2134	86
OMH - Licensed	248	17
OMH - State Operated	408	17
Totals	9232	263

Type of Adult Abuse Allegations Screened for Further Action from OMRDD & OMH Facilities 2008 (n=9232)



Neglect, physical abuse and sexual abuse were the most frequent types of adult abuse allegations, and constituted 97% of OMRDD and 98% of OMH allegations screened for further action.

Staff-to-individual abuse was alleged in 74% of adult abuse allegations from OMRDD facilities and in 85% of the allegations from OMH facilities.

Adult Care and Treatment Reviews

Care and Treatment Reviews are often commenced in response to individual requests or complaints, or are initiated by Commission investigators who have identified concerns regarding a particular individual in the course of another investigation or review at a facility. Care and Treatment Reviews address a variety of issues that affect the rights, safety or care of a particular individual, which include, but are not limited to, medication management, access to food and clothing, agency environmental concerns, inappropriate discharge and adequacy of medical care.

Adult Care and Treatment Reviews for OMH and OMRDD Facilities 2008 (n=141)

	Adult Care and Treatment Reviews
OMH - Licensed	49
OMH - State Operated	23
OMRDD - Licensed	46
OMRDD - State Operated	23
Total	141

The chart above lists reviews undertaken regarding the care and treatment of individuals residing in OMH or OMRDD systems residential care facilities.

Prison Mental Health Oversight

Chapter 1 of the Laws of 2008 charged the Commission with oversight responsibility for the quality of mental health care provided to inmates with serious mental illness in the New York State prison system. During the fall of 2008, Commission staff toured 16 maximum security facilities with staff from the New York State Department of Corrections and OMH.

Commission staff also met with the NYS Commission of Correction, former inmates, family members of inmates and other advocacy organizations to solicit recommendations for the role the Commission should play in improving the quality of mental health services provided in the New York State prison system. In 2009, the Commission will begin conducting systemic reviews of mental health services in prisons, starting with a review of Residential Crisis Treatment Programs.

DEATH INVESTIGATIONS

Deaths Reported to the Commission from Mental Hygiene Facilities (2008)

	Deaths
Total	2745
CQCAPD Investigations	105
CQCAPD Reviews	94

The Commission is charged with reviewing all deaths and, where appropriate, conducting investigations of unusual or unnatural deaths of individuals in State-operated or licensed OMH, OMRDD, and Office of Alcoholism and Substance Abuse Services (OASAS) facilities. Such facilities are required to report deaths of all individuals receiving services to the Commission. Adult homes and residences for adults licensed by the State Department of Health also are required to report the deaths of individuals receiving mental hygiene services to the Commission.

Commission staff nurses screen death reports and determine whether or not further review or investigation by the Commission is warranted. In such cases the Commission will either review the facility investigation or conduct an on-site investigation. The Commission may conduct an on-site investigation when:

- an individual commits suicide, either while an inpatient, or on authorized leave, or unauthorized leave, or within one week of discharge from a facility operated or licensed by OMH or OMRDD;
- an individual commits suicide within 72 hours of presentation at a Comprehensive Psychiatric Emergency Program (CPEP) or Emergency Room (ER);
- there is an allegation of abuse involving the circumstances of death:
- a death occurs within several days of restraint or seclusion;
- a death occurs within several days of an altercation with a peer; or
- there is an inquiry with expressed concern about care from an outside party.

In cases where more extensive medical or clinical expertise may be of assistance, the Commission will consult with its Mental Hygiene Medical Review Board. If corrective action is recommended, the case will remain open pending an acceptable response from the facility.

CHILDREN'S OVERSIGHT, INVESTIGATIONS & ADVOCACY

State Central Register (SCR) Investigations

Allegations of child abuse reported to the State Central Register's hotline involving children in OMH, OMRDD and OASAS operated or licensed residential facilities are required, under the New York State Mental Hygiene and Social Services Laws, to be investigated by the Commission. Commission investigators respond to these reports within 24 hours to ensure the safety of the children involved, and then begin investigations that results in recommendations to the New York State Office of Children and Family Services (OCFS).

Recommendations are either that a report be "indicated," meaning there is some credible evidence that abuse or maltreatment (as defined in Social Services Law) occurred, or that it be "unfounded," meaning there is no credible evidence that abuse or maltreatment occurred. In unfounded cases, records are subsequently sealed.

Residential Child Abuse Investigations at OMH and OMRDD Licensed/Operated Residential Care Facilities 2008 (n=363)

	Total Allegations	***Recommended Indications***
OMH – Licensed	134	16
OMH – State Operated	79	12
OMRDD – Licensed	129	20
OMRDD – State Operated	21	4
Totals	363	52

In 2008, the Commission conducted 363 child abuse and maltreatment investigations. This is a 16% increase in total investigations as compared to 2006, and a 12% increase from 2007. The chart above shows the number of allegations reported to the Commission from the State Central Register, and the number of those investigations that were indicated in OMH and OMRDD licensed or operated facilities for 2008.

- The overall rate of indication for residential child abuse investigations was 14% for 2008. This is an increase of 9% over the previous year.

Child Abuse Systemic Review

After receiving multiple State Central Register (SCR) allegations of abuse at one private psychiatric hospital, Commission staff conducted a systemic review of the hospital's children's unit.

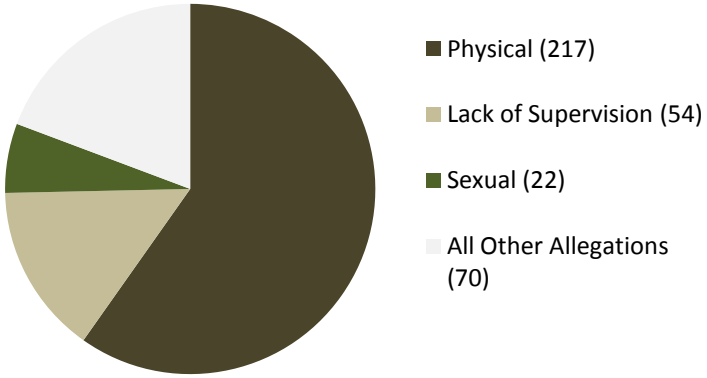
The Commission found several problems relating to staffing, supervision, and reporting and investigation of incidents. The Commission also found that the physical layout of the unit was not conducive to patient care and supervision.

In response to the Commission's review and findings, the hospital hired additional staff and initiated shift reports to monitor the adequacy of staffing levels. The hospital also developed and implemented a new incident report and monitoring system.

In response to the Commission's concerns about the physical layout of the unit, the hospital installed monitoring cameras in the common area and initiated discussions with the New York State Office of Mental Health to relocate the unit.

The chart below identifies the types[2] of residential child abuse allegations reported to the Commission. There were no significant differences between OMH and OMRDD operated/licensed residential facilities.

Allegations of Residential Child Abuse Reported to CQCAPD by State Central Register 2008 (n=363)



The category of "all other allegations" encompasses allegations that cover more than one type of abuse or issues such as improper medication, verbal abuse, or failure to provide adequate medical treatment.

Children's Care and Treatment Reviews

The Commission also conducts investigations of complaints regarding the care and treatment of children with disabilities in residential care facilities operated or licensed by OMH and OMRDD that are not reported to the Commission through the SCR.

Care and Treatment Reviews are commenced in response to complaints, or by Commission investigators who have additional programmatic concerns after the completion of one or more investigations into the treatment of a child at a facility. Care and Treatment Reviews address a variety of issues that affect the rights, safety, and care of a particular child, some of which include but are not limited to medication management, access to food and clothing, agency environmental concerns, inappropriate discharge and inadequate medical care.

Child Abuse Case Example

The Commission received an allegation of abuse from the State Central Register that a long-time agency employee at a residential treatment facility was in a sexual relationship and using drugs and alcohol with a child residing in the facility. The Commission worked with the agency to conduct an extensive internal investigation.

As a result of this investigation, the staff member was terminated and the facility implemented many changes to ensure appropriate staff conduct and increase mechanisms for early detection of potential abuse of residents by staff.

These changes included staff re-training on mandated reporting; implementation of monthly safety meetings with residents; revision of staff rounds; and post-discharge surveys of children and young people discharged from the residential treatment facility.

[2] Physical abuse includes allegations regarding the use of restraints

Children's Care and Treatment Reviews for OMH and OMRDD Facilities 2008 (n=40)

	Total Care and Treatment Reviews
OMH – Licensed	19
OMH – State Operated	5
OMRDD – Licensed	15
OMRDD – State Operated	1
Total	40

The chart to the left lists reviews undertaken by the Commission regarding the care and treatment of children residing in an OMH or OMRDD licensed/operated residential care facility.

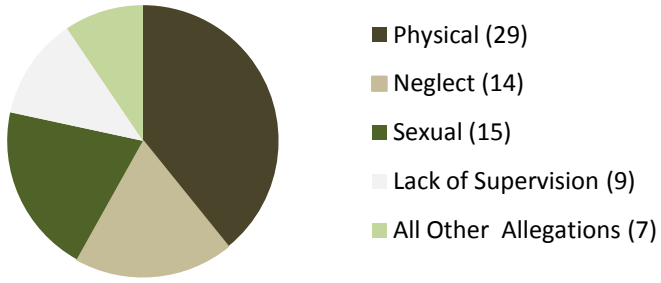
Children's Non-SCR Allegations of Abuse

Children's Non-SCR Allegations of Abuse Reviewed by CQCAPD in 2008 (n=74)

	CQCAPD Reviews
OMH - Licensed	29
OMH - State Operated	6
OMRDD - Licensed	33
OMRDD - State Operated	6
Total	74

Children's non-SCR allegations of abuse and neglect are those whose facts place the reports outside the jurisdiction of Social Services Law, yet are reported to the Commission by programs pursuant to the State Mental Hygiene Law.[3] Commission staff screen each allegation and make a determination on how to handle the matter. Depending upon the nature of the allegation, the Commission may review the quality of the facility investigation, and may seek corrective actions or re-investigation by the facility, or choose to open a care and treatment review. The chart above lists the number of non-SCR allegations of abuse reviews undertaken as a result of allegations reported to the Commission.

Types of Abuse for Reviews of Children's Non-SCR Allegations from OMH &OMRDD Facilities 2008 (n=74)



The top five types of abuse alleged in Children's Non-SCR reviews were similar to those received by the Commission through the SCR. Physical abuse was the most frequent allegation reviewed by the Commission.

[3] OCFS investigates all allegations of child abuse or neglect from the State Central Register at facilities with dual licensures from either OMRDD or OMH and OCFS. These facilities are often referred to as co-located facilities.

The category of "All Other Allegations" encompasses allegations that cover more than one type of abuse, or issues such as improper medication, verbal abuse, or failure to provide adequate medical treatment.

Child Advocacy and Family Training

The Commission contracts with a statewide network of legal services corporations and non-profit organizations through the federally-funded Protection and Advocacy Program for Persons with Developmental Disabilities (PADD) program.

Over 50% of PADD cases involve children under the age of 21 and most of these cases concern access to appropriate special education and related services. PADD attorneys and paralegals assist families at Committee on Special Education (CSE) meetings, resolution negotiations, impartial hearings and, in limited situations, appeals to the State Review Officer (SRO) and the courts.

In 2008, concerns relating to the education system made up 78% of all PADD cases in the 0-22 years age group.[4] The three most prevalent case categories in this age group were directly related to special education services, and were the same top three in 2006, 2007, and 2008.

Top Three Case Categories for 0-22 Years Age – Protection and Advocacy for Persons with Developmental Disabilities (PADD) Program Years 2006-2008

PADD Case Category	2006	2007	2008
Total Cases for 0-22 Years Age Group	625	644	746
Individualized Education Plan (IEP) not appropriate	157	179	231
Child not receiving special education services	45	83	133
IEP not being implemented	89	57	58

Commission staff also conduct training to ensure that persons with disabilities, their families, service providers and other concerned parties have an understanding of the rights established by both State and Federal law for persons with disabilities, and to help individuals and their families engage in self-advocacy.

PADD Case Example

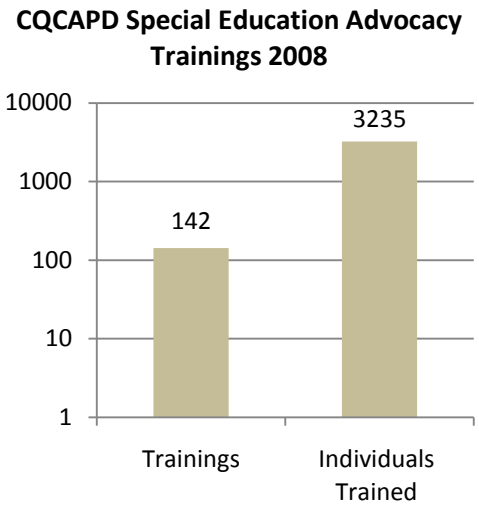
The Commission's PADD contractor in New York City, New York Lawyers for the Public Interest (NYLPI), secured the pro-bono services of Strook, Strook & Lavan LLP to assist a nine year old boy with autism and developmental delays.

The boy moved to New York City from another state and, when his father enrolled him in one of the New York City public schools, he requested evaluations for special education services. The boy was placed in a general education classroom but the school asked him to leave after severe behavior problems.

The boy remained at home for several months awaiting evaluation and placement. Finally, an Individualized Education Plan (IEP) was developed, recommending placement in a self-contained classroom, but implementation was delayed.

The attorneys were able to effectively advocate for the appropriate class placement and obtain needed educational services.

[4] Cases can be categorized into 49 different types based on the needs of the client. 17 of the 49 categories are related to the education system.



In addition, the Commission contracts with three non-profit agencies to provide special education training and advocacy activities throughout the State. The graph to the left illustrates the Commission's Special Education Advocacy training efforts in 2008.

The Commission increased training in 2008 by 8% over the previous year (131 trainings were completed in 2007).

PROTECTION AND ADVOCACY

In 1975, Congress created the first Protection and Advocacy (P&A) program to provide legal and other advocacy services to persons with disabilities in order to protect and promote their rights. Over time, the number of federally-mandated P&A programs has grown. The Commission on Quality of Care and Advocacy for Persons with Disabilities is designated to administer all eight of the federal P&A programs in New York State. In addition, the State has provided funding for advocacy programs for residents of adult homes and parents with psychiatric disabilities which the Commission also administers.

In 2008, the Commission contracted with over 30 not-for-profit agencies to provide P & A programs throughout the State. These programs served over 43,000 people by providing information and referral services, training, direct representation in legal and administrative matters and systemic advocacy, including class action litigation.

The table below summarizes the P & A programs that are administered by the Commission:

Name of Program	Number of Individuals Impacted in 2008
Protection and Advocacy for Persons with Developmental Disabilities (PADD) assists individuals and their families with developmental disabilities services.	11,064
Protection and Advocacy for Individuals with Mental Illness (PAIMI) assists individuals with mental illness with advocacy related services.	7,916
Client Assistance Program (CAP) assists people with disabilities secure training and services that support employment and independent living.	6,497

P & A Helps Individual Go to Work

The parents of a seven-year-old child with severe disabilities were provided with information and advice about obtaining and keeping SSI and Medicaid benefits while continuing to work.

At the time the parents sought help from the P&A program, the boy's mother worked full time and his father had quit his job in order to care for their son.

His parents had been told by the Social Security Administration (SSA) that the father could not work if they wanted to continue to receive SSI and Medicaid for their son's extensive health care costs.

The P&A program staff advised the parents of the correct SSI rules and this has enabled the boy's father to go back to work on a part-time basis while his son continues to get the health care and support he needs.

Name of Program	Number of Individuals Impacted in 2008
Protection and Advocacy for Individual Rights (PAIR) serves people with disabilities not covered by the federally authorized PADD, PAIMI or CAP programs.	3,660
Protection and Advocacy for Assistive Technology (PAAT) aids people with disabilities who require assistive devices (e.g. wheelchairs, special communication equipment) in their everyday lives.	572
Protection and Advocacy for Beneficiaries of Social Security (PABBS) provides advocacy services to assist people receiving Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) obtain, maintain or regain employment.	4,225
Protection and Advocacy for Persons with Traumatic Brain Injury (PATBI) provides legal and other advocacy services for individuals with traumatic brain injury.	811
Protection and Advocacy for Voting Access (PAVA) ensures the full participation of people with disabilities in the electoral process.	5,763
Parents with Psychiatric Disabilities Legal Advocacy (PPDLA) Project is authorized by New York State Chapter 54 of the Laws of 2007. PPDLA provides services to parents with psychiatric disabilities experiencing issues around parenting.	1,292

P&A Helps Individual go to School

A young woman with a psychiatric disability sought a waiver from the NYS Education Department Office of vocational and Educational Services for Individuals with Disabilities (VESID) in order to complete a Bachelor of Social Work degree.

The woman's disability required her to take some time off from school and to take fewer classes at certain points, lengthening the time required to complete her degree.

VESID initially refused to grant the waiver. Advocacy provided through the Client Assistance Program (CAP) led to approval of three additional semesters so she could complete her degree.

Name of Program	Number of Individuals Impacted in 2008
Adult Home Advocacy, established by New York State Law in 1995, provides advocacy services on behalf of people with psychiatric disabilities living in adult homes.	2,062

For more information on the Commission's Protection and Advocacy programs, visit www.cqcapd.state.ny.us/advocacy/advocacy.htm

ADVOCACY AND OUTREACH

The Division of Advocacy and Outreach (A & O) was created to foster internal and external collaborative efforts around advocacy and training, and to provide technical assistance and outreach to individuals with disabilities, their families, advocacy organizations, community agencies, local governments and others on issues of concern to people with disabilities. Although this Division serves all individuals with disabilities, it is especially concerned with addressing advocacy needs of people with physical and sensory disabilities to help ensure that they are afforded the opportunity to exercise all of their rights and responsibilities.

In 2008, the Division provided 222 trainings to over 6,700 individuals on topics including the Americans with Disabilities Act, accessibility, special education, assistive technology, and disability and diversity awareness offered in various school, community and workplace settings.

Other highlights included:

- 290 agency attorneys, human resource managers, ADA/504 coordinators and affirmative action officers of 60 New York State agencies attended the Non-Discrimination in Employment and Government Services training that was co-sponsored by the Commission, the Governor's Office of Employee Relations (GOER), the Division of Human Rights, and the Department of Civil Service.

- The Commission, in collaboration with the State Board of Elections, conducted a series of regional training forums on the implementation of the federal Help Americans Vote Act (HAVA). Trainings were held at the NYS Election Commissioners' Association conference, and at regional sites, including Watertown, Rochester, Waterloo, Otsego, and in Putnam, Erie and Saratoga counties.

Advocacy & Outreach Assists Family

The parent of a 16-year-old child with a sensory disability called for assistance and information on how to request additional evaluations, receive testing accommodations for the SAT exam, and explore assistive technology funding and options.

Staff provided technical assistance to the mother and helped guide her through the process of requesting the necessary assessments and testing accommodations.

The mother was then referred to the Commission's regional Technology Related Assistance for Individuals with Disabilities (TRAID) Center, and received assistance in addressing her questions and concerns about access to AT devices and funding avenues.

ASSISTIVE TECHNOLOGY

Through a federal grant from the Rehabilitation Services Administration (RSA), the Commission administers the Technology-Related Assistance for Individuals with Disabilities (TRAID) Program. TRAID's mission is to coordinate statewide activities to increase access to and acquisition of assistive technology in the four domain areas of education, employment, community living and information technology/telecommunications.

TRAID contracts with 12 regional centers to provide information, training, device demonstration and loan, technical assistance and advocacy on how to obtain and use assistive technology services and devices. During 2008, 1,133 devices were re-utilized/recycled for a savings of $528,346 to individuals and programs. Additionally, during the past year 9,361 equipment loans were made and 9,715 devices were demonstrated to persons with disabilities.

The TRAID Program, in collaboration with the NYS Department of Health Early Intervention (EI) Program, provides funding to the regional centers for equipment loan libraries for infants and toddlers with disabilities and their families. During 2008, the regional centers re-utilized/recycled 353 devices to EI children and their families for a cost savings of $102,646. There were 1,843 loans of devices made and 1,419 devices demonstrated.

For more information on TRAID and where Regional TRAID Centers (RTC) are located visit www.cqcapd.state.ny.us/advocacy/assisttechtraid/asst-tech-traid.htm

Access to Assistive Technology can Avoid Injury and the Need for Residential Care

A TRAID Center was contacted by a community service provider on behalf of an individual who lives alone and had a broken power chair.

The individual was unable to get out of her apartment, or even out of bed, and didn't have a manual chair.

The community support worker was concerned that the individual might need to go into a nursing home or lapse on her medication if she could not get the assistance she needed.

The TRAID Center was able to assist by loaning the individual a power chair until hers was repaired and returned.

INTERAGENCY COORDINATING COUNCIL FOR SERVICES TO PERSONS WHO ARE DEAF, DEAF-BLIND OR HARD OF HEARING

Pursuant to the requirements of Chapter 174 of the Laws of 2007, the Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-blind or Hard of Hearing (the Council) was established to promote a comprehensive service system for individuals who are Deaf, Deaf-blind or hard of hearing. The Council is comprised of 15 members from the public and government agencies.

In 2008, the Commission convened and provided staff support for the Council and, prior to the effective date of Chapter 174, CQCAPD conducted public forums to obtain input from people who are Deaf, Deaf-blind or hard of hearing, their family members, advocates, interpreters and service providers in the following locations: Mill Neck (Nassau Co.), Rochester, Buffalo, New York City, and Syracuse. The forums were well attended and comments were provided by a diverse cross section of individuals representing various geographic regions across the State.

The comments and concerns addressed unmet needs in some of the following categories:

- Need for data on incidence/prevalence of persons who are Deaf, Deaf-blind or hard of hearing
- A clearinghouse of services and resources
- Communication barriers and services
- Receiving and referring complaints to the appropriate regulatory agency
- Assistive technology
- Health care and emergency services

The initial Council report, describing the progress that has been made to date in addressing the requirements of Chapter 174, is planned to be issued in November 2009. For more information on the Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-blind or Hard of Hearing visit www.cqcapd.state.ny.us/advocacy/council-deaf/interagencycouncil.htm.

FISCAL/POLICY STUDIES AND REVIEWS

Fiscal

The Commission's Fiscal Bureau is charged with reviewing the cost-effectiveness of mental hygiene programs and procedures with particular attention to efficiency, effectiveness, and economy in the management, supervision and delivery of such programs.

Highlights of the fiscal studies and reviews released during 2008 are:

- February 2008: "*Lessons Learned – Changes Made, The Case of Evelyn Douglin Center for Serving People in Need*." This report documents how the agency's executive director utilized agency funds for personal enrichment, concealed critical information from the board of directors and misrepresented his educational background. Upon completion of the Commission's investigation, the board of directors acted to correct the problems. The board's actions served as a model of best practices for other agencies to replicate.

- November 2008 – "*PSCH, Inc.: An Investigation into Financial Practices and Corporate Governance*." This Commission report details findings regarding fiscal mismanagement at PSCH by its long-time executive director. Upon completion of the investigation, the Commission made a referral to the Attorney General's Office, which with assistance from the Commission, began its own investigation of PSCH. That investigation resulted in a settlement with PSCH and the resignation of the executive director.

In addition to these reports, Commission staff conducted over 17 investigations into the fiscal practices of specific agencies in 2008.

Policy

The Commission's Policy Bureau is charged with reviewing the organization and operations of the Department of Mental Hygiene, advising and assisting in developing policies, plans and programs for improving the administration of mental hygiene facilities and the delivery of services therein, and ensuring that the quality of care provided to persons with disabilities is of a uniformly high standard.

A policy study was conducted in 2008:

- July 2008 – "*Mental Health Comprehensive Medicaid Case Management: A Review of Systems Coordination and Support for People with Serious Mental Illness*." This report provides findings from the Commission's review of the experience of 50 adults receiving mental health case management services from 13 agencies in urban and rural New York State. The report provides information regarding the quality of case management services and the satisfaction and opinions of people receiving case management services.

The Quality Initiative:

In 2008, the Commission, in partnership with 18 organizations involved in providing services and supports by, with and for people with disabilities, formed the NYS Quality Initiative Coalition. Coalition members began working together to learn more about the diverse lives of people with disabilities. With the Commission as lead agency, the group decided to hold focus groups hosted by various advocacy groups and associations to better understand what people thought constitutes a good quality of life; what challenges were faced to have a good quality of life; and what still needed to change.

Over 400 people with disabilities statewide voiced their perspectives and experiences related to a wide variety of quality of life areas including employment, education, transportation, housing, health, community participation and more in these focus groups. Findings will be widely disseminated in 2009.

All of these reports can be found online at http://www.cqcapd.state.ny.us/OnlineReports.

ADULT HOMES

The Commission oversees the quality of care provided to residents of impacted[5] adult homes by conducting comprehensive reviews of adult homes, investigating complaints and deaths of adult home residents, and monitoring adult home closures.

In 2008, the Commission conducted 20 comprehensive reviews of adult homes serving over 1,800 people. During these reviews, staff assessed basic living conditions, fire safety, food services, personal care, medication management, case management, resident activities and protection of resident rights. Reports of findings and, where warranted, requests for plans of corrective action were issued to all adult homes reviewed, with copies to the State Department of Health, Office of Mental Health and Office for the Aging.

In addition, the Commission made 17 visits to homes to investigate deaths or complaints or to follow up on problems found in previous visits in 2007. The Commission also monitored the closure of four adult homes serving people who received mental health services.

Adult Care Facilities Futures Workgroup

The Commission was asked by the Governor's Office to convene and coordinate the meetings of an Adult Care Facilities Futures Workgroup. The Workgroup includes State agencies, advocates, service providers, and individuals living in adult homes. The purpose of the Workgroup is to develop recommendations to improve the quality of services provided to individuals living in adult homes and to increase opportunities for these individuals to move out of adult homes if they choose to do so. In 2008, the full Workgroup met three times and agreed to identify and promote replication of "best practices" in admission, retention and discharge.

Adult Home Case Example

The Commission conducted a comprehensive review of an adult home after 16 people moved there when the adult home they were previously living in closed.

Commission staff found that some of these residents were wearing dirty clothes and not receiving needed mental and physical health services.

The Commission notified the NYS Office of Mental Health and Department of Health about these conditions.

Both State agencies responded to the Commission's report by sending staff to review conditions, provide direction to improve services and correct the situation.

[5] Adult homes serving significant numbers of individuals with mental disabilities (25 residents or 25%, whichever is less) are considered "impacted."

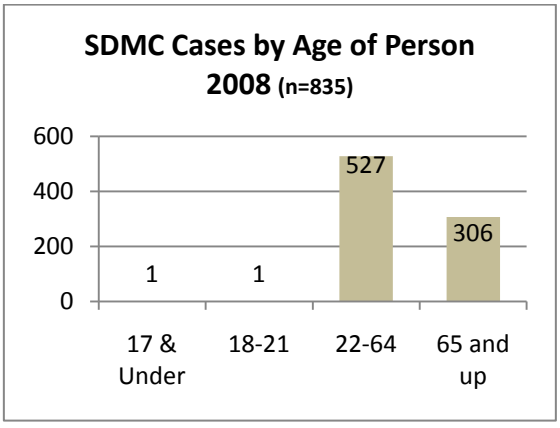
SURROGATE DECISION-MAKING COMMITTEE PROGRAM

Surrogate Decision-Making Committees (SDMC) were established as an alternative approach to the court system for obtaining informed consent for non-emergency medical treatment for persons with mental disabilities who:

- reside or once resided in facilities or programs licensed, operated, or funded by an office of the New York State Department of Mental Hygiene, or receive case management or service coordination approved, funded or provided by OMRDD;
- lack the mental capacity to provide an informed consent; and
- do not have a family member or other legally authorized surrogate to act on their behalf.

SDMC uses specially trained volunteer panels to review declarations regarding a person's capacity and need for treatment and then renders a decision at a hearing. Whenever possible, the person in need of the treatment attends the hearing. On average, SDMC decisions are made within 16 days from the time the case is sent to the Commission. This service is offered free of charge.

In 2008, over 1,700 volunteers assisted 993 people in need of medical procedures and 835 people had their case sent to a SDMC panel for a decision. Ninety-five percent of the people whose cases were considered by a SDMC had a developmental disability and 5% had a psychiatric disability; 61% were male and 39% were female. The age of people whose cases were considered by a SDMC is broken out in the chart below.



SDMC Case Example

A 45-year-old male patient had a stroke, and a request was made to withdraw a mechanical ventilator and withhold IV nutrition and hydration.

When the SDMC volunteer panel went to visit the man on the day of the hearing and asked questions of the physicians, it became clear that the man was breathing on his own. When questioned by the SDMC volunteers, neither doctor could testify that there was no reasonable hope of maintaining life.

Following the questioning, the neurologist revisited the patient and came back to provide the SDMC volunteer panel with new information. The new information led the SDMC volunteer panel to deny the request to withdraw and withhold treatment.

All parties agreed that once this request was denied there would be an immediate need to provide for a tracheotomy and feeding tube placement.

Three SDMC volunteers were able to stay and hear a subsequent request. Within 30 minutes of the decision to deny the request to withhold and withdraw treatment, the SDMC volunteers granted consent for the tracheotomy and feeding tube placement.

2008 SDMC Legislation

Two laws were enacted in 2008 affecting the SDMC program. Chapter 198 of the Laws of 2008, effective January 1, 2009, eliminated the requirement that a person discharged from facilities or programs licensed, operated, or funded by the New York State Department of Mental Hygiene must have been the subject of a previous SDMC determination before his or her case could be reviewed by SDMC. This change ensures that people who have been discharged from mental hygiene facilities into nursing homes or the community can continue to qualify for SDMC decision-making.

Chapter 262 of the Laws of 2008, effective January 3, 2009, authorized SDMC panels to make a decision to withhold or withdraw life-sustaining treatment for a person with mental retardation or developmental disabilities if no guardian or authorized family member is available.

To find out more information about the SDMC Program or becoming a volunteer, please visit www.cqcapd.state.ny.us/sdmc/sdmcforms/sdmc.htm.