Fatality Review Board for Persons with Disabilities

2005-2006

Annual Report

History

In February 2002, Governor John G. Rowland issued Executive Order #25, creating two distinct, multi-member review boards to examine the deaths of people supported by the Department of Mental Retardation (DMR): the Independent Mortality Review Board (IMRB) and the Fatality Review Board for Persons with Disabilities (FRB). Each has a distinct role. The IMRB receives extensive staff support from DMR and coordinates its activities with DMR's internal, regionally-based mortality review process. The FRB is supported by the Office of Protection and Advocacy for Persons with Disabilities (OPA) and operates independently of the DMR review structure. It tracks all reported DMR client deaths and pursues preliminary inquiries and full, independent investigations into selected cases. The Executive Order also requires development of a protocol for reporting and sharing information between DMR and OPA, and requires the FRB to report annually on its activities and findings. As of this writing, Connecticut General Assembly is considering legislation that would establish statutory authority for the FRB.

Fatality Review Board Members

Executive Order #25 designates OPA's Executive Director as Chair of the FRB, and charges it with conducting investigations into the circumstances surrounding those deaths of DMR clients "which, in the opinion of the Executive Director, warrant a full, independent investigation." The Board has five other members drawn from medical, law enforcement and human service professions and appointed by the Governor. These individuals are:

- Timothy Palmbach, Director, Forensic Science Program, University of New Haven, 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, Associate Director, United Cerebral Palsy (UCP) of Eastern CT, a professional in the field of mental retardation;
- Gerard Kerins, M.D., Chief of Geriatrics, Hospital of Saint Raphael; and
- Kirsten Bechtel, M.D., Emergency Pediatric Medicine Specialist, Yale New Haven Hospital

David Carlow, R.N., Director of Health and Clinical Services for DMR, represents the Commissioner of DMR on the FRB as a non-voting member. James McGaughey, the Executive Director of the OPA, chairs the FRB. Anne Broadhurst, a full-time Project Manager employed by OPA, provides investigative and staff support to the FRB. Barbara L. Roy, OPA's Executive Secretary, provides administrative support.

Mortality Statistics
(July 1, 2005 - June 30, 2006)

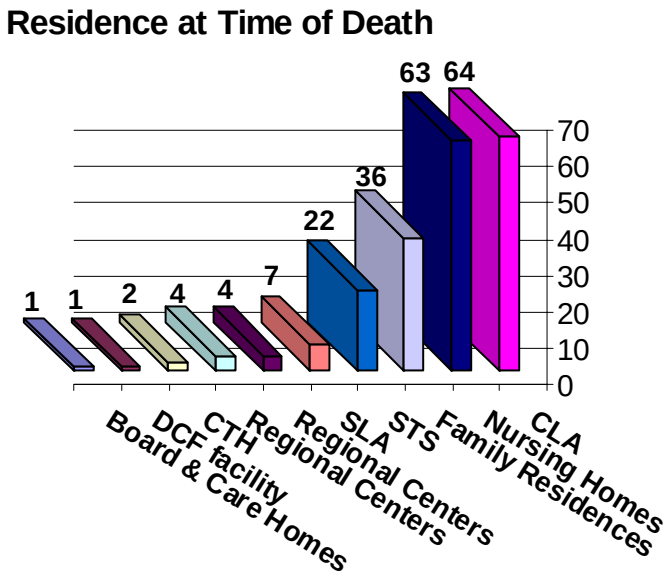
Age and Mortality

Between July 1, 2005 and June 30, 2006, 202 deaths were reported to OPA by DMR. According to the information received from DMR, 93 of the people who died had "Do Not Resuscitate" (DNR) Orders, and 43 had been receiving Hospice services. Autopsies were performed in 14 cases. 100 of those who died were women, 102 were men. These figures are generally consistent with DMR mortality reports from recent years.

As may be expected, the largest number of deaths occurred in the over-60 age group, with 99 deaths reported. 41 deaths occurred in the 51 to 60 age group; 18 deaths in the 41 to 50 age group; 15 deaths in the 31 to 40 age group; 12 deaths in the 21 to 30 age group; 9 deaths in the 11 to 20 age group; and 8 deaths in the age group birth-to-10.

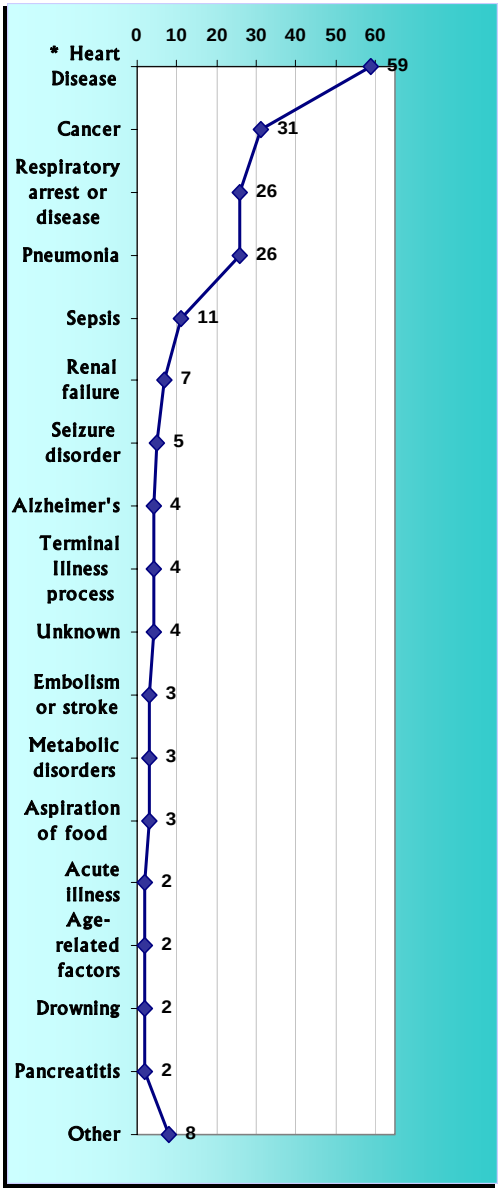
Residence at Time of Death

64 individuals were living in community living arrangements (CLA's, often referred to as "group homes") at the time of their deaths. 63 were living in nursing homes; 36 lived at home with their families; 22 at Southbury Training School (STS); 7 in supported living arrangements (SLA's); 4 in State operated regional centers; 2 in licensed community training homes (CTH's). In addition, 2 people who died were living in the community with minimal support at the time they died: one lived in a residential care home (board and care home); the other in a DCF facility.



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 CLA prior to his or her death, but may have actually died in a hospital. In fact, 88 of the deaths reported occurred in hospitals. 41 people died in nursing homes; 19 in CLA's; 14 in hospital emergency departments; 13 each at STS and family homes; 3 in regional centers; 2 each in SLA's, vocational placements and hospice facilities; and 1 each in a CTH and DMR-operated locked transitional unit. (3 deaths were recorded as having occurred in "unknown locations". These individuals lived with their families, receiving infrequent, minimal support services from DMR. See note below.)



Causes of Death

Cardiac arrest, cardiopulmonary arrest, cardiovascular disease and congestive heart failure accounted for a total of 59 deaths during the reporting period. Other causes of death listed in rank order include: 31 attributed to cancer; 26 to respiratory arrest or disease; 26 to pneumonia; 11 to sepsis; 7 to renal failure; 5 to seizure disorder; 4 each to Alzheimer's disease, terminal illness process, and unknown cause; 3 each to embolism or stroke, metabolic disorders, and aspiration of food; 2 each to acute illness, age-related factors, drowning, and pancreatitis; and (other) 1 each to accidental trauma, asphyxia by ingestible item, bowel obstruction, diabetes, drug overdose, cerebral hemorrhage, internal hemorrhage and surgical complications.

The leading causes of death recorded by the FRB during the reporting period are generally consistent with mortality experience from previous years. Statistics made available in DMR'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.
Preliminary investigations by the FRB into the circumstances surrounding four deaths reported as being due to accidental trauma (1), drowning (2) and drug overdose (1) indicated there was no

reason to suspect abuse or neglect by caretakers played any role. These deaths all involved individuals who were living with their families.

The deaths that were due to aspiration of food (3) and asphyxia by an ingestible item (1) did raise suspicions of abuse or neglect, and were fully investigated by the Office of Protection and Advocacy for Persons with Disabilities Abuse Investigation Division (OPA/AID).

(NOTE: References to "unknown" or partial information in these statistics arise from situations where DMR has provided minimal supports and has had very limited contact with the person or the person's family. Despite efforts by FRB staff to contact family members or others knowledgeable about the circumstances of the person's death, the requested information remains unavailable, and there is little likelihood of obtaining it.)

Allegations of Abuse/Neglect

Executive Order #25 creates general authority for the FRB to pursue a full, independent investigation into any death of a person with a disability. However, legislation enacted in 2004 charged OPA, as an agency, with specific responsibility for conducting direct investigations into allegations where abuse or neglect played a role in the death of an adult with mental retardation. OPA's Abuse Investigation Division conducts primary investigations into most of these deaths, although due to the location or other circumstances surrounding a particular person's 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. Consistent with its established practice, the FRB monitors the status of all fatality-related abuse/neglect investigations and reviews the resulting reports. When the FRB determines that circumstances warrant doing so, it conducts more extensive reviews of investigations initiated by other entities into such allegations.

During the twelve month time period between July 1, 2005 and June 30, 2006, the FRB reviewed the circumstances surrounding twelve deaths where there was reason to suspect that abuse or neglect may have been a contributing factor. These twelve deaths were also reported to OPA/AID for investigation. (A thirteenth case was investigated by the DCF Special Investigations Unit and monitored by the Office of the Child Advocate (OCA), as it involved a medically fragile two-year-old who died in a DCF licensed and operated facility.) As of this writing, two out of the twelve cases still remain under investigation. One of these two is being investigated by the OPA/AID; the other is still being investigated by DPH and monitored by the OPA/AID.

Of the ten completed cases, one case was investigated by DPH and monitored by the OPA/AID and two were investigated both by the OPA/AID and DPH, as the individuals' deaths occurred in Intermediate Care Facilities for the Mentally Retarded (ICF/MR), which are Medicaid-funded. Two of the ten closed cases resulted in referrals to the DPH Practitioner's Unit for possible investigation into concerns about the performance of licensed health care providers. Neglect was substantiated in eight of the ten completed cases; abuse was not substantiated in any.

Information taken from the ten completed cases, grouped according to significant issues, is summarized below.

Issue #1: Poor Quality Care in a Skilled Nursing Facility

One of the cases investigated by DPH and monitored by OPA and the FRB involved a woman with an intellectual disability who received poor care at a nursing home. She had been sent to the facility for short-term rehabilitation following a fall in her apartment. Neither her support agency nor DMR were aware that DPH had placed the facility on probation. While at the nursing home, the woman fell and fractured her hip. She was admitted to an acute care facility for hip surgery and died approximately two weeks later following a complicated post-operative course. DPH investigated the circumstances surrounding the woman's fall at the nursing home and found that the facility failed to address her "unsafe" behaviors. Although the woman was identified as a fall risk on admission, DPH found that there was a lack of a care plan and supervision. There were also many inconsistencies identified by DPH regarding both the type and level of support the woman needed to get in and out of bed, to stand and to walk. In essence, after reading the DPH investigation report and the statements given by facility personnel, it was apparent that no one at the nursing home really knew her or understood her needs.

This case is similar to other cases reviewed by the FRB in previous years, including the first comprehensive investigation completed by the Board in October 2003, where a young man with an intellectual disability died as a result of serious deficiencies in care in a nursing home where he had been sent for short-term rehabilitation. In that case, the Board found that while the young man's admission to the nursing home, which followed customary hospital discharge routine, did not include research into the particular nursing home's reputation for serving clients with intellectual disabilities, its history of DPH citations, or its suitability for meeting specific rehabilitation needs. The Board found that deviations from the young man's care plan and alarming lapses in communication among facility staff resulted in a failure to identify and respond to his health care and personal needs, including a significant medical emergency.

Issue #2: Death Due To Choking on Food or Indigestible Items

Four of the cases investigated by the OPA/AID involved choking deaths. Neglect was substantiated in three of the four investigations. The fourth case involved the death of a person who obtained food without the knowledge of support staff and choked on it. Because he had no prior history of taking and consuming food without staffs' knowledge, it was determined that his behavior at the time of the choking incident could not have been anticipated by staff.

The three investigations in which neglect was substantiated involved:

1) A woman who was known to ingest nonfood items and who was supposed to receive either one-on-one or line of sight supervision. The woman choked on ingestible material she attempted to eat at her day program.
2) A man who was on a ground food diet, had a history of taking food without staffs' knowledge, and was supposed to be on 15-minute checks and within earshot of direct care staff. The man choked on a piece of food that was apparently left out on the kitchen counter by a staff person.
3) A man who required one-on-one supervision due to medical and behavioral concerns, had a history of swallowing risks and was on a ground food diet. The man choked on an item of food he acquired without staffs' knowledge.

All three of these cases illustrate the vigilance direct care and supervisory staff must maintain in order to properly support individuals who are known to ingest nonfood items, have histories of taking food without staffs' knowledge, or are on special diets and/or have chewing or swallowing difficulties. In all these cases, investigators found that behavioral support plans or individual plans that called for "hands on" or "one-on-one" supervision existed, but were not consistently followed. The meaning of the terms "hands on" or "one-on-one" support was unclear to those charged with implementing these individual plans, and staff was not always familiar with individual dietary requirements and food consistency guidelines. Staff support was not consistently provided to individuals during mealtimes and staff was not uniformly aware of individuals' high risk behaviors and support needs across programs.

As a result of these deaths and a similar death by choking which occurred prior to this reporting period, DMR organized a Safety Summit in July 2006 for department and provider staff. Recommendations for a DMR Safety Action Plan were developed that focused primarily on additional training on ways to identify and address potential health and safety issues before they occur. The Department has adopted two analytic approaches to improving safety: "Failure Mode and Effect Analysis" or (FMEA), examines existing policies and procedures looking for areas to improve, and "Root Cause Analysis", which seeks to identify underlying factors that may have contributed to or directly caused a harmful or life-threatening event. DMR also implemented a new Level of Need (LON) Assessment and Screening Tool which attempts to identify specific needs and risks confronting individual clients. The Level of Need tool will be highlighted in a later section of this report.

Issue #3: 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 contributed to all four of the following deaths.

Case #1

A woman with an intellectual disability residing in a CLA had cataract surgery as an outpatient and was discharged that same day to the community living arrangement (CLA) she shared with several other DMR clients. Records show that, upon her return to the CLA, she was still sedated. However, after her return home, she began to get sick. Sometime between 8:00 PM and 8:30 PM, the provider agency's nurse (RN) called the CLA to check on the woman's post surgical condition. The nurse was told that the woman had vomited a few times, but that she appeared okay at the time, and that staff was getting ready to give her some Jell-O and/or clear liquids. At 9:00 PM, one of the two staff members on duty in the CLA reached the end of her shift and went home. However, over the next several hours the woman continued to vomit increasingly larger amounts. At approximately 10:30, the sole remaining staff member on duty, who was responsible for supporting all the CLA residents, called the nurse. She was instructed to call the primary care physician to see if he wanted the woman to return to the hospital. Shortly thereafter the nurse received another call. The staff member reported that the woman was still vomiting, and that she (the staff member) was having a hard time keeping the woman's hands away from her eye. The agency nurse told the staff member that the woman needed to be seen at the hospital and that she should go by ambulance, but advised the staff person to call the primary care physician first. However, several minutes later the nurse called back and advised the staff member to simply call 911. Notes from the paramedics who arrived on the scene reported that they found the woman semi-conscious. They suctioned copious amounts of vomit from her airway and transported her to the hospital. The hospital emergency department (ED) admission notes reported that the woman had been sedated with Ativan and had a history of acid reflux disease, which may have contributed to her repeated vomiting, difficulty handling of secretions. The woman was admitted to the ICU with a diagnosis of aspiration pneumonia and was placed on mechanical ventilation. Despite aggressive treatment, her condition failed to improve and she died several weeks later. The OPA/AID investigation substantiated neglect and made recommendations to DMR.

Case #2

A woman with an intellectual disability living in a CLA was being treated for what appeared to be symptoms of a cold or flu over a holiday weekend. When the third shift staff person came on duty Monday night into Tuesday morning, the woman was awake and was talking with staff until about 2:30 AM. At a little after 3:00 AM, the staff person completed a regular check. The woman was found to be unresponsive, felt cold and looked blue. Staff initiated CPR and after a few minutes with no response, called

911. The woman was transported by EMS to a local hospital, where she was pronounced dead in the ED. No autopsy was done, per the family's wishes. Though the woman's cause of death was characterized as sudden and untimely, the manner of death was determined to be natural and the cause of death was listed as seizure disorder. However, an investigation completed by the OPA/AID and reviews completed by DMR and DPH revealed that direct care staff had noted that the woman was not feeling well on the previous Friday, was congested, had a temperature and had vomited. The agency on-call nurse had been called and Tylenol was given. There was no documentation that the nurse was informed of the woman's vomiting at that time. Four hours later, the woman's temperature was below normal. On Saturday, during first and second shifts, Tylenol was given for aches and the woman had no signs of a fever throughout the day and evening. On Saturday third shift staff had telephoned the on-call nurse reporting that the woman had vomited a dark red mixture of fluid and that there was a bright pink pool of liquid between her legs. The on-call nurse was also told several hours later that the woman had a dark red spot of blood on her pillow which seemed to be coming from her right nostril and mouth and that her tongue was also coated with dried dark red material. The on-call nurse instructed the staff to try sips of water and to document incidents of vomiting and nosebleeds each shift. On Sunday morning the on-call nurse was again contacted by the staff, who reported that the woman had an elevated temperature. The on-call nurse instructed staff to give the woman Tylenol, encourage fluids and call the nurse for continued elevated temperature, vomiting or bleeding. No further incidents of vomiting, elevated temperature or bleeding were noted that day. On Monday, first shift staff noted that the woman was not doing well that day, and there were concerns noted of the woman's mouth and hands being blue; however there was no documentation that this was reported to the nurse. Sometime early Tuesday morning, the woman was found cyanotic and unresponsive by third shift staff and, as indicated above, 911 was called. The OPA/AID investigation substantiated neglect and made recommendations to DMR. As a result of the DPH investigation, the RN on-call, or practitioner in this case, received a reprimand and was placed on probation for one year, subject to a number of conditions, including attending and successfully completing remedial education.

Case #3

This case involved a man with an intellectual disability and a medical history of genitourinary problems and immediate medical condition of low urine output and an elevated temperature. He died of cardiac arrest due to sepsis caused by a urinary tract infection related to an ileal conduit or stoma. (An external appliance that collects urine at the site of the stoma.) On the Saturday before his death, the man had an elevated temperature and coughing and was prescribed Tylenol and Robitussin. On Sunday, a LPN (Licensed Practical Nurse) working at the CLA noted that his temperature was elevated in the morning and normal at noon, but he appeared to not be feeling well. He was put to bed in the afternoon, (he was non-ambulatory), and it was noted to check for decreased urinary output. Extra fluids were given with a notation to monitor and evaluate that evening. However, there was no notation that the supervising RN

(Registered Nurse) was notified by the LPN of the man's change in status, elevated temperature and decreased urinary output. (LPNs are not trained or licensed to independently conduct health status assessments; typically they work under the supervision of RNs). According to the Sunday schedule at the CLA, the RN was not working. The LPN worked from 7:00 AM until 3:00 PM, and was to return at 4:00 PM and 8:00 PM to dispense medications. (The agency, which served medically involved clients, had a vacant LPN position for the 3:00 PM to 11:00 PM shift.) The investigation completed by OPA/AID revealed that at 7:30 PM that Sunday night direct care staff went into the man's room to check on him and found him to be pale and cold. The staff member ran to get another staff person to let them know that the man was dead. The staff then called 911, the nurse and the residential coordinator. The local police department responded to the 911 call. On arrival, the CLA staff said that the man had been lying in bed all day. They also said that they checked on the man every 15 minutes and that the man had been heard making noises at about 7:15 PM. Staff also told emergency responders that they noticed that the man wasn't moving or breathing and called 911. Upon EMS arrival, the man was warm to the touch and CPR was started. It was unclear how long it had been since the man had last been seen alive. The OPA/AID investigation determined that CLA staff failed to initiate CPR immediately and failed to accurately describe the man's condition to the 911 dispatcher. OPA/AID also determined that the agency LPN failed to ensure the health and safety of the man by neglecting her professional responsibilities. Although the agency LPN was aware of the man's medical history, including his immediate medical condition, (low urine output and elevated temperature), and was aware that there was no nursing coverage on 2nd shift, the LPN postponed admitting the man to the ED, and instead instructed staff to be prepared to transport him to the ED. The agency LPN also failed to inform other medical personnel of the man's medical condition prior to leaving work.

Case #4

The fourth case involved a woman who lived in a CLA and died of cervical cancer, which had metastasized to her liver. In June 2004, over a year and a half prior to her death, a routine PAP smear produced abnormal findings. The lab report recommended further evaluation to rule out endometrial or cervical pathology. The CLA addressed this by scheduling a follow-up appointment with the woman's gynecologist in September 2004, where a second PAP test was performed. An endo-cervical surgical scraping done at the same time produced "material insufficient for diagnosis." A postcard from the gynecologist's office was subsequently received at the CLA incorrectly reporting that the September PAP smear test was normal. However, the lab results from this second test correctly indicated the presence of a "squamous intraepithelial lesion high grade." Both the lab results and the erroneous postcard were sent to the CLA. However, no further testing or referrals were scheduled for the woman. When the agency's nurses became aware of the discrepant information, they stated that they attempted to make contact with the gynecologist's office seeking clarification. (No documentation of the inquiry could be located; however, a second copy of the lab findings, with handwritten notes that were apparently added by the gynecologist's office, was faxed to the agency in

January, 2006 from the gynecologist's office after the woman had been diagnosed with cervical cancer. The handwritten notes indicating the need to take steps to follow-up, including arranging for a colposcopic examination, were not observed on the first copy of the lab report sent to the CLA in 2004.) Investigators found confusion existed between CLA staff and agency nursing staff over who was responsible for following up on notices mailed to the CLA. The absence of an effective system to communicate and document contacts with the client's gynecologist also contributed to delays in following up on the abnormal test findings. In addition to investigating the conduct of the agency nurses for possible professional discipline, the DPH practitioners unit also initiated an investigation into the gynecologist's actions. That investigation remains open.

What Went Wrong in These Cases?

Each of these cases involved delays in securing timely, appropriate medical interventions on behalf of people who were entirely dependent on others to arrange for their health care. In the first three cases, direct-care staff was expected to "monitor" the condition of an individual who was ill, and report to an "on call" nurse whose role was somewhat ambiguous. Investigations into these deaths found that an absence of clear standards and expectations concerning the responsibilities of direct-care staff, on-call nurses and administrators contributed to delays in seeking definitive medical care. While the fourth case did not involve an acute illness or "on-call" nurse, the failure of agency staff, including nursing staff, to pursue timely follow-up interventions in the wake of troubling test results proved equally detrimental to the client's health.

The FRB has previously recommended that DMR clarify expectations for nursing supports in residential and day programs. An additional recommendation regarding initiation of a process for clarifying roles and expectations is included in this report. DMR's responses to earlier recommendations are summarized in a later section of this report.

Issue #4: Severe Pancreatitis Associated with Use of Valproic Acid

The FRB monitored an investigation into the sudden death of a woman who lived in a CLA and who had fallen and sustained a possible head injury. The hospital to which she had been transported following the fall found that the head injury was not serious. However, routine diagnostic tests revealed that she was suffering from severe pancreatitis. Neither the OPA/AID investigation nor mortality reviews by DMR identified any indications that the woman had been experiencing health problems in the month preceding her death, or that there had been any evidence of neglect in her care. It was noted, however, that the woman was taking valproic acid, an anti-convulsant medication commonly marketed under the trade name, Depakote. Valproic acid is approved for use to treat seizure conditions, the manic phase of bi-polar disorders, and to prevent migraine headaches. It is also frequently prescribed "off label" as a behavior modifying medication. However, because the use of valproic acid is also sometimes

associated with development of pancreatitis, "...in July, 2000, the Food and Drug Administration instituted new black box warnings in the package labeling for valproic acid to include the risk of pancreatitis." (*Pancreatitis Associated with Valproic Acid: A Review of the Literature*, Pharmacotherapy, Chapman, Wacksman & Patterson, available through Medline, www.medscape.com/viewarticle/418324)

The FRB linked this case to cases reviewed in previous years where pancreatitis had been diagnosed in clients who had been taking valproic acid. Because the drug is commonly prescribed for DMR clients, both for seizure control and behavioral issues, both the FRB and the OPA/AID recommended that DMR consider issuing a Medical Advisory reminding practitioners about the potential risk of pancreatitis associated with valproic acid. DMR indicated that it would contact Food and Drug Administration to report such incidents, as identified through mortality review. In addition, DMR indicated that they would request additional information from the manufacturer of the drug and then send reminders to providers regarding the risks of adverse effects with anticonvulsants. DMR also reported that they would review the current recommended schedule for obtaining blood serum levels to ensure appropriate monitoring, as advised by the drug manufacturer.

Cases Reviewed by the FRB

In addition to monitoring abuse/neglect fatality investigations, FRB staff receive, review and record reports of all deaths known to DMR. 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 obtains pertinent data, 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 works jointly with OPA/AID investigators in the investigation of deaths, which are of particular interest to the FRB. During the time period between July 1, 2005 and June 30, 2006, thirty-five cases were subject to such in-depth discussion, monitoring, investigation and review. As the examples cited below indicate, many of these inquiries determine that care was, in fact adequate. However, in certain cases, the Board felt that recommendations for improvement were in order.

Case Examples

- A young woman living at home with her family died suddenly. An autopsy was completed by the State of Connecticut Office of the Chief Medical Examiner (OCME) and it was determined that the woman's cause of death was associated with hypertensive and atherosclerotic cardiovascular disease. The FRB had questions about the circumstances prior to the woman's death because the autopsy report revealed multiple contusions on many areas of her body, some of which seemed unlikely areas to sustain bruises. Board staff obtained information concerning the woman's history, care and treatment. Records were reviewed and her Case Managers (past and present), local mental health provider and treating psychiatrist were contacted. Following a review of this material, the FRB recommended that Board members and FRB staff meet with the OCME to review the results of the woman's postmortem examination. A meeting was held with the Chief Medical Examiner, Associate Medical Examiner and OCME's Lead Investigator. OCME staff indicated that the pattern of bruising on the woman's body at the time of her death was not consistent with a pattern of physical or sexual assault. They also indicated that the age of the bruises was consistent with a reported incident involving the woman falling out of bed, and breaking her bed, as the bruises were typical of ones sustained as the result of a fall.

- A young girl with Down Syndrome died as a result of an un-witnessed, accidental drowning, according to the local authorities. The Board obtained additional information regarding the circumstances of the girl's death as well as her medical records from the hospital that had provided her primary care and treatment. The Board learned that the girl was being treated with medication for a condition known as "metabolic disorder" (pre-diabetic condition), which is usually marked by the presence of high blood pressure, obesity, and high blood sugar levels. Due to the unexpected manner of the girl's death, the Board wondered whether the girl's family had received instruction in monitoring her blood sugar levels, as well as information concerning the potential side effects of the prescribed medication. The medical provider indicated that the girl's family had received instruction regarding monitoring her blood sugar levels as well as information concerning the potentially significant side effects of the prescribed medication. However, the medical provider also reported that the girl had a history of medication non-compliance and that her family seemed to have an incomplete understanding of her needs. The Board felt that in-home supports and/or community based services might have been useful options for the girl and her family, and sent a letter to the medical provider informing them of the voluntary service options available to families through DCF.

- A man living at home with his parents died suddenly of an apparent heart attack. Through interviews with his case manager and primary care physician, as well as a review of his medical records, the Board learned that the man had a congenital heart condition (conductivity blockage), and that a pacemaker had been placed almost ten

years prior to his death. The Board recommended that a letter be sent to the man's surgeon, asking whether there was any type of ongoing monitoring of him provided by the surgeon or the surgeon's practice, or if there had ever been any complications associated with the pacemaker's use. In response to the letter, the surgeon contacted FRB staff directly to report that the man was seen in the surgeon's office every three months to have his pacemaker checked. The surgeon reported that the man almost always kept these appointments, and that no complications with his pacemaker were ever observed.

- The FRB completed a comprehensive review of the care and treatment provided to a woman living in a nursing home, based upon concerns expressed by a family member living out of state. DMR did not complete a mortality review of this case because the woman had been placed in the nursing home by family members. Based upon its review, the Board was unable to determine that the care and treatment provided to the woman prior to her death was inadequate.

- The FRB reviewed several cases, which involved DMR not receiving timely notification from nursing homes after residents who were clients of the Department had died. In one case, a DMR Case Manager learned of the death of someone on her caseload by seeing the obituary in the newspaper. In another instance, a nursing home filed its intent to close the facility with the Department of Social Services (DSS) and DMR began looking into whether any clients of the Department were living in the facility. In doing so, a man who was known to DMR surfaced. When DMR contacted the nursing home to check on him, they learned that he had died three years before. In another instance, a DMR Case Manager was informed of the death of someone on his caseload when he visited the nursing home to participate in a meeting for another client. Further inquiry revealed that the man in question had been hospitalized and subsequently died eight months earlier from complications of coronary artery disease. No one at the nursing home had notified the Case Manager of the man's hospitalization or death. It is important to note that pursuant to Public Law 104-315, Section 2(a), nursing facilities are required to notify DMR and the Department of Mental Health and Addiction Services (DMHAS), as appropriate, "promptly after a significant change in the physical or mental condition of a resident who is mentally ill or mentally retarded." The same notice requirements are contained in Connecticut General Statutes (CGS) Sec. 17b-360.

- A young man who had been diagnosed with a progressive neuro-muscular disease depended on a portable respirator to assist his breathing. The device was equipped with an alarm to alert caretakers in the event of malfunction. The alarm sounded while he was being driven home from his day program. The driver of the van, who was familiar with the young man and the operation of his equipment stopped and corrected an apparent problem with the tubing leading to the respirator. However, after resuming travel, an alarm sounded again. This time, the young man appeared unresponsive. Help was called, and the young man was transported to a hospital, where he was pronounced dead. The Medical Examiner determined that the cause

and manner of death was "undetermined". Because the alarm had sounded, and because there was a preliminary report indicating that a relative had made some adjustments to the young man's equipment earlier that day, an examination of the respirator was in order. It was later determined that the adjustment was to the man's wheelchair, not the respirator. It was also determined that the man had likely died due to a fatal myocardial infarction. However, neither the Office of the Chief Medical Examiner nor the local police department were able to locate an independent laboratory source to conduct forensic tests of the function of the respirator. The FRB checked with the FDA, which approves the marketing of medical devices such as the respirator in question, and determined that there had been a manufacturer's voluntary recall on a similar model. However, a check of the model and serial number of the respirator used by the young man indicated that it was not subject to the recall. A more recent case reviewed by the FRB raised similar questions concerning the functioning of portable life support equipment. As indicated in the recommendations section of this report, clear protocols need to be developed for forensic testing of life support equipment when there is reason to suspect it may have malfunctioned.

FRB Recommendations

1. To encourage nursing homes to fulfill their obligation to keep DMR informed of any significant changes in the condition of individuals with mental retardation who have been placed into those facilities, the Commissioners of Mental Retardation, Social Services and Public Health should jointly issue a letter to all licensed nursing facilities in Connecticut reiterating the State and Federal mandates that require that DMR be notified of any significant change in the physical or mental condition of any nursing facility resident who has mental retardation. [Public Law 104-315 and CGS 17b-360 (d)] While forms outlining notification responsibilities are sent to facilities by DMR for inclusion in individual records whenever a person with mental retardation is screened under federally mandated procedures for admission, the letter referred to in this recommendation would be addressed to facility administrators. By way of explanation it could cite recent examples where facilities failed to provide required notification. Optimally, the letter should include information about the DMR regional structure, directions for notifying DMR Case Managers and regional after hours on-call managers, as outlined in DMR Procedure I.E. PR005, and it should encourage facilities to discuss any questions or problems regarding individual clients with DMR's Regional Health Services Directors. The letter should also recommend that facilities identify particular staff members who are to be responsible for ensuring that DMR is given

timely notification of changes in clients' conditions and circumstances, and ensure that those staff members are properly trained.

2. DMR 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 mental retardation has undergone a significant change in condition. Procedures should specify who is responsible for acting on information concerning "whether the resident requires the level of services provided by the nursing facility or requires specialized services." [CGS 17b-360 (d)], and for taking appropriate actions with respect to DNR orders and major medical care issues (e.g. to withhold nutrition and hydration or other medical interventions and treatments).

3. Building on its past efforts, DMR should pursue a process to develop more consistent standards regarding nursing support services for all residential programs. To comply with legal requirements for supervising the administration of medications by direct care staff, both State operated programs and private provider agencies typically rely on "on-call" nursing systems. Many provider organizations contract with nursing agencies or hire individual nurses to fulfill this responsibility and, depending on the agency's circumstances, for other services as well. (Other nursing services may include health care coordination for agency clients, consumer education, administrative functions and delivery of direct clinical services to clients.) In addition to identifying situations where the judgment of individual nurses was found lacking, investigations have also surfaced confusion amongst various parties over expectations surrounding the role of on-call nurses in different programs. Because that confusion has contributed to delays in obtaining definitive care for individuals who were ill and who ultimately died, the FRB believes that further clarification regarding nurses' roles is very much in order. However, the Board also recognizes that different programs and provider agencies have different needs, structures and resources, and, further, that individual nurses hold different types of professional licenses that carry somewhat different levels of professional responsibility. It is also widely understood that nurses of all types are generally in short supply. Accordingly, instead of recommending that DMR develop detailed, universal standards for nursing services, the Board recommends that DMR expand on recent efforts by pursuing a determined, interactive <u>process</u> to achieve clarity regarding nursing roles and expectations within each of the different types of support programs and the different provider agencies the Department operates, licenses or funds. As part of that process, DMR should also determine whether any system-wide resource or policy development needs exist. After extensive discussions, the Board believes that engaging in an interactive process will likely be more successful than simply attempting to promulgate

system-wide standards. However, to be meaningful, the process will need to maintain an intense focus on client needs, and seek specific outcomes. These outcomes include;

a. Ensuring that direct care staff, supervisors, administrators and nurses in each program level, provider agency and organizational unit have clear, consistent understandings of the roles of any nurses employed by, contracted for or assigned to that program, agency or unit, and of the protocols for communicating and responding to clients' health care needs.

Specifically:

- that nurses are assigned responsibilities consistent with their level of training and licensure;
- that nurses and others know whether and/or under what circumstances nurses are expected to personally assess a client's condition;
- that agency expectations regarding nursing documentation has been articulated and aligns with generally accepted professional expectations;
- that if nurses perform an "on-call" function, they know the extent and limitations of direct care staff competencies in reporting signs and symptoms of illness;
- that if nurses perform an "on-call" or triage/consulting role for direct care staff, they be well trained on telephone-based nursing triage protocols;
- that staff involved in direct care, supervision and management of each program know the parameters and limitations of the particular "on-call" nursing supports available to them and their clients.

b. Ensuring clarity regarding the duties and competencies required of direct care, supervisory and administrative staff at all levels as they relate to client health issues, and particularly with respect to clients who are ill or who may be experiencing distress. Although the levels of client need may vary considerably between various types of programs and agencies, each organizational unit needs:

- to be clear about, and periodically review who is responsible for coordinating clients' health care;

- to ensure clarity regarding responsibilities for following-up on physician recommendations, results of laboratory studies and specialty evaluations, etc.;
- to ensure sufficient staffing levels to cover client illnesses and provide adequate support following surgery or medical procedures;
- to ensure that minimal requirements for certification in CPR and Medication Administration are met and kept current; and that staff are trained in basic techniques for obtaining and reporting vital signs.

4) As increasing numbers of people with significant disabilities are relying on personal life-support technology to allow them to live in their own homes and communities, it is predictable that further questions regarding possible malfunctioning of that equipment may be raised during investigations into individuals' deaths. 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 or when there may be a question of tampering or inexpert manipulation. Accordingly, the FRB recommends that the Commission on Medicolegal Investigations direct the Office of the Chief Medical Examiner in establishing a definitive protocol and that it support the OCME in obtaining the resources necessary to make such testing available.

Previous FRB Recommendations and DMR Responses

Since the FRB began its reviews in September 2002, a number of recurrent issues meriting close attention by providers, service planners and policy makers have been identified in FRB investigation reports and annual reviews. Recommendations were made to address many of those issues. In an effort to ascertain the impact of its recommendations, FRB staff met with DMR staff to discuss DMR's response to the FRB's recommendations. The information summarized below was obtained as a result of discussions with David Carlow, DMR Director of Health and Clinical Services, Beth McArthur, Assistant to the DMR Deputy Commissioner, and Kathleen Egan, DMR Legal and Government Affairs Division.

FRB Recommendation

Significantly improve health care coordination for individuals living in the community who have chronic medical problems.

DMR Response

A. Level of Need and Safety Screening Assessments

Under a Systems Change Grant for Community Living, which was awarded to DMR by the Centers for Medicare and Medicaid Services (CMS), a steering committee comprised of DMR staff, providers, advocates, family members and consumers participated in the development of a new Level of Need (LON) Assessment and Screening Tool. The fourteen-page LON assessment, which will be completed for all individuals who have an Individual Plan or Follow Along Plan, identifies areas where a person needs or requires support. These areas include health and medical, personal care activities, daily living activities, behavioral and mental health, safety, comprehension and understanding, communication, transportation, social life and recreation and community activities. Other areas include identifying the support needs of the person, during both waking and overnight hours, the person's own caregiving or parental responsibilities, as well as a comprehensive description of the person's unpaid sources of support.

A Health and Safety Risk Profile is developed from any areas highlighted in the LON assessment which hold the potential for risk. Many areas of potential risk

have been identified as concerns by mortality review. These include the identification of swallowing disorders, the careful monitoring of medications for side effects and other medication risks, assistance with bathing or showering, eating or drinking non-food items, the refusal of critical supports or services and support staff being unfamiliar with the person's needs. The Health and Safety Risk Profile also includes a checklist for the development of strategies to address any identified risks.

Information obtained on the LON assessment and Health and Safety Risk Profile are addressed in the person's Individual Plan or IP. Ultimately, DMR plans to assign specific costs according to individual support level, which is based on areas of identified need and potential risk.

DMR is currently developing a Risk Profile, which will specifically address people living on their own, in supported living arrangements, or less structured settings. The completion of the LON assessment and associated Risk Profile for this sub-set of individuals will help DMR identify those people who may require a more structured system of health care coordination and monitoring. DMR is also in the process of standardizing other key health and medical assessments, such as those used to assess a person's ability to self-administer medications.

The implementation of LON assessments began in April 2006. Over 4,100 have been completed to date. DMR plans to have LON assessments completed for all people receiving Medicaid waiver-funded services by July 1, 2007, which will be for a little over 7,000 individuals. The remainder of people receiving non-waiver-funded services will have their LON assessments completed over a three-year period.

Between January of 2005 and January of 2006, individuals in receipt of supported living services who had Follow Along Plans had their planning process converted to the 'Individual Plan' process. As of January 2006, all individuals in receipt of supported living services have Individual Plans. Since the fall of 2006, case managers and other support team members have participated in enhancement training in the development of Individual Plans, in order to improve the plans and to better link the Individual Plan to the Level of Need assessment.

B. Managed Health Care Coordination Pilot

DMR is initiating a pilot project to improve health care coordination and support for people living in supported living arrangements, which are operated by the private sector in the North Region. Approximately forty people supported by a variety of qualified providers will participate in the project. Participants will be selected for participation in the project based on their having fairly significant

health, behavioral health and medical support needs, as identified through the completion of LON assessments and case management referral.

The coordinator of the project will be a Nurse Consultant with significant experience in developmental disabilities nursing practice, and will be under the supervision of the DMR North Region's Director of Health Services. He or she will review and assess the person's health and medical support needs and identify gaps in community-based health care support services. The Nurse Consultant will collaborate with a community-based nursing agency, such as the Visiting Nurse Association (VNA), to identify and develop best practice guidelines for coordinating and monitoring the delivery of health and medical services for individuals in supported living. Acting as their identified source of health care coordination and advocacy, the project coordinator will meet with all of the participating consumers directly, at least every ninety days, to ensure that their health care needs are being met.

As of this writing, DMR has hired a registered nurse for the Managed Care Coordinator position. DMR anticipates that the pilot project, if successful, will be implemented in the West and South Regions as well.

FRB Recommendation

Develop health and wellness education programs specifically designed to reach people with intellectual disabilities.

DMR Response

The pilot project designed to improve health care coordination and advocacy described above will include a "Health and Wellness" component. The "Health and Wellness" component will address such areas as smoking cessation, nutrition/healthy eating habits, physical fitness and any other health and wellness needs that have been identified in LON assessments and the Individual Planning process.

For individuals supported by public sector supported living staff, DMR is planning to initiate a small pilot program (groups of ten to fifteen people) in each of the three regions. Utilizing a curriculum developed for people with intellectual disabilities, the program will focus on the promotion of health education and wellness, and will be individualized and personalized based on individual need and interest. The health curriculum will provide training for staff as well as consumers and will also include an evaluation component.

The "Health and Wellness" curriculum was finalized in January 2007 and regional programs began in late February of this year. A basic outline of the curriculum, or some of the possible topic areas, is listed below:

- Making healthy choices
- Eating foods that are good for one's self (use of a personal notebook)
- Taking care of one's body by eating healthy foods
- Discuss benefits of good nutrition
- Discuss the effect of nutrition on physical and emotional well being
- Understand the advantages of including different types of food in one's diet
- Food pyramid (my pyramid)
- Field trip to a grocery store
- Nutrition cards
- Nutritious snacks
- Feeding your body
- Handouts/worksheets
- Nutrition planning
- What foods do I like to eat?
- How much water am I drinking?

FRB Recommendation

Avoid nursing home placements; where possible, establish a network of preferred nursing home providers to meet short-term rehabilitation needs.

DMR Response

One of the recommendations made by the FRB was that DMR, where possible, establish a network of preferred nursing home providers to meet short-term rehabilitation needs. In past discussions, DMR noted that Massachusetts has developed a "preferred provider" approach. After researching this area, it was learned that Massachusetts has no such system. It seems unlikely that DMR will be able to generate a formal network of preferred nursing home providers. Investigations conducted by the Department of Public Health (DPH) only indicate whether minimum standards of care established in state and federal regulations have been met. Information concerning the results of DPH nursing home investigations is available on the DPH website, as well as a link, "Health

Care Quality", to the United States Department of Health and Human Services "Comparing Nursing Homes" national database.

Additionally, the Consumer Reports *Nursing Home Quality Monitor*, published in August of 2006, provides a state by state breakdown of nursing homes that are likely to provide better quality care. It looks at deficiencies cited in each nursing homes' three most recent state inspection surveys; staffing levels for registered nurses, licensed practical nurses and nurse's aides; and certain quality indicators required by the Center for Medicare and Medicaid Services (CMS).

FRB Recommendation

Clarify expectations for nursing supports in residential and day programs.

DMR Response

A. Medication Administration

DMR is seeking to revise the current medication administration regulations to more adequately reflect DMR's current practice and various medication related systems changes that have emerged over the years. The current regulations were developed at a time when people supported by DMR were living in more structured traditional settings. The current medication regulations require that a nurse be available to supervise and provide some degree of oversight to non-licensed staff who administer medications across all settings, including to those consumers who are taking advantage of increasingly flexible support options available through various waiver and self-determination initiatives. The intention of the proposed regulatory changes concerning the administration of medications would permit trained, non-licensed staff, including those hired by the consumer, to administer medication in settings other than "residential facilities" and "day programs" without the supervision or oversight of a registered nurse. This addition to the regulations authorized by Public Act No. 05-150 would allow the nurse to devote more time to providing clinical coverage and provide a level of quality assurance which would not be available if such staff relied solely on the exemptions set forth in CGS Sec. 20-101.

B. DMR Public Nurse Managers/Health Services Directors

Historically, DMR's three regional Health Services Directors have been responsible for the clinical supervision of nursing support services in the public sector and reviewing the quality of nursing services in the private sector. DMR has recently created a "Public Nurse Manager" position for each of DMR's three

regions. The primary responsibility of the Nurse Manager will be to clinically supervise all aspects of nursing support services in the public sector, or DMR-operated facilities. Therefore, the Health Services Directors will concentrate their efforts on nursing and health services provided by the private sector, including skilled nursing facilities.

In partnership with Nurse Consultants employed or utilized by agencies in the private sector, the Health Services Directors will focus on ensuring that standards of nursing practice established by DMR and other medical experts and DMR's expectations for nursing support are thoroughly communicated and understood. It is expected that private sector Nurse Consultants will meet at least quarterly with the Health Services Directors/regional Nurse Consultants. The purpose of these meetings will be to evaluate the quality of nursing support services, communicate pertinent information resulting from mortality reviews, identify gaps in service and ensure that consistent standards and expectations regarding nursing support services are met in all facilities.

It is also hoped that the realignment of the Health Services Directors' responsibilities will enhance the level of monitoring and health care oversight and coordination when individuals supported by DMR are admitted to nursing homes.

DMR Additional Service System Enhancements

"Quality Service Review"

DMR is currently developing mechanisms to better track and evaluate the performance of service providers, both in the public and private sector. Performance measures to be considered would include the type and frequency of abuse/neglect reports, provider response to investigation findings and recommendations, mortality review findings as well as the type and frequency of critical incident reports, in addition to other outstanding issues or concerns. With input from the provider, the quality service review would allow DMR Resource Managers to set specific expectations and performance objectives as well as to work with providers to develop strategies to address specific concerns. It would also allow for DMR to develop a comprehensive, comparative analysis of provider performance for the public's information and review.

"Systemic Responses to OPA Regional Death Investigation Recommendations"

In order to facilitate a timely and adequate response to systemic recommendations stemming from OPA/AID death investigations, DMR has assigned a senior staff person to act as a liaison and "point person" between DMR and the OPA/AID.

Conclusion

DMR has made efforts to follow-up on issues the FRB has brought to its attention as a result of investigations, annual reports and recommendations. The DMR Safety Campaign and managed health care coordination pilot are two notable initiatives the agency has undertaken to improve client services.

However, issues affecting people living in nursing homes and expectations for nursing supports in residential facilities and support programs continue to be areas of concern. As the 2005-2006 death cases summarized in the body of this report illustrate, at least some people with mental retardation continue to receive poor care in nursing homes, and the absence of clear expectations regarding nursing support services in residential and other support programs continues to contribute to confusion and delays.

This publication is available in alternative formats upon request.

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