

Fatality Review Board for Persons with Disabilities

2006 – 2008 Report

∞ History ∞

The Fatality Review Board for Persons with Disabilities (FRB) was created in response to repeated complaints from family members and a series of news reports regarding inadequate information being made available concerning investigations into the deaths of clients of the Department of Mental Retardation (now called the Department of Developmental Services or “DDS”). Formally established by Executive Order #25 in February 2002, the FRB tracks all reported DDS client deaths and pursues inquiries and full investigations into selected cases. The Executive Order designates the Executive Director of the Office of Protection and Advocacy for Persons with Disabilities (OPA) as Chair of the FRB, and charges it with investigating circumstances surrounding those deaths of DDS clients “which, in the opinion of the Executive Director, warrant a full, independent investigation.” The Board operates independently with support from OPA staff. Its members represent medical, law enforcement and human service disciplines specified in the Executive Order. All members are appointed by the Governor. Executive Order #25 also mandated that DDS cooperate with the FRB’s activities, and established an Independent Mortality Review Board (IMRB), which is appointed by the DDS Commissioner. The IMRB receives extensive support from DDS staff, and coordinates its activities with DDS’ internal, regionally-based mortality review process.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Fatality Review Board Members

The Board is chaired by OPA Executive Director, James D. McGaughey. Its membership is drawn from medical, law enforcement and human service professions. Currently, these individuals are:

- ✚ Lieutenant David Rice, Commanding Officer, Division of Scientific Services, State of Connecticut Department of Public Safety, serving on the FRB as the designated law enforcement professional with a background in forensic investigations;
- ✚ Supervising State's Attorney John DeMattia, representing the Chief State's Attorney;
- ✚ Patricia Mansfield, R.N., Executive Director, United Cerebral Palsy (UCP) of Eastern CT; representing an organization that provides services; and
- ✚ Gerard Kerins, M.D., Chief of Geriatrics, Hospital of Saint Raphael, one of two medical professional appointed by the Governor. (The other slot is currently vacant).

David Carlow, R.N., Director of Health and Clinical Services for DDS, represents the Commissioner of DDS on the FRB as a non-voting member. During the period covered by this report, Major Timothy Palmbach, Director Emeritus of the State Police Division of Scientific Services, and Kirsten Bechtel, M.D., also served on the Board. OPA staff who support the board include: Anne Broadhurst, a full-time Abuse Investigator, and Christine Gaynor, a full-time Human Services Advocate. Barbara L. Roy, OPA's Executive Secretary, provides administrative support.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Accomplishments

2002

- DDS and OPA developed a Memorandum of Understanding outlining a protocol for sharing information regarding client deaths. In order to facilitate collaboration with other agencies with partially overlapping jurisdiction, the FRB met with, and developed communication protocols with, the Office of the Child Advocate (OCA) and the Department of Public Health (DPH).
- By-laws were developed and adopted defining procedures for conducting FRB meetings, including executive sessions to discuss confidential case information, and for reviewing and adopting reports.

2003

- The FRB issued its first full investigation report concerning the circumstances surrounding the death of a man with an intellectual disability who died following his admission to a nursing home in Norwich, CT. The FRB investigation uncovered a long list of problems and alarming oversights at the nursing facility and concluded that multiple lapses in the quality of the man's care and failures in communicating critical information constituted significant neglect of his needs. As a result of the investigation, recommendations were made to DDS, which were intended to lessen the risk of similar occurrences for other DDS clients. The ARC of the United States distributed press accounts of the report around the country, underscoring that its members not assume that people with developmental disabilities will be well-served in skilled nursing facilities.
- The FRB issued its first annual report, summarizing issues which emerged as recurrent themes in the untimely deaths of DDS clients. These issues included: (1) Faulty communication of important information between health care providers; (2) Some individuals with chronic health problems who live independently appeared to need more support with health management than they were receiving; (3) Some individuals with developmental disabilities who had been placed in skilled nursing facilities died as a result of receiving poor care; and (4) In some situations it appeared that licensed practical nurses employed by private service providers were not working under the supervision and direction of a registered nurse, as required by law.

2004-2005

- The FRB issued a full investigation report concerning the circumstances leading up to and surrounding the death of Ricky W., a thirty-nine-year-old Hartford man with an intellectual disability who died following a vicious assault in the lobby of his apartment building. Immediately following the release of the FRB's investigation report, DDS issued a public statement indicating that DDS conducted an evaluation

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

of quality assurance systems for persons living in similar circumstances. The Commissioner of DDS also directed his staff to “make a comprehensive evaluation of the FRB’s report and develop any additional safeguards necessary to best protect the safety and well-being of the Department’s consumers.”

- In November 2005, DDS hosted a Supported Living Symposium for staff and persons receiving DDS-funded support. The symposium was dedicated as a tribute to the life and death of Ricky W. and organized in response to the issues raised and recommendations made as a result of the FRB investigation into his death.
- The FRB issued its second annual report, which identified a number of recurrent issues meriting close attention by providers, service providers and policy makers. Recommendations made by the FRB included: (1) Significantly improve health care coordination for individuals living in the community who have chronic medical problems; (2) Develop health and wellness education programs specifically designed to reach people with intellectual disabilities; (3) Avoid nursing home placements; where possible establish a network of preferred nursing home providers to meet short-term rehabilitation needs; (4) Clarify expectations for nursing supports in residential and day programs; (5) Provide detailed, timely information regarding untimely and unwitnessed deaths to the Office of the Chief Medical Examiner (OCME); and (6) Increase staff support to the FRB.
- As part of its 2004-2005 annual report, the FRB released “Health Care: An Emerging Challenge as DDS Consumers Become More Independent” a policy analysis requested by OPA and produced by Dale Borman Fink, Ph.D. and Jessica Jagger, MSW, staff of the A.J. Pappanikou Center for Excellence in Developmental Disabilities (UCEDD), University of Connecticut Health Center.

2005-2006

- The FRB issued its third annual report. Recommendations made as a result of its case reviews included: (1) The Commissioners of DDS, DSS and DPH should jointly issue a letter to all licensed nursing facilities in Connecticut, reminding them of the State and Federal mandates that require that DDS be notified of any significant change in condition of any nursing facility resident who has mental retardation; (2) DDS should clarify the responsibilities of Case Managers, Regional Health Services Directors, Regional Directors and Central Office personnel with respect to information received indicating that a nursing facility resident with an intellectual disability has undergone a significant change in condition; (3) Building on its past efforts, DDS should pursue a process to develop more consistent standards regarding nursing support services for all residential programs; and (4) As increasing numbers of people with significant disabilities rely on personal life-support technology, state investigative agencies need to develop plans and resources to ensure that such equipment can be tested when, in conjunction with a fatality investigation, the functioning of that equipment is called into question.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

- In response to a recommendation made by the FRB, which urged DDS to improve health care coordination for individuals living in the community who have chronic medical problems, DDS initiated a pilot project for people receiving individual supports in their own homes, operated by the private sector, in the North Region. The coordinator of the project, a DDS Nurse Consultant, reviews and assesses the person's health and medical support needs, identifies gaps in health care services and acts as their identified source of health care coordination and advocacy.

2006-2008

- In 2008, the FRB initiated a review of a sample of deaths of DDS clients occurring in nursing homes over a five-year period between January 1, 2002 and December 31, 2007. The primary purpose of this inquiry was to examine variables which might influence nursing home placement and the length of nursing home stay. A draft of the results of this inquiry was cited in a report to the Legislative Program Review and Investigations Committee on *Planning for Needs of Aging Individuals with Developmental Disabilities* in December 2008.
- Plans are underway to submit the results of the Board's nursing home SNF inquiry for publication in a peer review journal. The following findings were of significant note:
 - ⇒ There was no statistical relationship between the length of someone's stay in the nursing home and his or her age on admission.
 - ⇒ In addition, there was no statistical relationship between the length of someone's stay in a nursing home and the reason for his or her placement.
 - ⇒ Age on admission ranged from twenty to eighty-nine years and length of stay from one year or less to as long as thirty-seven years.
- In response to concerns that have emerged concerning the deaths of DDS clients living in nursing homes, and in collaboration with the Connecticut Council on Developmental Disabilities and the University of Connecticut Center for Excellence in Developmental Disabilities, OPA hosted a symposium, "*Including Our Elders with Disabilities: A Symposium on Aging in Place*" for policy makers, people with disabilities, advocates, and public and private service providers. The purpose of the symposium was to provide an opportunity for invitees to participate in a facilitated discussion with the intention of developing an action plan to ensure that people with disabilities have the freedom to age in place in the community.
- In response to a continuing concern voiced by the FRB regarding the failure of nursing homes to fulfill their obligation to keep DDS informed of any significant changes in the condition of persons with intellectual disabilities who have been placed into skilled nursing facilities, a letter signed by the Commissioners of DDS, the Department of Public Health (DPH) and the Department of Mental Health and Addiction Services (DMHAS) was sent to all nursing homes in Connecticut

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

reminding them of the State and Federal mandates, which require that DDS be notified of any significant change in the physical or mental condition of any nursing home resident who has an intellectual disability.

- Subsequent to this reporting period, DDS hired a statewide Coordinator for Aging Services and a nurse located in its Central Office to work with the DDS Ombudsperson to visit clients in nursing homes and review their records. In addition, the DDS Frequency of Case Management Contact Procedure was revised to require a minimum of one face-to-face Case Manager visit per year and quarterly case management contact to individuals who live in long-term care facilities. The procedure also stipulates that Case Managers develop an Individual Plan and Level of Need (LON) and update the plan and LON at least annually.
- In response to a concern raised by the FRB that the Office of the Chief Medical Examiner's (OCME) decision not to assert jurisdiction in a particular case may have been unduly influenced by a person's having a disability, the OCME completed a general review with its staff to reinforce the criteria for which cases should be reported and brought in for autopsy examinations. The OCME also plans to have a representative from the FRB conduct an in-service on disability issues for physicians at the OCME.

Mortality Statistics (July 1, 2006 - June 30, 2008)

Between July 1, 2006 and June 30, 2008, four-hundred-sixteen (416) deaths were reported to the FRB by DDS. One-hundred-ninety-four (194) or 47% of those who died were women, two-hundred-twenty-two (222) or 53% were men. These figures are generally consistent with numbers from previous reporting periods

Age and Mortality

As may be expected, the largest number of deaths occurred in the over-60 age group, with 192 (46%) deaths reported. 91 (22%) occurred in the 51 to 60 age group; 53 (13%) in the 41 to 50 age group; 26 (6%) in the 31 to 40 age group; 25 (6%) in the 21 to 30 age group; 20 (5%) in the 11 to 20 age group; and 9 (2%) in the age group birth-to-10.

Residence at Time of Death

123 (29%) of the individuals were living in nursing homes at the time of their deaths; 120 (29%) in community living arrangements (often referred to as "group homes"); 78 (19%) at home with their families; 48 (11.5%) at Southbury Training School (STS); 21 (5%) were receiving individual supports in their own homes (previously referred to as supported living arrangements); 7 (2%) in State operated regional centers; 7 (2%) in licensed community training homes; 6 (1%) in their own homes with minimal support (case management services only); 3 in a hospital setting, such as the Hospital for Special Care; 1 in a residential care home (board and care home); 1 in a foster home; and 1 in a hospice facility.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Location of Death

The residence of a person at the time of his or her death is not necessarily the location that person died. For example, a person may have lived in a community living arrangement prior to his or her death, but may have actually died in a hospital. In fact, 201 (48%) of the deaths reported occurred in hospitals. 89 (21%) in nursing homes; 34 (8%) in hospital emergency departments; 30 (7%) in family homes; 20 (5%) at STS; 19 (4.5%) in community living arrangements; 7 (2%) in hospice facilities; 7 (2%) in their own homes receiving individual supports; 4 (1%) in their own homes receiving minimal supports; 2 each in State-operated regional centers, and licensed community training homes; and 1 in the community with no support.

Causes of Death

Cardiac arrest, cardiopulmonary arrest, cardiovascular disease and congestive heart failure accounted for a total of 129 (31%) of all deaths during this reporting period. Other causes of death listed in rank order include: 77 (18.5 %) attributed to pneumonia; 42 (10%) to cancer; 40 (10%) to respiratory arrest or disease; 30 (7%) to sepsis; 16 (4%) to renal failure; 12 (3%) to Alzheimer's disease; 10 (2%) to a metabolic disorder; 10 (2%) to a cerebral hemorrhage, embolism or stroke; 9 (2%) to a terminal illness process; 8 (2%) as the result of a seizure disorder; 4 as the result of infectious disease; 3 each to aspiration of food and gastrointestinal illness; 2 each to pancreatitis and homicide; and 1 each to accidental trauma, acute illness, asphyxia, bowel obstruction, diabetes, drowning, internal hemorrhage and surgical complications.

Five (5) deaths were recorded as having "unknown cause". Two (2) of these deaths involved persons under the age of eighteen with complex medical needs, and were reviewed by the Office of the Child Advocate (OCA). One (1) involved an eighty-six year-old woman who was placed in a nursing home by her family and transferred to hospice facility after being hospitalized for an infection that did not respond to treatment. One (1) death was determined by the Office of the Chief Medical Examiner (OCME) as being due to a "cardiac collapse of unknown etiology." One (1) death involved a man who lived at home with his family and died of an apparent heart attack.

Four (4) deaths were recorded as having "other cause". One (1) of those was due to cerebrovascular disease; one (1) "failure to thrive"¹; one hypovolemia²; and one (1) advanced sickle cell disease.

Two (2) deaths were recorded as "undetermined cause". One (1) was an "undetermined cause of death in setting of esophageal and gastrointestinal dilation", per the OCME. The

¹ Taber's Medical Dictionary, 19th Edition, defines "failure to thrive" as a condition in which elderly persons lose the physiological or psychosocial reserves needed to care for themselves. The causes include almost any chronic and debilitating condition.

² Taber's Medical Dictionary, 19th Edition, defines hypovolemia as a decreased blood volume that may be caused by internal or external bleeding, fluid losses, or inadequate fluid intake.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

other involved a man with Down syndrome and diabetes who lived at home with his family and died suddenly after experiencing what was thought to be a “vaso-vagal episode”³.

Two (2) of the three (3) deaths that were due to aspiration of food raised suspicions of abuse or neglect and were referred to the Office of Protection and Advocacy for Persons with Disabilities Abuse Investigation Division (OPA/AID) for investigation. The other involved a woman living in a nursing home whose death was reviewed by the IMRB. The one (1) death that was due to asphyxia involved a two-year-old with complex medical needs and was reviewed by the OCA. The one (1) death due to accidental trauma was investigated by the OPA/AID and local authorities, who found that there was no reason to suspect that abuse or neglect by caretakers played any role. The two (2) deaths due to homicide were investigated by the OPA/AID and local police authorities. Abuse was substantiated by the OPA/AID. The one (1) death caused by drowning was investigated by the OPA/AID and local authorities. Neglect was substantiated on the part of the private provider and the staff person who was supporting the person at the time of the drowning. Due to the severity of neglect pertaining to the staff person’s actions in association with the incident, a copy the OPA/AID investigation report was also forwarded to the appropriate State’s Attorney for review.

The leading causes of death recorded by the FRB during this reporting period are generally consistent with mortality experience from previous years. Statistics made available in DDS’s most recent Mortality Annual Report (dated February 2007) indicate that in both Connecticut and Massachusetts, the leading causes of death for persons with mental retardation for the years 2002, 2003 and 2004 were heart disease, respiratory disease (including aspiration pneumonia), cancer and sepsis.

Do Not Resuscitate Orders; Hospice Services, Post Mortem Examinations

According to the information received from DDS, two-hundred-forty-nine (249) or 60% of the people who died during the reporting period had “Do Not Resuscitate” (DNR) Orders, and eighty-six (86) or 21% were receiving hospice services when they died. Autopsies were performed in twenty-nine (29) or 7% of all cases.

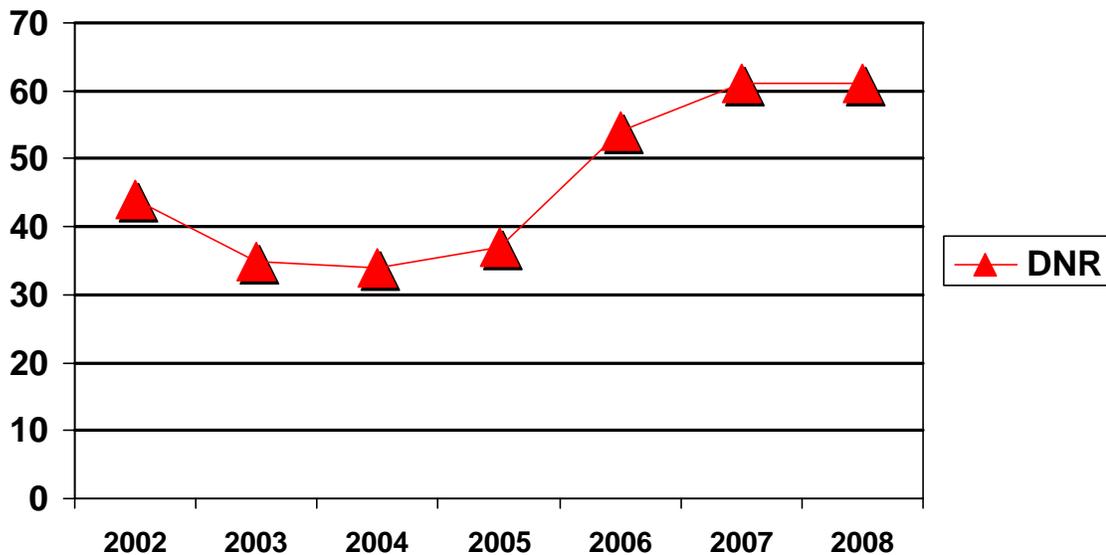
While the percentage of people receiving hospice services and the percentage of autopsies performed are generally consistent with previous experience, the percentage of DNR Orders has grown from previous reporting periods. During the July 2003 to June 2005 reporting period, 36% of those who died had DNR orders in place. From July 2005 to June 2006, the percentage rose to 46%. During the current reporting period, DNR Orders were in place in 60% of all deaths. A number of factors may be contributing to this trend, including: greater awareness of the procedures available to establish DNR Orders for DDS clients, a possible general increase in the use of DNR Orders by practitioners and health care facilities, and possible shifting views regarding the usefulness or medical appropriateness of resuscitation efforts, Increasing use of DNR Orders amongst DDS

³ Merriam Webster’s Medical Dictionary, 2005, defines “vaso-vagal episode” as a usually transitory condition that is marked especially by fainting associated with low blood pressure.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

clients does not necessarily signal a problem. However, given that people with disabilities have historically experienced discriminatory denials of life-sustaining medical treatment, and, further, that DNR Orders have sometimes been interpreted as direction to withhold beneficial treatment, the FRB plans to explore this issue further.

Percentage of Deaths with DNR Orders



Cases Reviewed by the FRB

FRB staff receive, review and log into a database reports of all deaths known to DDS. Reports of deaths occurring under unusual circumstances, those of unknown cause or those suggesting possible deficiencies in care and treatment are identified for further in-depth review and/or preliminary investigation. In cases requiring in-depth review, Board staff obtain pertinent data relative to each case, including autopsy reports, medical and other clinical records, police and ambulance reports and investigations completed by other agencies. FRB staff also contact family members, agency staff, medical professionals and others having knowledge of the person's history and/or the circumstances surrounding the person's death. Investigative activities may also include site visits and consultations with Board members and other experts. Information concerning these cases is prepared for the Board to review. The Board then makes recommendations for further review, investigation or action in each case. FRB staff also work jointly with OPA/AID investigators in the investigation of these deaths, where abuse or neglect are suspected to have played a role, and the Board has a particular interest.

During the time period between July 1, 2006 and June 30, 2008, two-hundred and twenty-two (222), or 53% of all reported deaths were the subject of in-depth discussion, monitoring, investigation and/or review. During these inquiries and discussions, the FRB addressed a number of issues, including:

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

- **Emergency Department Discharge Practices**

The FRB has reviewed several cases where there has been a question as to whether someone who had been brought to a hospital Emergency Department (ED) was well enough to have been discharged. In one case, an elderly man was seen in the ED of a local hospital, treated for possible pneumonia and released back to his community living arrangement even though he continued to have an elevated temperature. According to records made available by the hospital, the man was evidently considered for admission to the hospital but was not admitted because “no beds [were] available at that time.” By the following day, the man’s condition had not improved and he was subsequently admitted to the hospital for further evaluation and treatment. While it cannot be conclusively demonstrated that delaying the initiation of hospital-level therapies (e.g. I.V. antibiotics) contributed to the man’s death, the Board questioned whether discharging an elderly person exhibiting signs of pneumonia was appropriate. In response to an inquiry made by the FRB concerning the hospital’s ED discharge practices, the hospital noted that (in contrast to this particular case) patients are typically maintained in the ED if the hospital is filled to capacity. The hospital also noted that there was a mechanism in place to take care of overflow by transferring patients to other community hospitals if an admission was needed. Questions about discharge decisions by Emergency Departments have also arisen in several other cases.

- **The Role of the OCME and Law Enforcement Professionals in Investigations Involving Unexplained Drug Overdoses**

During the reporting period, the FRB reviewed two cases where results of forensic toxicology studies indicated the individuals died due to overdoses of prescription drugs. (One of the individuals died during the prior reporting period, but much of the follow-up inquiry occurred during this reporting period.) While the OCME determined that, in both cases, the manner of death was an “Accident,” no satisfactory explanation was obtained as to how the overdoses might have occurred, and there was no inquiry or follow-up by local law enforcement to ascertain, or attempt to ascertain how the overdose occurred. In both cases, OCME staff demonstrated considerable sensitivity to the effect of their findings on family members of the deceased. (Finding that the manner of death was “Accident” may give more comfort than a finding of “Undetermined”.) However, in both cases reviewed by the FRB there are significant unanswered questions. For example, in one case, a young woman who lived at home with her family died unexpectedly of cardiac arrhythmia due to an apparent overdose of medications that were prescribed by her psychiatrist. The psychiatrist (who had followed the woman for a number of years and was familiar with her behaviors and living situation) indicated to FRB staff that she was not able to take her medications independently. FRB staff learned that family members had been giving her the same medications for quite some time at the same doses, apparently without ill effect. However, toxicology reports indicated that blood levels of the drugs were extremely high – far higher than would be expected from therapeutic doses, or even from common errors in medication administration (e.g. double or triple dosing). The Board’s review of this case revealed that although an Associate Medical Examiner had spoken to the woman’s mother over the phone, and by all accounts the mother had been devoted to her daughter’s welfare,

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

she could offer no information or explanation concerning the apparent overdose. Neither the OCME nor local authorities conducted any further inquiries to determine how the young woman might have ingested toxic levels of her prescribed medications. In fact, there does not seem to have been any formal notification given to local law enforcement officials.

In the other case, toxicology reports indicated that a young man's death was caused by extremely high levels of two of the prescription medications he was taking. FRB/OPA investigators determined that the man's prescriptions were being filled at different pharmacies, and that he may have been obtaining greater quantities than were intended by prescribers. While his medications were administered by either a home health agency RN or a family member, and he generally complied with medical instructions, he was being treated for chronic pain. In addition, there is some question about his ability to manage complex health information. He lived with relatives, and received in-home nursing supervision to assist him in managing his diabetes which had previously been uncontrolled. However, the nurse's responsibilities apparently did not include monitoring non-diabetes related medications. Again, as in the first case, there were many unanswered questions as to how the overdose occurred, and, again, no formal mechanism to ensure that local law enforcement would conduct a follow-up inquiry. (Note: Acting on advice from their attorney, the family refused to participate in FRB/OPA interviews.)

- **Supporting People With Serious Health Concerns Who Resist Typical Service and Support Configurations**

The DDS Individualized Residential Supports program model offers considerable flexibility in meeting the needs of many individuals with intellectual disabilities who are living in their own homes rather than more traditional group home or institutional settings. This innovative approach both respects personal choices and autonomy, and allows considerable creativity in constructing individually appropriate supports. However, in the course of reviewing a number of client deaths, it has become apparent that supporting healthy lifestyles for some individuals who receive Individualized Residential Supports presents unique challenges. Even with persistent, committed case management and other supports, problems can occur for people who have significant health-related problems. The FRB completed an investigation concerning the death of one such man who resided in an efficiency apartment at a local YMCA. He had a history of chronic health problems, and manifested various risk factors for heart disease and stroke. Although he received counseling regarding healthy lifestyle choices from his DDS Case Manager, and from doctors and nurses at a local medical clinic where he was a long-standing patient, it is fairly clear that he did not fully understand or appreciate the implications of his unhealthy eating habits, of not consistently taking his blood pressure medication, and not keeping medical monitoring appointments at the clinic. All involved agreed he needed more consistent assistance. However, the man was unwilling to move to a more structured residential program, and was much more comfortable interacting with local merchants and neighbors than with state agencies.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

When he was not seen or heard from for a few days, his DDS Case Manager went to check on him, and found him dead on the floor of his apartment. An autopsy report revealed his cause of death to be atherosclerotic disease, with an underlying condition of hypertension, the medical problem for which he was being treated.

When the FRB reviewed this case, two major concerns were noted. First, although DDS records indicated that the man was willing to work with a private provider and to provide them with a spare key (access) to his apartment, DDS never attempted to arrange in-home support services for him at the YMCA. Instead, efforts were focused on moving him out of the YMCA to a more structured service facility, which he resisted. Second, the man's DDS records noted that funds had been allocated to provide him with the kind of drop-in assistance he said he would accept sometime in 2006 or 2007 by the DDS Planning Resource Allocation Team (PRAT). However, case management notes indicated that his Case Manager, who had been quite actively involved with the man, was unaware of this allocation. In response to the Board's review and findings in this case, the FRB recommended that DDS devote more resources to affirmatively develop the capacity to provide personalized supports to people whose preferences include remaining in their own homes. In addition, the Board recommended that DDS ensure a mechanism is in place to make certain all assigned Case Managers are made aware of DDS PRAT allocations in a timely manner in order to preserve these critical funding opportunities. In response to the FRB's concerns, the DDS Region indicated that it now informs staff via email of the result of an allocation at the time of a PRAT meeting with a follow-up by hard copy of the PRAT's decision.

It is important to note the while the number of deaths of this nature is not numerically that significant, it is clear that the social service system still encounters a great deal of difficulty supporting people whose intellectual disabilities impact their ability to appreciate and manage their chronic health problems on their own.

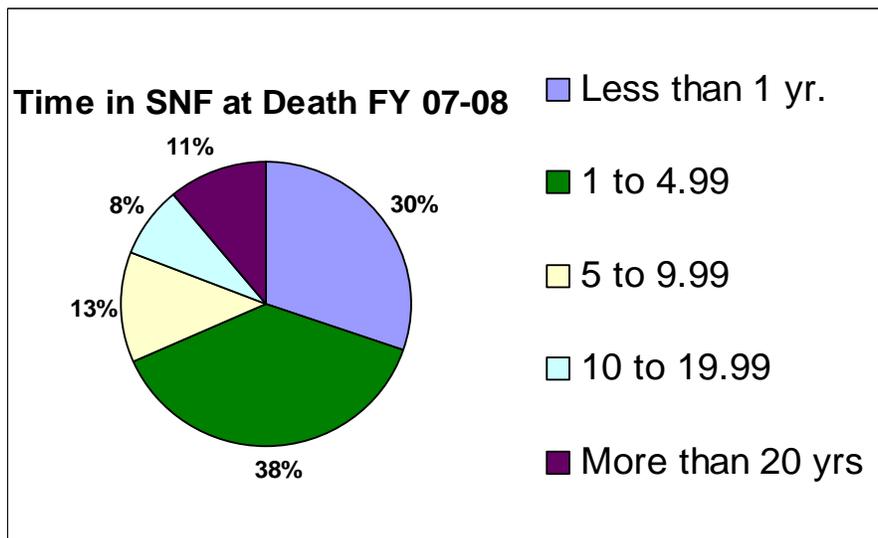
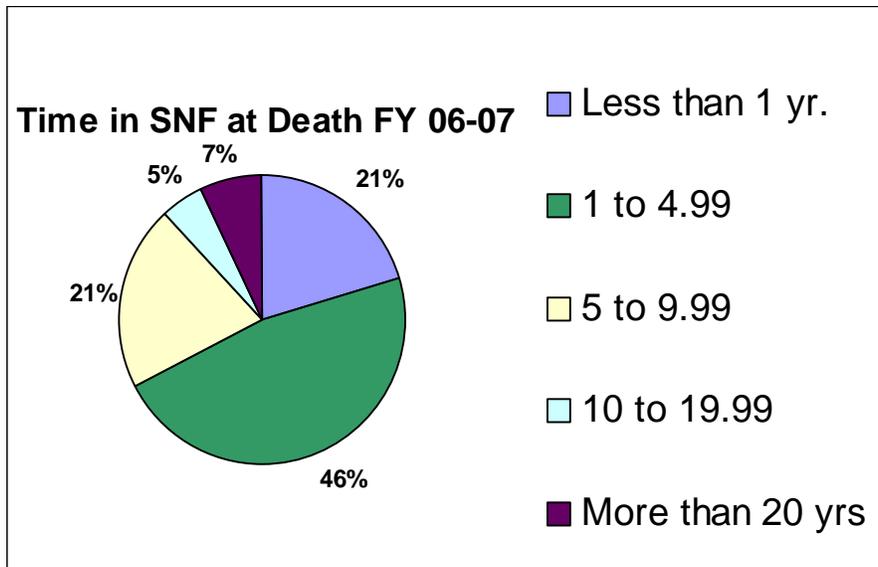
- **Accessing Care in the Appropriate Setting at Southbury Training School (STS)**

The FRB reviewed the deaths of three people living at Southbury Training School (STS) who were admitted to the STS Healthcare Unit (HCU) in lieu of being transferred to a local hospital. The HCU does not offer hospital-level services, and is not intended to treat acutely ill people. Southbury's newly appointed Medical Director responded to a Board inquiry indicating that after these deaths occurred, a new policy had been developed. Southbury's most current admission policy to the HCU states that residents of STS are to be sent to local Emergency Departments (ED) for evaluation of acute medical conditions, and only admitted to the HCU under prior approval and expressed consent by the STS Medical Director.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Issues Identified for DDS Clients Living in Nursing Homes

As in previous years, the largest number of deaths reported to and reviewed by the FRB involved individuals living in nursing homes. As the following charts illustrate, many of these individuals have lived in skilled nursing facilities for an extended period of time.



Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

The FRB's review of these cases resulted in the identification of a number of issues, many of which have been documented by the FRB in previous investigations and reports.

- Nursing homes often fail to inform DDS when a resident who is a DDS client dies or experiences a significant change in health status. (The FRB has written in past reports about the failure of extended care facilities to fulfill their obligations to keep DDS informed of any significant changes in the condition of individuals with intellectual disabilities, including death. In response to these concerns, and at the Board's request, the Commissioners of Developmental Services, Public Health, Social Services and Mental Health and Addiction Services have issued two joint letters to all licensed extended care facilities in Connecticut, reiterating their State and Federal reporting responsibilities.)
- Historically, deaths of people with intellectual disabilities residing in nursing homes have revealed instances where inadequate care and in some cases neglect on the part of a nursing home has clearly contributed to an individual's death. During this reporting period, several such instances have been reviewed, including the death of a man who had been diagnosed with cancer of the cheek and lacked an appropriate pain management plan.
- People are often moved to nursing homes because their residence – a community living arrangement, their own apartment or family home – could not be readily adapted to meet their needs for increased care. Either the residence was not physically accessible, or staffing patterns were not adjusted to meet increased support needs. In some cases, individual provider policies limited the types of supports people could receive in their homes.
- People are often placed in nursing homes that are far away from friends and family, sometimes creating an abrupt end to supports and relationships that are essential for interpreting the person's needs.
- Hospital discharge practices sometimes result in people being transferred to nursing homes with incomplete medical histories. This phenomenon poses unique risks, especially when the person is not well able to articulate his or her needs and DDS has discontinued monitoring of the person's health care.
- The identity and needs of DDS clients living in nursing homes is sometimes lost by DDS. For example, DDS records indicate that when she had first been admitted to a nursing home, the deceased's person's Case Manager had visited her regularly and had tried to arrange an alternative placement. However, over time, as different Case Managers were assigned, contacts diminished and then ceased altogether several years prior to the woman's death.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Case Example

A FRB investigation regarding the death of an elderly woman with Down syndrome and Alzheimer's disease illustrates some of the above concerns. The FRB learned that the woman had lived in a community training home (CTH) for many years prior to her nursing home admission. She entered the nursing home after being hospitalized for an acute illness, although she had also experienced a progressive decline in her health status that left her unable to negotiate the stairs in the CTH that led to her bedroom. When she was first admitted to the nursing home, the CTH provider regularly visited the woman and took her out into the community. But it became difficult for the provider to maintain these visits, as the woman always expressed the desire to return to the CTH. Prior to admittance to the nursing home, the woman had been involved in DDS-operated day programs for nearly twenty years. When her day program was discontinued, the woman had few activities available to her other than socializing with nursing home staff at the nurses' station. Placement in the nursing home also meant the end of the woman's long-term relationship with her DDS Case Manager, as DDS assigns only a few specified Case Managers to support nursing home residents once a person is admitted. Fortunately, her nephew, who was also her guardian, visited her regularly. He had been told that DDS was working on another placement for her, but none materialized.

The FRB investigation focused on the quality of care and treatment the woman received in the skilled nursing facility. The FRB learned that for several days prior to her death she was uncharacteristically lethargic and uninterested in food. Just prior to the woman's death, she was brought from her room to the facility's small dining lounge where an aide fed her her evening meal. (Normally, she was an enthusiastic eater and fed herself.) While being assisted with her meal by facility staff, the woman collapsed, vomited and became unresponsive, necessitating a call to 911 and transport to a local hospital. According to hospital records, suctioning revealed that food particles were present in the woman's lungs. The woman was subsequently transferred to another hospital, where she died the following day. Her cause of death was listed as respiratory failure due to aspiration pneumonia.

Following a preliminary FRB investigation, this case was referred to DPH and the State's Attorney's Office for further investigation. The State's Attorney's Office investigators interviewed witnesses and determined that there was no criminal aspect to this case. DPH also interviewed the witnesses and reviewed records, but found that concerns over failure to respond to her lethargy and inadequate supervision of the aide involved in feeding the woman were "unsubstantiated due to a lack of evidence." (Following receipt of their findings, FRB staff met with representatives from DPH to discuss the DPH findings in greater detail. As a result of this meeting, the FRB learned that since it appeared that the woman had had periods of lethargy in the past, DPH could not determine whether she was experiencing a "change in status" for which she should have been assessed by a nurse the evening of the incident. The FRB also learned that since DPH identified no issues with the performance of the aide who fed the woman her evening meal, they would not expect the nursing home to institute a program for monitoring her future work performance. FRB staff who had interviewed the aide were concerned because she had no recollection of the incident.)

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Recommendations and Lessons Learned from FRB Investigations and Reviews

1. The FRB agrees with and supports the recent recommendations made by the Legislative Program Review and Investigations Committee concerning the establishment of a quality assurance system by DDS to “systematically oversee the requirements for DDS clients in nursing homes.” Specifically, the Committee recommended:
 - ➔ “As part of its audit of nursing home records, DDS should collect and verify (at a minimum) information ensuring that Case Managers are assigned to individuals and have met the requirement of quarterly contact and yearly face-to-face contact; whether or not the nursing home has notified DDS if someone has experienced a significant change in condition, been hospitalized or died; that health records are complete and accurate; and that accurate and up-to-date contact information is contained in the person’s file;”
 - ➔ “The term ‘significant change in condition’ should be defined in guidelines, including the process that nursing homes must follow in notifying DDS, what actions must be taken by DDS upon receipt of such notification, and circumstances that should initiate face-to-face contact between a client and his or her Case Manager, and/or require an assessment by a DDS nurse consultant. The roles and responsibilities of the Case Manager Supervisor and regional manager on-call should also be defined, including any actions that must be taken by them when such notification occurs;” and
 - ➔ “DDS should establish a centralized data system to capture information on clients residing in nursing homes in order to document: (a) reason(s) for nursing home admission; (b) lengths(s) of stay; (c) admitting rates to nursing homes by hospital; (d) frequency of Case Manager contact, with uniform documentation and alerts generated when frequency of contact is not being met; and (e) notification of a significant change in a client’s condition, including an identification of the change. DDS should randomly audit a sample of cases in the database to ensure its accuracy.”
2. DDS and DSS should re-examine how funding can be directed to allow for the greatest flexibility of services and supports to DDS clients as they age and/or their health needs change. This portability of funds should include the elimination or modification of architectural and transportation barriers in community-based settings; allow for staff support to be provided to clients in hospitals or extended care settings; and the continuation of day services to clients in extended care settings if they are not able to return to their home in the community.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

3. If placement in a nursing home cannot be avoided, every consideration should be given to placing people in geographic proximity to their previous residence, in order to facilitate the continuation of meaningful relationships with support staff, family, co-workers and friends.
4. Due to the increased number of *Do Not Resuscitate* (DNR) Orders from previous reporting periods referred to in the mortality statistics section of this report, DDS should ensure that mechanisms are in place to review and rescind (if necessary) DNR Orders if a person's medical condition changes and will no longer lead to imminent death.

Allegations of Abuse/Neglect

Although the FRB is authorized to pursue full, independent investigations, Connecticut legislative changes in 2004 directly charged OPA with responsibility for conducting investigations into most deaths of adults with mental retardation when abuse or neglect is suspected of having played a role. OPA's Abuse Investigation Division (OPA/AID) conducts primary investigations into most of these deaths, although due to the location or other circumstances surrounding a particular death, other regulatory or law enforcement agencies, such as the Department of Public Health (DPH), the Department of Children and Families (DCF), and various law enforcement agencies may have primary jurisdiction. The FRB monitors the status of all death investigations involving allegations of abuse and neglect, reviews reports from primary investigating agencies (including OPA/AID) and, if warranted, pursues additional inquiries.

Of the 416 cases reviewed by the FRB during the reporting period, only twenty-eight (28), or 6.7 %, were considered to involve allegations of abuse or neglect. Of these twenty-eight (28) deaths, twenty-four (24) were directly investigated by OPA/AID. Four (4) cases resulted in referrals to the Department of Public Health (DPH) due to concerns about the performance of licensed health care facilities and/or individual providers.

Of the seventeen (17) abuse/neglect death investigations that were completed during this reporting period, neglect was substantiated by the OPA/AID and/or DPH in eight (8) cases; abuse was substantiated in two (2). Five (5) cases resulted in no substantiation of abuse or neglect; and, after a preliminary investigation, one (1) case was determined not to fall within the purview of the OPA/AID.

(Note: At this writing, eight (8) of the cases referred to the OPA/AID and three (3) of the cases referred to DPH remain under investigation.)

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Issues identified from completed investigations are discussed below.

Failure to Receive Services Necessary to Maintain Health and Safety

A young man who lived at home with his family received yearly case management contact from DDS, which sometimes involved telephone contact only. The home was rundown and cluttered. The man's death was attributed to cardiovascular disease, coronary atherosclerosis and diabetes. Evidence indicated that he was not under a doctor's care, nor was he being followed by any physician at the time of his death. Although the OPA/AID investigation did not substantiate neglect on the part of DDS, recommendations were made to ensure timelier reporting of suspected neglect in cases where DDS case management has infrequent contact with the home. Since that time, DDS has revised its case management procedures to require a minimum of one face-to-face Case Manager visit per year to individuals who receive minimal supports and who live in their own home or family home and are not on Medicaid or on a Home and Community-Based Services (HCBS) waiver and do not receive DDS-funded individualized supports.

Deaths due to Choking

Two cases involved individuals who received DDS-funded supports in community living arrangements.

Case #1

An individual with dysphagia (difficulty in swallowing) had an extensive protocol to prevent her from aspirating on food and liquids. However, the protocol did not address the administration of tablets (i.e. pills). When the individual was given a medication in pill form, she aspirated, precipitating pneumonia. The OPA/AID investigation found that the agency nurse was not familiar with the results of the individual's most recent swallowing evaluation and acknowledged that there was no protocol in place to assist the individual with swallowing medication.

Case #2

Another individual with dysphagia was only supposed to eat food of chopped consistency. This requirement was followed with respect to food prepared specifically for him. However, he also had a history of taking food which was not meant for his own consumption and which had not been properly prepared for him. Despite that propensity, there was no protocol or formalized procedure for ensuring his safety with respect to food he might inappropriately access. The individual died after choking on a piece of food that he had obtained from the kitchen area of his residence while support staff were out of the room.

In both cases, the OPA/AID made recommendations to ensure that the agencies involved have clearly written safety and behavioral protocols and that all support staff receive timely and adequate training in their implementation.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Failure to Receive and/or Seek Timely Medical Care

Although the circumstances in each of the following cases vary, investigations revealed that a delay in the provision of timely medical care, or poor health care coordination, contributed to all four of the following deaths.

Case #1

In this case, which was investigated by DPH and monitored by the OPA/AID, an individual living at home with her family had a history of chronic bedsores. The individual's mother was her primary caretaker, but a home health care agency nurse evaluated the individual twice a month. Between the primary caretaker and the home care agency, the person's bedsores were supposed to be monitored, a process that included measuring their size and severity. A clinical wound consultant employed by the home care agency was to be notified of the status of the person's bedsores by the visiting nurse for assistance, presumably so that aggressive treatment could be initiated if warranted. Two months prior to the individual's death, she was admitted to the hospital with a large bedsore, which necessitated her having a partial hip removal. The DPH investigation found that the home care agency failed to assess the effectiveness of the treatment plan and to consistently update and coordinate the treatment regimen with the person's primary care physician, clinical wound consultant and the primary caregiver. The home care agency's plan of correction, as recommended by DPH, included, among other measures, changes made to enhance the agency's clinical assessments in the area of wound care management and coordination of care and communication between disciplines.

Case #2

An individual who lived in his own apartment and received DDS-funded supports complained of vomiting and abdominal pain for three days prior to his death. Investigators learned that the person had called emergency medical services himself the day before his death, but refused transport to the hospital. Later that same day, he continued to vomit and had a low-grade fever. He spent the night alone as he typically did not receive overnight support. When his support staff arrived early the following morning, they found him unresponsive and called 911. The OPA/AID investigation found that none of the support staff working with the person had called the on-call nursing agency to report his illness, despite posted criteria which indicated the need to do so. It was also determined that no alternative plan was put into place for the person to receive overnight support, even though he was sick. Investigators also found that the medical components of the person's record were not thorough and were frequently inconsistent, and that support staff who discovered the person to be unresponsive neglected to perform CPR as DDS protocols require. The OPA/AID made recommendations to DDS to ensure that agency staff have a more complete understanding of the criteria used for contacting the on-call nursing agency and that the agency develop a contingency plan, as needed, for periods of time during which individuals who are ill may need enhanced support. The OPA/AID also recommended that DDS ensure that the agency performs regular audits of medical records to ensure that all pertinent medical information is present and consistently documented throughout the clients' files.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Case #3

An individual living in an apartment receiving DDS-funded in-home supports was found unresponsive by third shift support staff during a regular “check”. The OCME performed an autopsy and determined the person’s cause of death to be a small bowel obstruction. The OPA/AID investigation found that the support staff who discovered the person to be unresponsive failed to perform CPR. There was also no equipment in the apartment to aid in performing CPR, such as a face mask or mouth shield. It was also found that the provider agency’s former nurse had not entered information about the person’s history of surgical interventions and prior hospitalizations into the medical records maintained by the residential support agency. As a result her caregivers did not know about important information concerning her history of intestinal obstructions and ileostomy⁴. The OPA/AID made recommendations to DDS to ensure that the agency provide each community living arrangement with the equipment necessary for staff to effectively perform CPR as well as ensuring that complete medical information and history is available and updated throughout the clients’ files.

Case #4

Support staff at Southbury Training School (STS) found that someone in their care had removed her tracheostomy tube. This was not an unusual behavior for this person, and was usually re-inserted by a nurse. Support staff paged a nurse and left the person who had removed her tracheostomy tube to care for another resident. When support staff returned, however, the person was unresponsive and staff called 911. *(NOTE: The reporter noted that the nurse who was paged claimed she never received the page. The reporter also noted that there were “dead spots” in the paging system at STS. Based upon the known gaps in the paging system, the reporter considered it reasonably possible that the pager did not alert the nurse.)*

The OPA/AID investigation found that STS support staff, upon discovering the person’s tracheostomy had become dislodged, followed an unwritten protocol of contacting the STS main switchboard operator and having a staff nurse paged to come and attend to the person’s dislodged tracheostomy tube. OPA/AID investigators also found that the person who removed her tracheostomy tube was not checked for a period of twenty-nine (29) minutes between the time staff first discovered she had removed her tracheostomy tube and 911 was called, although the person was supposed to be monitored every fifteen minutes. Interviews with several STS staff members indicated that the on-grounds paging system rarely fails and that most of these infrequent incidents have involved staff receiving incomplete pages during inclement weather, or more rarely, in a more remote area of the campus. The OPA/AID investigation found that neither situation applied to the page which was issued to the nurse in this particular instance, and concluded that the nurse

⁴ Taber’s Medical Dictionary, 19th Edition, defines ileostomy as a surgical passage through the abdominal wall through which a segment of the small intestine is exteriorized. Fecal material then drains into a pouch, which is worn on the abdomen.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

failed to answer the switchboard page. The OPA/AID investigation also found that the person who removed her tracheostomy tube did not receive appropriate CPR measures. The OPA/AID investigation noted that for several weeks prior to the person's death, her medical condition had been changing. Despite these changes in condition, the nurse in charge of the person's building (or cottage) never reported this information to a STS medical practitioner. This same nurse noted that she was aware that the STS respiratory therapist had some tracheostomy reinforcer collars, which were made for the person to be used at the discretion of the nurse when the person removed her tracheotomy tube. This possible intervention was not documented on the Nursing Care Plan. Nor did the Nursing Care Plan include interventions to employ when the person removed her tracheostomy tube. The OPA/AID investigation found a staff person with only a few months in the employ of DDS was routinely assigned as the 3rd shift "charge" (i.e. person in charge), despite the fact that she was one of the most junior staff working in the cottage that night. The OPA/AID investigation also found that direct care staff lacked individual-specific training on tracheostomy care.

The OPA/AID made recommendations to DDS to ensure that STS discontinue the practice of assigning recently hired staff shift charge responsibilities and that STS ensure that all staff who work with individuals with specialized medical needs are trained appropriately in individual-specific needs, including specialized CPR training for staff who support individuals who have tracheostomy tubes. It was also recommended that STS ensure that the on-grounds pager system at STS is evaluated and updated as necessary to provide a fully reliable communication network.

Death due to Drowning

An individual who had recently moved into a community living arrangement was visiting a local park in the company of support staff when he waded into a body of water and drowned. OPA/AID investigators learned that the individual had autism and was known to have a seizure disorder which required that staff support remain within an arm's length distance when he was walking and out in the community. Investigators also learned that the individual was known to be attracted to water but was unable to swim. The OPA/AID investigation revealed that the support staff in question was aware of the individual's specific supervision requirements and was also aware that he was unable to swim. The staff person also indicated that he was not able to swim.

As a result of their investigation, OPA/AID determined that sufficient evidence existed to substantiate neglect against the provider agency for failing to have appropriate policies and procedures in place to ensure the individual's ongoing safety. Neglect was also substantiated against the support staff who accompanied the individual on the outing for failure to ensure the individual's ongoing health and safety by allowing him to enter a body of water unsupervised. In addition, neglect was substantiated against an off-duty support staff person who was present and who acted in a caretaker capacity for the individual while off duty, but later provided inconsistent statements about her interactions with the assigned staff person at the park. Due to the severity of neglect pertaining to the support staff's actions in association with this incident, as well as the fact that the local Police Department

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

opened an investigation into the events, a copy of the OPA/AID investigation report was forwarded to the State's Attorney for review. The OPA/AID made recommendations to DDS to ensure that all individuals who are unable to swim and have an attraction to water, or have scheduled activities near and around water are accompanied by water safety certified staff. In addition, the OPA/AID recommended that DDS ensure that the agency review and make changes as warranted regarding their off-grounds activities and initiate administrative procedures to ensure that any changes in staff support and individuals are immediately communicated to staff.

Deaths due to Homicide

A brother and sister who lived in separate community living arrangements funded by DDS were shot and killed by their father during a visit to their parents' home. The father also shot his wife and then himself. Investigations completed by the local police and the OPA/AID determined that the individuals' father acted alone in killing his family as evidenced by his suicide note and a telephone call he made to his adult children's stand-by guardian. He called the stand-by guardian, who was an old friend, after he had killed his family members and just before he took his own life. He had apparently become despondent over his own deteriorating physical abilities. OPA/AID investigated to ascertain whether there were any warning signs that should have been recognized prior to allowing the home visit. They found no evidence that the father had made any statements or taken any actions which should have created concern for the safety of his adult children prior to their being killed. The tragedy was difficult for all who knew the family, and especially difficult for those who knew the man's son and daughter. Both were well supported by their respective provider agencies and had numerous interests and strong relationships.

As a result of their investigation, the OPA/AID recommended that DDS develop a plan to provide grief counselors, similar to programs used by schools and other community based programs in response to sudden or unexpected deaths by violent means and establish procedures to ensure ongoing support for clients and support staff in dealing with the stages of the grieving process which are a natural consequence of sudden or unexpected deaths.

Fatality Review Board for Persons with Disabilities 2006-2008 Annual Report

Conclusion

The FRB continues to receive, review and record reports of all DDS client deaths. Reports of deaths occurring under unusual circumstances, those of unknown cause or those suggesting possible deficiencies in care are identified for further in-depth review and/or preliminary investigation. The FRB continues to monitor the status of all death investigations involving allegations of abuse and neglect, reviews reports from primary investigating agencies (including OPA/AID) and, if warranted, pursues additional inquiries. FRB staff also continue to work jointly with OPA/AID investigators in the investigation of deaths, which are of particular interest and/or concern to the FRB.

As a result of its investigations, annual reports and recommendations, the FRB continues to bring issues to the attention of DDS and other state departments, in an effort to effect positive systems changes which will benefit individuals who need and receive DDS support services as they make their lives in communities throughout Connecticut.

The FRB's interests in the coming year include issues affecting people with disabilities who are aging, particularly as this relates to developing person-centered alternatives to placement in long-term care facilities; improving the ability of the service system to secure the cooperation of people with disabilities who have significant, sometimes chronic, health problems and are reluctant to seek out or accept the services of health care providers; and developing more information regarding what seems to be an increasing utilization of "Do Not Resuscitate" (DNR) Orders.



This publication is available
in alternative formats upon request.

Contact Information:

State of Connecticut

Office of Protection & Advocacy for Persons with Disabilities

60-B Weston Street

Hartford, Connecticut 06120-1551

Telephone: (860) 297-4300

TTY: (860) 297-4380

Toll Free CT only: (800) 842-7303 (toll-free, voice/TTY)

Fax: (860) 566-8714

Website: www.ct.gov/opapd

Additional copies of this publication may also be
obtained on our internet site.

September 2009