



**Fatality Review Board for
Persons with Disabilities**

**2004 – 2005
Report**

History

In February 2002, responding to concerns voiced by family members and other advocates about the adequacy of existing mechanisms to review and investigate deaths of clients of the Department of Mental Retardation (DMR), Governor Rowland issued Executive Order #25. The Executive Order created two multi-member boards to review DMR client deaths, each with a distinct role. One of these – the Independent Mortality Review Board (IMRB) – assumed the quality assurance functions of DMR’s previous statewide mortality review body, and provides a comprehensive review of the circumstances surrounding those deaths identified by the Department’s service regions as requiring independent review. The other board - the Fatality Review Board for Persons with Disabilities (FRB) – is supported by the Office of Protection and Advocacy for Persons with Disabilities (OPA), and is largely focused on pursuing independent investigations into the circumstances surrounding a relatively small number of deaths that raise particular concerns.

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, 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.

Outcomes

- Between July 1, 2003 and June 30, 2005, three hundred sixty-one (361) deaths were reported to OPA by DMR. Data concerning all of these deaths is reviewed, tracked and entered into a database established in 2002 by OPA. Information on every death is summarized and reviewed by FRB members at meetings, which are held bi-monthly. Board members identify cases requiring further information gathering and, depending upon the information developed, recommend which cases the Executive Director should consider for an independent investigation or further review. Between this same time period, approximately thirty-five (35) cases were subject to such in-depth discussion, monitoring and review.
- The Board has sent several letters to Commissioners, agency heads, physicians and other professionals requesting responses to various issues and concerns raised as a result of case reviews.
- Board members have provided timely technical assistance, professional advice and, on occasion, direct intervention concerning cases under investigation by OPA Abuse Investigation Division (AID) investigators.
- In response to the Board's request that OPA provide it with additional support, OPA has established a clinical affiliation with Quinnipiac University to provide field work experience (internships) to nursing students enrolled in the university's forensic nursing program. The responsibilities of the interns are to assist the Project Manager by reviewing client records and other relevant materials and preparing a summary report of issues of concern and additional areas of inquiry. As of this writing, four nursing students have been placed in internships at OPA.
- In October 2003, the FRB issued its first full investigation report on the circumstances surrounding the death of a man with an intellectual disability who died following his admission to a nursing home located in Norwich. As a result of the investigation, the FRB made a number of recommendations to the Department of Mental Retardation (DMR), the Department of Public Health (DPH) and the Department of Social Services (DSS). The recommendations were intended to prevent the recurrence of similar deaths and to effect positive change and improvement in the quality of care and treatment for individuals who are similarly placed. In part because of the findings of the FRB in this case, along with serious and persistent deficiencies identified by DPH, the nursing home itself has closed. It's important to note, however, that the FRB never received formal responses from DSS, DMR or DPH regarding the recommendations made as part of its report.

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- In March 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 mental retardation who died following a vicious assault in the lobby of his apartment building in Hartford, CT. A police investigation into the assault resulted in the arrests of five juveniles. The assault was captured on surveillance videotape that depicted several of the youths throwing large, plastic soda bottles at Ricky. One of the bottles struck his head, knocking him to the ground. The tape showed that while he lay motionless, his pants were pulled down, soda was poured over him, and he was repeatedly kicked.
- Following Ricky's death, several newspaper articles quoted relatives and friends who questioned whether the urban neighborhood where Ricky had been living was an appropriate location for someone with his disabilities. The fact that Ricky had been assaulted by neighborhood youth had a deeply unsettling effect on people similarly supported in the community. Many advocates and service providers viewed Ricky's death as a hate crime. A coalition of advocacy groups began to pursue and successfully worked to pass legislation, which explicitly criminalizes hate crimes against people with disabilities. They dedicated their efforts to Ricky's memory.
- Immediately following the release of the FRB's investigation report, DMR issued a public statement indicating that DMR conducted an evaluation of quality assurance systems for persons living in circumstances similar to Ricky W.'s. According to the statement issued, the evaluation resulted in improvements to the assessment of risks facing persons who are similarly situated. The Commissioner 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."
- Following the release of the investigation report, OPA staff and members of the FRB also met directly with representatives from DMR and DPH to discuss the recommendations contained in the report.
- In November 2005, DMR hosted a Supported Living Symposium for staff and persons receiving DMR-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.
- After reviewing the FRB investigation report, DPH representatives stated that there was nothing in Ricky's case that DPH could take formal action on. However, they questioned the appropriateness of Ricky's discharge from the home health agency in November 2002, and wondered whether all efforts to elicit Ricky's cooperation had truly been exhausted.

***Recommendations and Lessons Learned from
FRB Investigations and Reviews***

Since the FRB began its reviews in September 2002, it has identified a number of recurrent issues that merit close attention by providers, service planners and policy makers. In recognition of those issues, the Board makes the following recommendations:

1. Significantly improve health care coordination for individuals living in the community who have chronic medical problems. Inadequate coordination of health care factored into several of the deaths that the FRB reviewed during this reporting period, and was identified as directly contributing to Ricky W.'s death. A number of individuals with chronic health care problems being supported in the community lack a clearly identified source of health care coordination and advocacy. DMR has acknowledged this issue and has begun a dialogue about addressing it. The FRB recommends that DMR invest in health care advocacy and coordination efforts for people with intellectual disabilities and families who are taking advantage of increasingly flexible funding options through the various waivers and self-determination grants currently available.

2. Develop health and wellness education programs specifically designed to reach people with intellectual disabilities. The FRB recommends that DMR, working in collaboration with health care providers, self-advocates and others having an interest in promoting health education and wellness, develop health education programs designed to reach people with intellectual disabilities. Recent research conducted by the A.J. Pappanikou Center for Excellence in Developmental Disabilities, University of Connecticut Health Center (UCEDD) points to best practices and possible approaches in this area. The results of that research are reported as an appendix to this report.

3. Avoid nursing home placements; where possible, establish a network of preferred nursing home providers to meet short-term rehabilitation needs. The largest number of deaths reviewed by the FRB involved individuals living in nursing homes (136). In reviewing these deaths, the FRB identified a number of instances where overall quality of care had been judged to be deficient by licensing and investigation staff from the Department of Public Health, and where failure to communicate or act on essential client care information likely contributed to death. Given these findings, DMR should review current practices and take action to address environmental and programmatic factors that prevent people from staying in their homes following a major illness or loss of mobility. No DMR client should be placed into a nursing home if he or she could otherwise live in their own residence (e.g. group home, apartment, own home) with reasonable accessibility modifications and programmatic adjustments. The FRB recognizes that there are some situations when a nursing home placement must occur

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(e.g. for short-term rehabilitation). However, the current practice of allowing hospitals to discharge a DMR client to “the first available bed”, does not lend itself to development of working relationships between service providers and nursing home personnel. The FRB recommends that DMR work to establish relationships with preferred skilled nursing facilities - facilities that have demonstrated they can meet requirements for basic care and rehabilitation of individuals with intellectual disabilities. These requirements should include having a licensed nurse to coordinate the intake process and act as a reliable liaison between facility staff, family members, service system staff, consulting specialists and primary care physicians who know the person.

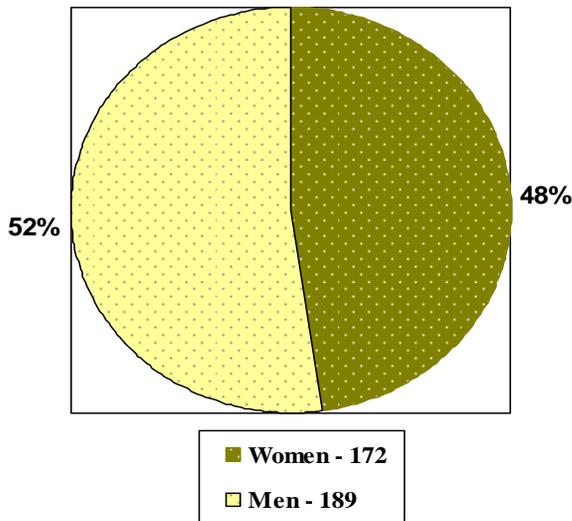
4. Clarify expectations for nursing supports in residential and day programs. Through its reviews, the FRB has been made aware of nursing oversight and nursing coverage issues in DMR licensed residential facilities. Some of these issues include problems where a death has occurred in a facility and there appeared to have been a lack of proper and detailed nursing documentation relating to the illness or medical events preceding the death, on call nurses being unavailable to perform necessary patient assessments, problems with direct care staff being required to assess client status, insufficient or even no responses to staff calls to on call nursing supports. The FRB recommends that DMR develop consistent standards and expectations regarding residential nursing support services in all licensed facilities. DMR should also develop nursing coverage protocols for all residential support models.
5. Provide detailed, timely information regarding untimely and unwitnessed deaths to the Office of the Chief Medical Examiner. It is critical that the Office of the Chief Medical Examiner (OCME) receive prompt notification of untimely deaths of DMR clients and that autopsies be pursued and conducted when warranted. The FRB recommends that DMR and OPA/AID ensure that all efforts are made to seek out and provide the OCME with thorough and reliable information regarding the immediate circumstances of the person’s death as well as relevant medical history, in order for the OCME to make informed judgments regarding the depth and scope of their involvement and the manner and cause of a person’s death.
6. Increase staff support to the FRB. To discharge its duties in a more satisfactory and timely manner, the FRB needs additional staff support. OPA has only one federally-funded staff member assigned to track, research, conduct inquiries and report to Board members on all deaths, as well as to conduct full investigations and draft major reports. Additional staff resources are necessary due to the large amount of work involved in preparing cases for the Board to review. There have been occasions over the past two years when the Board would like to have pursued recommendations or requests for information, but was unable to do so due to a lack of resources. Finally, the Board would like to undertake studies, initiate in-depth analysis and conduct research concerning various topics and issues, so as to better inform its policy recommendations. However, it lacks the staff to do so.

Mortality Statistics (July 1, 2003 – June 30, 2005)

Number of Deaths Reported

Between July 1, 2003 and June 30, 2005, three hundred sixty-one (361) deaths were reported to OPA by DMR.

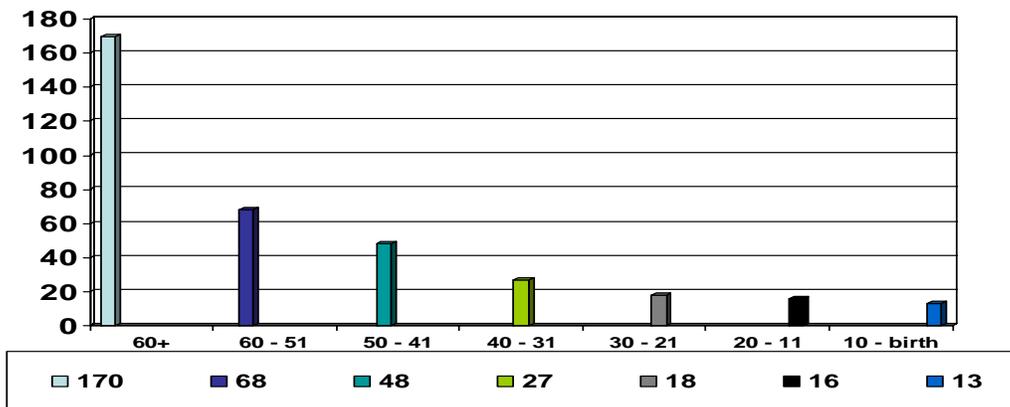
Gender and Mortality



The number of deaths for men was one hundred eighty-nine (189) or 52% of the total number. The number of deaths for women was one hundred seventy-two (172) or 48%.

Age and Mortality

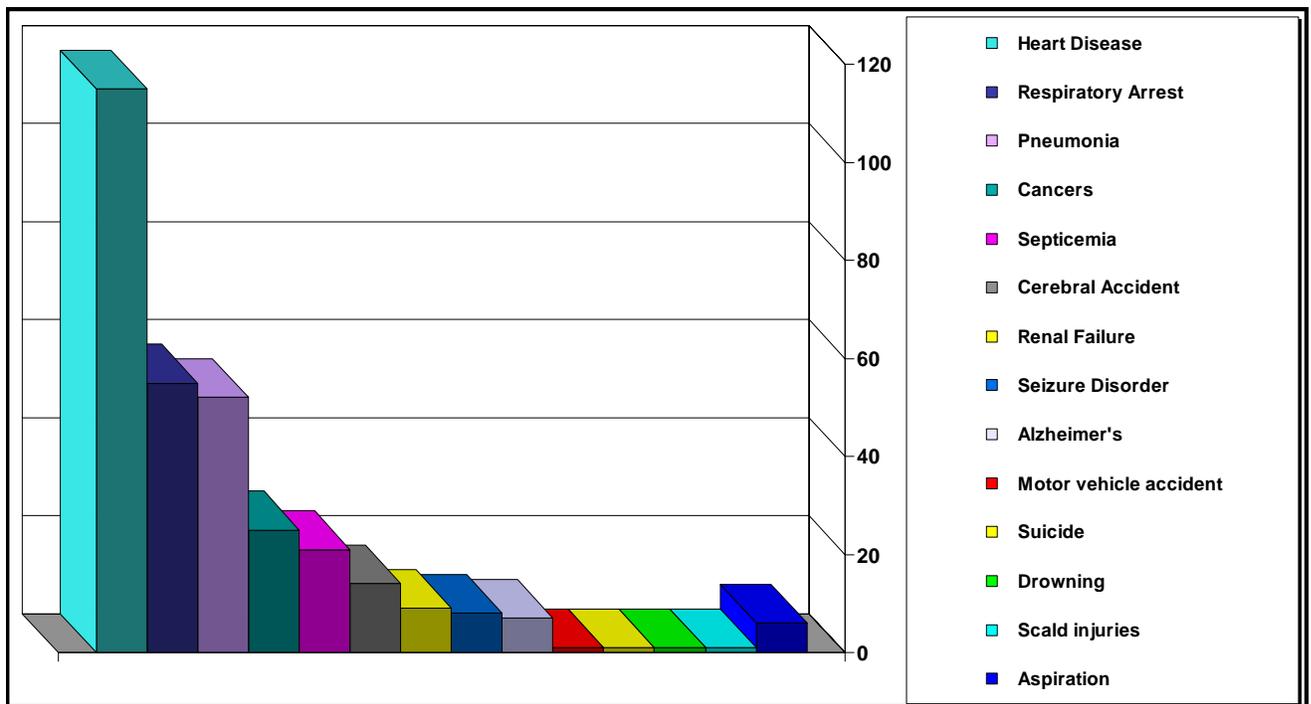
As to be expected, the largest percentage of deaths occurred in the over-sixty age group, with one hundred seventy (170) deaths reported, or 47% of the total number. Sixty-eight (68) or 18% of deaths occurred in the fifty-one to sixty age group; forty-eight (48) or 13% in the age group forty-one to fifty; twenty-seven (27) or 7% in the age group thirty-one to forty; eighteen (18) or 4% in the age group twenty-one to thirty; sixteen (16) or approximately 4% in the age group eleven to twenty; and thirteen or 3% in the age group birth to ten years old.



Causes of Death

Data for this category are based on the cause of death listed on the individual’s Death Certificate, which is usually completed by an attending physician, assistant medical examiner, or medical examiner.

The largest number of deaths, or one hundred fifteen (115), was attributed to cardiac arrest, cardiopulmonary arrest, cardiovascular disease, or congestive heart failure. Other causes of death listed, in rank order, include fifty-five (55) by respiratory arrest; fifty-two (52) by pneumonia; twenty-five (25) by cancer; twenty-one (21) by septicemia; fourteen (14) by cerebral hemorrhage, embolism, and stroke; nine (9) by renal failure; eight (8) by seizure disorder; and seven (7) by Alzheimer’s disease. Among the deaths that were accidental or not anticipated include one (1) by motor vehicle accident; one (1) by suicide; one (1) by drowning; one (1) by scald injuries; and at least six (6) by aspiration of food or other foreign object.



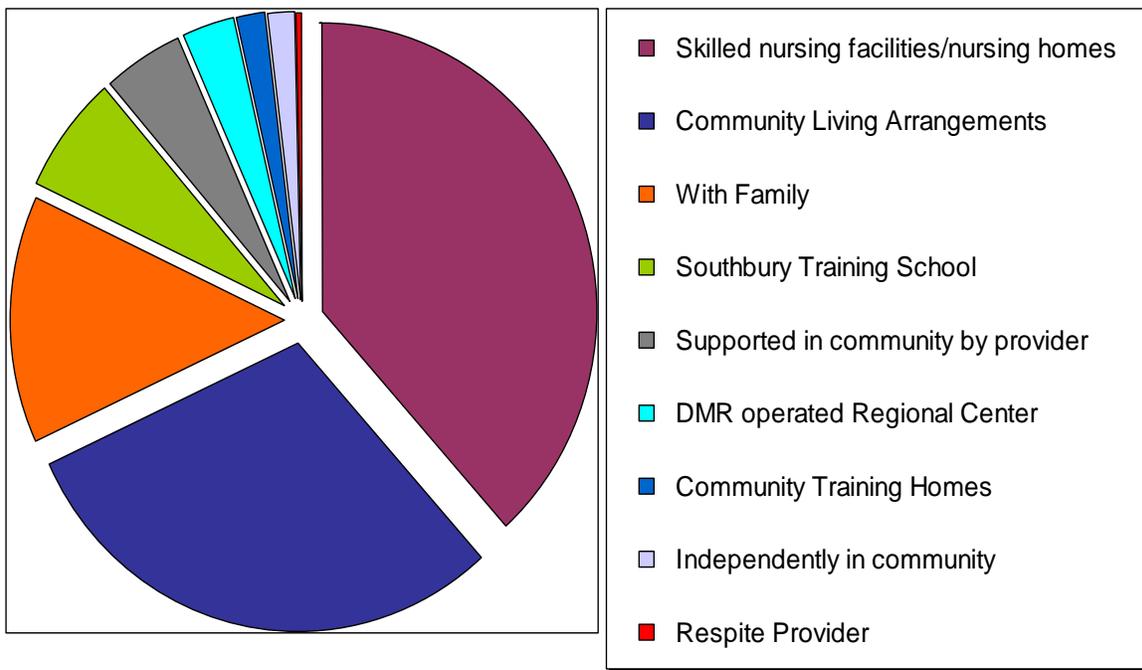
These leading causes conform fairly closely to the leading causes of death in the United States for the general population, which are listed by the Centers for Disease Control, 2002 National Vital Statistics Reports, as diseases of the heart; malignant neoplasms (tumors); cerebrovascular diseases; chronic lower respiratory diseases; accidents (unintentional injuries); diabetes mellitus; influenza and pneumonia; Alzheimer’s disease; renal diseases; and septicemia.

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Eleven (11) causes of death are listed as “other” and twenty-six (26) are listed as “unknown”. Examples of deaths listed as “other” includes disorders related to congenital malformations and chromosomal abnormalities, as well as metabolic disorders not included on the list of causes. Causes of death are most frequently listed as “unknown” in situations where DMR Case Managers are unable to contact family members for additional information, when individuals have refused DMR services prior to their death, or when a DMR Case Manager is newly assigned to an individual and has very limited contact with the individual or their family.

Residence and Mortality

During this time period, the largest number of individuals, or one hundred thirty-six (136), were living in skilled nursing facilities or nursing homes at the time of their deaths. This number is followed by one hundred six (106) living in community living arrangements (CLA); forty-nine (49) living at home with their families; twenty-four (24) living at Southbury Training School (STS); sixteen (16) supported in the community by DMR or a private provider; eleven (11) living in a DMR-operated regional center; six (6) living in community training homes (CTH); six (6) living independently in the community, often receiving self-determination funds and receiving case management support; and one (1) living with a respite provider. At the time of this report, one person’s residence at the time of her or his death was unknown.



Allegations of Abuse/Neglect

While the FRB pursues full, independent investigations into the circumstances surrounding a relatively small number of deaths, it also reviews reports of deaths where abuse or neglect are suspected to have contributed to the individual's death. When the FRB determines that circumstances warrant doing so, it conducts more extensive reviews of investigations initiated by other entities into such allegations. The Department of Public Health (DPH), the Department of Children and Families (DCF), DMR, law enforcement agencies and OPA's own Abuse Investigation Division (OPA/AID) may conduct these other investigations.

(NOTE: Public Act 03-146 mandates the OPA/AID to conduct direct investigations into all deaths of adult DMR clients occurring after October 1, 2003, when abuse or neglect are suspected to have contributed to the death. In keeping with OPA/AID's statutory mandates, those investigations focus on determining whether the allegation of abuse or neglect can be substantiated, and, if so, whether protective services are needed to protect the health and safety of other individuals.)

During the twenty-four (24) month time period between July 1, 2003 and June 30, 2005, the FRB reviewed the circumstances surrounding thirty-five (35) deaths where there was reason to suspect that abuse or neglect may have been a contributing factor. It is important to note that the type of residence the person was living in at the time of their death is not necessarily where the person's death occurred. For example, someone living in a community living arrangement (CLA) may have died as a result of inadequate care in a hospital setting.

Listed below is a summary of these cases:

1. Nature of allegation: unexpected, unwitnessed death. Age: 39. Residence: Community Living Arrangement/Group Home (CLA). DOD: 7/16/03. (OPA/AID intake: 7/21/03). Residential staff found the client unresponsive. Client took medications for seizures, and medication for his constipation. Client would often dump his medication and not take medications. In addition, the client was unable to talk. The OPA/AID requested that DMR review this case to determine if there were any further reasons to suspect abuse or neglect.

Status: OPA/AID monitored the request for further information. Neglect not substantiated by DMR or OPA/AID.

2. Nature of allegation: possible inadequate medical care. Age: 49. Residence: CLA. DOD: 7/31/03. The DMR Nurse Investigator (NI) questioned why, with all of client's various symptoms during a given time period as well as behavioral issues, an in-patient hospitalization and work-up was never pursued, especially during the 2 weeks prior to the client's death. The results of the DMR Medical Desk Review were forwarded to the DMR region for expedited mortality review as well as to the DMR Independent Mortality

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Review Board (IMRB). In addition, this case was referred to the Department of Public Health (DPH) for investigation surrounding the client's care and treatment at the hospital and the care and treatment provided to the client by his primary care physician. The FRB requested copies of the DPH investigation reports on 2/11/04.

Status: On 3/4/04, the FRB received a copy of the DPH investigation report. According to the report, the focus of the DPH investigation was to see that the client's Intermediate Care Facility Mental Retardation (ICF/MR) residential facility provided services to him in accordance with ICF/MR regulations. The care the client received at the hospital was not the emphasis of the DPH investigation, although DPH indicated that if a problem had been discovered it would have been referred to the licensing unit that investigates hospitals or to the unit that investigates practitioners. The IMRB reviewed this case on 7/28/04. According to one of the IMRB physicians, the hospital did evaluate the client every time he came into the ED, and he had a chest x-ray twice. The IMRB physician stated that the tendency for the hospital would be not to admit unless there was a clear need to do so.

3. Nature of allegation: possible neglect in medical facility. Age: 53. Residence: Supported Living Arrangement (SLA). DOD: 8/3/03. The DMR NI had concerns regarding the nursing/medical care received while the client was a patient in a psychiatric unit of a general hospital (7/31-8/2/03) and in the same hospital ER (7/6 and 7/27) where no psychiatric treatment was provided until the client was re-seen on 7/28/03. The DMR Regional Health Services Director made a referral to DPH regarding a question of neglect on the part of the hospital. DPH stated that they would assign this case for investigation. In addition, this case was forwarded for an expedited regional mortality review and review by the IMRB. On 3/31/04 this case was reviewed by the IMRB and a decision was made to keep the case open pending the DPH investigation.

Status: On 7/26/04, the FRB received a copy of the DPH investigation. As a result of the DPH investigation, violations were identified and a Plan of Correction to address the violations was submitted by the hospital. The FRB reviewed this case on 11/15/04. As a result of its review, the FRB wrote a letter to the hospital requesting that the hospital identify any quality improvement measures identified and addressed by the hospital in this case, in addition to those included in the Plan of Correction submitted to DPH. In response to questions posed by the FRB, the Director of Quality/Risk Management at the hospital forwarded a summary of the measures taken by the hospital as part of their performance improvement processes as a result of the DPH investigation and since the event occurred. This case was reviewed by the IMRB on 7/28/04. The IMRB members did not come to any decision regarding the DPH investigation, agreeing to bring this case back for review, along with the entire file, at the next meeting.

4. Nature of allegation: possible neglectful medical care. Age: 40. Residence: CLA. DOD: 8/22/03. (OPA/AID intake: 5/11/04). The client's cause of death was Disseminated Intravascular Coagulation and sepsis secondary to peritonitis, as per the Death Certificate. The client's past medical history included diagnoses of moderate mental retardation,

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malnutrition, a seizure disorder, hypothyroidism, osteoporosis, mood disorders, organic affective disorder, aspiration pneumonia, and decubitus ulcer.

A review of the chart indicates that interdisciplinary team (IDT) members, who included a RN, Ph.D., direct care staff, an OT, PT, Registered Dietician (RD), and a MD, were aware of the client's weight loss and inability to eat beginning in April 2003. Although multiple assessments took place and guidelines were developed, evidence shows that guidelines were not implemented prior to the client's hospitalization in August 2003. The Medical Desk Review completed by the DMR NI identifies a possible delay in care by the IDT and also a failure of the direct care staff and RN to ensure client received adequate nutritional and fluid requirements.

Status: The OPA/AID investigation remains open.

5. Nature of allegation: possible failure to maintain health and safety. Age: 67. Residence: CLA. DOD: 9/4/03. A concern was raised by the DMR NI due to the documented number of falls that had occurred with some documentation of head trauma, and others that did not specifically mention the head as no apparent injury was noted. The DMR NI found no evidence that an agency nurse personally assessed the client following a fall on 7/17/03, which resulted in her being admitted to the hospital on 7/18/03 and diagnosed with a subarachnoid hemorrhage. In addition, while direct care staff were advised to prevent the client from falling, one day after the client returned to the group home from a nursing home following her hospital admission, she fell out of her wheelchair.

Status: As the client was 67 years old at the time of her death, this case was referred to the Department of Social Services (DSS), before OPA/AID had jurisdiction for such cases. This case was also referred for an expedited mortality review. This case was reviewed by the IMRB on 5/5/04. The IMRB felt that the client's medical care was appropriate. However, their concerns were with the follow-up and care she received at home to ensure her safety. DMR Quality Assurance members on the IMRB agreed to check and see if DMR has an active Safety Committee, to review the circumstances of this case in an effort to prevent similar occurrences with other individuals. On 6/28/04, the FRB received a copy of the DMR Investigation Report. The result of the investigation was that neglect was substantiated. The FRB reviewed this case on 9/20/04. The DMR Liaison to the FRB indicated that the IMRB had requested information from the private provider, which would be reviewed by the IMRB at its next meeting in October 2004. At its meeting in October 2004, the IMRB agreed that the DMR Director of Health and Clinical Services would send a letter to the private provider requesting that the agency submit protocols and procedures for monitoring and preventing falls to maintain health and safety.

6. Nature of allegation: possible neglectful medical care. Age: 46. Residence: CLA. DOD: 11/21/03. (OPA/AID intake: 11/26/03). The client was allegedly sent to her day program all week with cold or flu-like symptoms, and was not properly evaluated by either a residential nurse or vocational program nurse, even though the vocational program sent

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correspondence to the client's group home indicating that she was too sick to attend the program. The client was eventually hospitalized and later died of pneumonia.

Status: The OPA/AID investigation substantiated neglect on the part of the residential and vocational providers. Recommendations were issued to DMR.

7. Nature of allegation: possible neglectful medical care. Age: 20. Residence: 24-hour SLA. DOD: 12/2/03. (OPA/AID intake: 12/1/03). The client was found unresponsive on the floor in his bedroom by a staff person assigned to provide him with 1:1 supervision on the morning of 11/27/03. An ambulance was called, and the client was transported to a local hospital. The client was described as unresponsive and hypothermic, with a temperature of 85 degrees. His pupils were sluggish to react, his BP was 86/64, and his pulse was 34. According to the report to the OPA/AID, the client received 24-hour, one-to-one supervision in his apartment. When tested at the hospital, the client's sodium level was also reported to be very low (120). According to the initial report, prior to his being found unresponsive, the client was upset and had been lying on the bedroom floor. He had refused to take his medications and had not been eating. When the client arrived at the hospital, his CK level (creatin kinase) was 8000, which is indicative of muscle tissue not moving over a long period of time.

Status: The OPA/AID investigation remains open.

8. Nature of allegation: possible lapse in supervision and inadequate medical care. Age: 60. Residence: CLA. DOD: 12/7/03. (OPA/AID intake: 12/30/03). On 10/30/03, the client reportedly fell while in the shower at her CLA (community living arrangement) and sustained a broken neck. Following the fall, she was taken by emergency services personnel to a local hospital. Later that same day, she was released with a diagnosis of having only sustained bruises. The client's primary physician ordered x-rays for her on 10/31/03, but the client's behavior prevented x-rays from being taken. The client was administered a CAT scan on 11/1/03 and diagnosed with having cervical fractures on 11/4/03. It was reported that the client was placed in a halo device to treat her fractures on 11/4/03. The client died on 12/07/03 from cardiac arrest. The client was known to be unsteady on her feet and did have prior incidents of falling. She also had a written bathing procedure which required staff to have one hand placed on her at all times while she was showering. The FRB reviewed this case in June 2004. Information related to the Board's discussion was provided to the OPA/AID investigator. This case was also referred to DPH for an investigation regarding the care provided to the client at the hospital.

Status: The OPA/AID investigation did not substantiate neglect on the part of CLA staff. An investigation by DPH substantiated neglect regarding the care provided by the hospital.

9. Nature of Allegation: possible neglectful medical care. Age: 41. Residence: Community Training Home (CTH). DOD: 12/11/03. (OPA/AID intake: 12/12/03). The client had been home from work on Friday, 12/5/03, with cold-like symptoms. The next day, the

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client felt well enough to return to work. On 12/9/03, the client said that her stomach hurt. The community training home (CTH) operator took her to Wal-Mart to pick up prescription medication for herself. At that time, the client did not look well and the CTH operator contacted her doctor who wanted to see client that day. The client refused to go to the doctor. At about 1:30 AM on what was the following day, the CTH operator heard a thump from the client's bedroom and called 911. It was later determined that the client died of a duodenal ulcer, which may have been a treatable condition.

Status: The OPA/AID investigation substantiated neglect and recommendations to DMR were issued.

10. Nature of allegation: possible neglectful medical care. Age: 50. Residence: CLA. DOD: 1/21/03. (OPA/AID intake: 4/22/04). The client's death was anticipated due to an irreversible, terminal cardiac condition and there was a Do Not Resuscitate (DNR) order in place. However, the client was in acute cardiorespiratory failure for 17 hours prior to her death and the only treatment provided during that time by residential program staff was an increase in oxygen therapy. It was reported that the client did not receive appropriate medical assessment upon her change in physical status and there was no nursing plan of care to follow. There was also no evidence of assessments performed by an RN, and evidence that LPN's were performing assessments and providing directives to residential staff regarding the client's changes in physical status, duties which were outside of a LPN's scope of practice.

Status: The OPA/AID investigation substantiated neglect, and recommendations to DMR were issued.

11. Nature of allegation: possible neglectful medical care. Age: 41. Residence: Regional Center Campus. DOD: 2/10/04. (OPA/AID intake: 2/11/04). The client was put on a treatment plan designed to decrease his Haldol medication intake, due to risks associated with long-term side effects. The client was put on Seroquel, which medication dosage was gradually increased while his Haldol dosage was decreased. The client began to experience drop episodes, in which he would fall and lose consciousness. The client died on 2/10/04.

Status: The OPA/AID investigation substantiated neglect, and recommendations were issued to DMR.

12. Nature of allegation: possible failure by DMR to provide services necessary to health and well-being. Age: 38. Residence: Family Home. DOD: 3/7/04. The FRB became aware of the client's death on 5/11/04, when DMR faxed a letter (dated 4/30/04) to the OPA/AID in response to repeated requests from the OPA/AID for a response to a protective service plan request, which had first been made on behalf of the client on 12/4/02. According to DMR's 4/30/04 letter to the OPA/AID, the client died of pneumonia on 3/7/04 at Hartford Hospital. On 8/9/04, the FRB received and reviewed

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copies of the client's records pertaining to Hartford Hospital outpatient clinic visits dating from 5/3/99 through 2/4/03.

Status: This case was reviewed and discussed by the FRB on 9/20/04. At that time, the Executive Director of OPA and FRB Chair indicated that DMR's capacity to respond to immediate protective services requests in a timely fashion has improved since such a request was made on behalf of this client by the OPA/AID in 12/02. Committee members agreed that if DMR has implemented systems changes, which adequately address identified gaps in the delivery of services to those individuals in urgent need of support, no additional action on the part of the FRB concerning this particular case was required at this time.

13. Nature of allegation: possible neglect by facility staff. Age: 59. Residence: CLA. DOD: 3/17/04. (OPA/AID intake: 3/17/04). The client sustained burns to over 45% of her body when she was bathed in scalding water early in the morning on 3/17/04. The client was airlifted to a Connecticut hospital's burn unit where she died later that same day.

Status: The OPA/AID investigation substantiated neglect, and made protective services recommendations as follows: 1) DMR should require all DMR licensed residential facilities to have anti-scald devices installed in their domestic hot water systems; 2) DMR should ensure that facilities inspections conducted by the Division of Quality Management include a water temperature check at all hot water fixtures in the facility; and 3) DMR should ensure that all public and private service providers and residential staff throughout the state are specifically alerted to the necessity of checking the water temperature immediately before assisting a client into a bath or shower. This alert should be issued as a medical advisory or as some other official DMR communication.

14. Nature of allegation: possible neglect by facility staff. Age: 41. Residence: Regional Center Campus. DOD: 5/15/04 (OPA/AID intake: 5/12/04). This case was reported to OPA/AID because of a possible delay on the part of direct care staff in phoning 911. The OPA/AID monitored an investigation completed by DMR, due to initial representations by DMR that the allegation of neglect did not bear on the person's death.

Status: Neglect was substantiated by DMR and OPA/AID. The OPA/AID made protective service recommendations to ensure that staff were in-serviced in notifying 911 in a timely manner in emergency circumstances.

15. Nature of allegation: unexpected, unwitnessed death. Age: 60. Residence: CLA. DOD: 5/16/04. (OPA/AID intake: 12/10/04). On Sunday, 05/16/04, staff found the client unresponsive in the living room of his apartment within his CLA. The client died of Asystole per the Death Certificate. The client's family raised concerns that there may have been an inadequate level of supervision provided to him on the day of his death. According to intake information, facility staff members were required to be on site assisting either upstairs or downstairs residents. Allegedly, the client's family was

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concerned that client may have been alone at the time he experienced symptoms of ill health in the moments leading up to his death.

Status: The OPA/AID investigation did not substantiate neglect.

16. Nature of allegation: possible neglect by facility staff. Age: 35. Residence: CLA. DOD: 6/13/04. (OPA/AID intake: 7/22/04). The client died five days after experiencing a fall at his group home. The Death certificate indicated that the client died of a sub-dural and epidural bleed, which was due to a closed head trauma as a consequence of a fall. The Death certificate also stated that the fall occurred after the client experienced a seizure. The client had a seizure disorder; however, it was not clear whether the client experienced a seizure before or after falling. The client also had a visual impairment.

Status: The OPA/AID investigation substantiated neglect and recommendations to DMR were issued.

17. Nature of allegation: possible neglectful medical care. Age: 59. Residence: CLA. DOD: 6/26/04. According to the DMR Medical Desk Review, the client was seen and treated at a hospital emergency room and released. There was a question regarding whether client was properly diagnosed and treated at the time. The DMR NI found no evidence of neglect by the client's residential or nursing staff. However, the results of the Medical Desk Review were forwarded to the appropriate DMR region for an expedited mortality review and to the IMRB for review due to a possible failure of the hospital ER physician and primary care physician to identify and treat the client's illness in a timely manner. This case was reviewed by the IMRB on 3/9/05. It was determined that the client was seen at the ER on 6/12/04, where a CT scan was done. Test results were consistent with a diagnosis of sigmoid volvulus, but she was sent home. On 6/15/04, she returned to the same ER and was admitted to the hospital with a diagnosis of sigmoid volvulus. One of the IMRB physicians stated that a sigmoid volvulus is a potentially treatable condition.

Status: The IMRB agreed to refer this case to DPH for investigation of the facility.

18. Nature of allegation: possible neglectful medical care. Age: 43. Residence: CLA. DOD: 6/30/04. The DMR Medical Desk Review indicated that the client's death was due to sepsis as a consequence of urethral injury during bladder catheterization. A consulting urologist noted the impression was urinary clot retention secondary to prostatic urethral trauma. Results of a cystoscopy showed urethral trauma. The DMR NI stated that based on the information available for review, there was reasonable cause to suspect that the client had been neglected. There was a physician's order for a straight catheter for a urine culture, but there was not an order to insert a Foley catheter, with balloon, which was left in place for several hours and taped in place to a sterile, closed specimen container.

Status: The agency nurse involved in performing the catheterization was referred to DPH, Practitioner's Unit, as an unapproved technique had been utilized. The ED facility was also referred to DPH, Facilities Unit, due to a concern that the ER should have performed

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a cystogram immediately instead of waiting 5 hours. The DMR regional Health Services Director wrote a letter of direction to the involved RN, with a note that the RN was not to perform invasive procedures until she had completed training, and that she could not place catheters unsupervised until the DPH investigation was completed. Documentation was to be submitted to the DMR regional Health Services Director evidencing the RN's successful completion of training.

19. Nature of allegation: possible failure to provide services necessary to health and safety. Age: 43. Residence: Nursing Home. DOD: 7/9/04. (OPA/AID intake: 7/9/04). The client lived in a nursing home and received regular visits from a recreation counselor, who would take him out into the community. On 7/9/04, the client and the recreation counselor went out to eat and the client choked on a piece of meat while at the restaurant. 911 was called and the client was transported by ambulance to a local hospital, where he died that same day of asphyxia and anoxic brain injury. Although not responsible for completing a Medical Desk Review (as the client was living in a nursing home at the time of the incident), the DMR NI questioned if the client had any dietary restrictions regarding the consistency of his meals, or if a swallowing evaluation had ever been done. The DMR NI also wondered if the client had experienced any previous episodes of aspiration or choking.

Status: It was determined that the client did not have swallowing issues and was not thought to require food consistency guidelines. Based on this information, OPA/AID did not assume direct jurisdiction but did monitor a follow-up investigation conducted by the private provider. That investigation also determined that the recreation counselor was not culpable in any way for the client's having choked and that her actions prior to and during the choking incident were appropriate. The case was closed without recommendations.

20. Nature of allegation: possible neglectful medical care. Age: 57. Residence: Nursing Home. DOD: 8/3/04. The client lived in a nursing home, and had significant, multiple diagnoses, but he remained relatively healthy until May 2004, when he was diagnosed with osteomyelitis.

Status: The DMR regional mortality review committee referred this case to the IMRB for a review of the medical/personal care the client received at the nursing home. This case was reviewed by the IMRB on 6/10/05. The IMRB agreed with the DMR region's findings regarding an apparent delay in treatment for the client's osteomyelitis. Both the nursing home and the attending physician were referred to DPH for investigation.

21. Nature of allegation: unexpected, unwitnessed death. Age: 24. Residence: 24-hour SLA. DOD: 8/4/04. (OPA/AID intake: 8/4/04). The client had a severe seizure disorder for which he took medications. The client lived alone in an apartment, which was a 24-hour, DMR-staffed home. DMR staff members found the client on the floor in his apartment when checking on him at about 8:15 AM. He was not alert and non-responsive and was later pronounced dead. It was documented that the client had a seizure disorder, and that his seizure medications were administered as prescribed.

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Status: The OPA/AID investigation substantiated neglect and recommendations were made to DMR.

22. Nature of allegation: possible failure to provide services necessary to health and safety. Age: 30. Residence: CTH. DOD 8/4/04. (OPA/AID intake: 8/4/04). The client lived in a community training home (CTH). The CTH operator took the client to swim at a campground. There were no lifeguards on duty. The client was known by the CTH operator to require a flotation jacket due to her inability to swim. The CTH operator did not put a flotation jacket on the client before she entered the water and went for a swim. The client went under water and did not come up. The cause of death was drowning.

Status: The OPA/AID investigation substantiated abuse and neglect. Recommendations were issued to DMR. The operator in question no longer has a license to operate a CTH.

23. Nature of allegation: unexpected, unwitnessed death. Age: 23. Residence: SLA. DOD: 9/19/04. (OPA/AID intake: 9/21/04). The client, who resided in her own apartment, with support staff for approximately 4 hours a day was found dead by staff on a Sunday afternoon. It was later determined that the client had been dead for over 24 hours. The client had been sick the Tuesday prior to her death, but went to work on Wednesday. The client was again not feeling well on Thursday and was taken to see her physician who prescribed medication and ordered blood work to be drawn the following Monday. On Saturday morning, a staff member spoke with the client over the telephone to remind her to take her medication. On Saturday evening, a staff member called to tell the client that a planned activity would not be taking place due to inclement weather. The client did not answer her phone, so the staff member left a message. The next day, Sunday afternoon, a staff member discovered the client's body in the bedroom of her apartment.

Status: The OPA/AID investigation remains open.

24. Nature of allegation: possible failure to provide services necessary to health and safety. Age: 49. Residence: CLA. DOD: 9/21/04. (OPA/AID intake: 9/22/04). The client died after collapsing at his group home. He was unable to be revived after being transported to the hospital. Group home staff initially believed the client was having a heart attack, but emergency responders noted that the client had a bolus (soft mass) of "toilet paper" in his mouth, leading to the hospital's determination that the client died of an aspiration incident.

Status: The OPA/AID investigation substantiated neglect on the part of the agency, but not the individual caretaker. Recommendations were made to DMR.

25. Nature of allegation: possible neglectful medical care. Age: 57. Residence: CLA. DOD: 9/26/04. The client's death was due to aspiration pneumonia, most likely secondary to a gastroparesis (delayed stomach emptying). Based on the evidence available for review, the DMR NI found reasonable evidence to suspect that the client was neglected by nursing and possibly residential staff. The DMR NI found that although the client had been

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vomiting from at least 9/8/04 until her eventual hospitalization, all staff involved considered this “spit up” and “vomiting” to be due to a post-nasal drip. It was later determined that the client was probably suffering from a small bowel obstruction. The results of the Medical Desk review were forwarded to DMR for an expedited regional mortality review. In addition, the results of the review were forwarded to the IMRB.

Status: This case was reviewed by the IMRB on 3/9/05. The IMRB noted that there were no documented nursing assessments done regarding the client’s status in the weeks prior to her death. It was agreed that the DMR Director of Health and Clinical Services would send a letter to the private provider and copy the DMR Contract Division regarding contractual nursing service requirements. In addition, it was agreed that a letter would be sent by the IMRB to the client’s neurologist regarding medication management. It was noted that DPH was not taking this case as it was viewed as an administrative RN oversight issue to be addressed by DMR.

26. Nature of allegation: unexpected, unwitnessed death. Age: 50. Residence: CLA. DOD: 10/4/04. (OPA/AID intake: 10/5/04). The client had been admitted by her private provider to a local hospital approximately fifteen days prior to her death because she had decompensated after the discontinuation of two medications due to harming physical reactions to her body (kidney and liver). The medications discontinued were Lithium and Depakote. The client was discovered deceased in a seclusion room by hospital staff. At the time of her death, the client had no known physical issues that could have attributed to her passing.

Status: The DMR regional mortality review committee referred this case to DPH due to concerns regarding the medical care provided to the client by the hospital. The DPH investigation resulted in significant findings against the hospital, and corrective actions were taken. The OPA/AID investigation substantiated neglect on the part of Stamford Hospital. A recommendation was made to Stamford Hospital.

27. Nature of allegation: possible inadequate medical and dental care. Age: 46. Residence: Nursing Home. DOD: 10/27/04. (OPA/AID intake: 10/29/04). The client resided in a nursing home. On 10/7/04, the client went to a hospital for dental work under anesthesia. A full mouth extraction (32 teeth) was performed after which the client hemorrhaged and was kept in the hospital overnight for observation. Allegedly, the client did not go into the hospital prior to surgery for preoperative blood work, which would have provided an indication of clotting time, and determined the number of teeth that could safely be extracted. The client also carried a diagnosis of MRSA or Methicillin Resistant Staphylococcus Aureus, an antibiotic resistant infection. On 10/8/04, the client was discharged back to the nursing home. On 10/21/04, the client was diagnosed with septic arthritis in his knee and ankle. On 10/22/04, the client was sent to a different hospital emergency room for a PIC (peripherally Inserted Central) line to receive IV antibiotics. A PIC line was not inserted and the client was not admitted. On 10/27/04, the client was admitted to Bridgeport Hospital because he had become septic. He was pronounced dead on 10/28/04, 13 hours after admission. The hospital listed the cause of death as Cardio-

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Pulmonary Arrest. The IMRB and the FRB reviewed this case, and referred it to DPH for investigation of the care and treatment the client received at the nursing home, and at both hospitals.

Status: DPH completed their investigations regarding the care provided to the client at both the hospital that performed the dental surgery and the hospital that treated the client for sepsis following his surgery. DPH cited the hospital where the client was treated for sepsis for failing to call a code or initiate CPR when the client was found unresponsive. The DPH investigation concerning the care the client received at the nursing home resulted in findings against the facility. The OPA/AID investigation remains open.

28. Nature of allegation: possible neglect in medical facility. Age: 44. Residence: CLA. DOD: 1/25/05. The client developed pneumonia and was hospitalized for a period of time prior to his death. Residential staff had concerns regarding the care and treatment provided to the client during his hospital stay. Specifically, the client developed skin ulcers while hospitalized prior to his death. This case was reviewed by the IMRB and referred to DPH for investigation.

Status: DPH determined that the hospital failed to implement preventive skin protocols and the client developed a Stage 2 decubitus. In addition, the hospital was not aware of the decubitus until a staff member employed by the private provider told the hospital nurse. As a result of the investigation, a violation letter was issued to the facility and corrective actions were taken by the hospital.

29. Nature of allegation: possible failure to maintain health and safety. Age: 21. Residence: SLA. DOD: 2/6/05. (OPA/AID intake: 2/8/05). The client died as a result of a one-car accident that occurred on 2/6/05. The client was driving the automobile at the time of the accident, even though the car was not his and he did not possess a driver's license. Investigators determined that the car belonged to the client's girlfriend, and the client frequently used it. According to police reports, the client was driving at a rate of speed faster than the posted 30 mile an hour speed limit. The car crossed into another lane, flipped on its side and hit a row of trees. A 15-year-old minor was a passenger in the car with the client at the time of the accident. The passenger did not sustain life-threatening injuries.

Status: The OPA/AID investigation substantiated neglect on the part of the provider for failure to provide the client with the number of support hours agreed upon by the interdisciplinary team, and per the agency's DMR contract. Recommendations were issued to DMR.

30. Nature of allegation: possible medical neglect. DOD: 2/28/05. Age: 52. Residence: CLA. The client died after experiencing a number of life-threatening complications upon discharge from a hospital following the administration of routine diagnostic procedures. The nature of the allegations concerned the care and treatment surrounding the procedure performed at the hospital, the decision regarding the resident's discharge home, and the

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lack of communication between hospital departments regarding the resident's condition and needs. The IMRB and the FRB reviewed this case. The IMRB agreed to refer this case to DPH for review regarding the circumstances surrounding the procedures performed at the hospital; the decision regarding the client's discharge; and the communication between hospital departments.

Status: The DPH investigation is pending.

31. Nature of allegation: possible failure to maintain health and safety. Age: 53. Residence: CLA. DOD: 3/9/05. (OPA/AID intake: 12/30/04). The client moved from a CLA operated by a private provider to a DMR-operated CLA on 1/24/05. On that date, the client weighed only 55 lbs. and was malnourished. DMR met with the client's guardian and arranged for him to receive a g-tube within a week of his admission to the public CLA, so he could begin to gain weight. Nursing staff at the public CLA became concerned due to the client experiencing lung congestion and on 3/3/05, an MD examined the client. Nursing staff asked for a chest x-ray, but the physician did not order an X-ray at that time, and the client was sent home. The client's condition worsened and he was taken to the ER on 3/7/05. The client died on 3/9/05 of cardiac arrest.

Status: The OPA/AID investigation substantiated neglect against the public and private provider. Recommendations were issued to DMR.

32. Nature of allegation: possible medical and programmatic neglect. Age: 48. Residence: SLA. DOD: 4/13/05 (OPA/AID intake: 5/23/05). The client died on 4/13/05 from injuries sustained as a result of a four-story fall from his apartment window. The initial report to the OPA/AID indicated that the client was discharged from a mental health facility on 4/11/05 after a three-week hospitalization, in which he was admitted for increased hallucinations and paranoid thinking. The client was admitted to the mental health facility on 3/21/05 because he heard voices telling him "he should kill himself or they would put a knife in him." The client had several previous psychiatric hospitalizations for unstable behavior. Discharge plans called for the client to have increased staffing levels at his residence, which was a supervised apartment. The agency's records show that the client was to receive staffing support on the date of his death from 8:00 AM to 1:00 PM and from 4:00 PM until 10:00 PM. This meant that there was no staff scheduled or present with the client at the time of his apparent suicide at 3:20 PM on 4/13/05.

Status: The OPA/AID investigation remains open.

33. Nature of allegation: possible medical neglect. Age: 44. Residence: CLA. DOD: 5/9/05. (OPA/AID intake: 7/22/05). Allegedly, the agency nurse did not properly evaluate the client after he developed a cough and fever of 100.3 degrees. Direct care staff called the primary care physician (PCP), who questioned whether the client had tracheitis (a bacterial infection of the trachea). The PCP treated the condition with Zithromycin, an antibiotic, for five days and to call if condition worsened. The client's condition did

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worsen, but the PCP was not notified. No nursing notes were available for review. The client's mother refused to send the client to the hospital when recommended doing so by staff. However, staff notes do not indicate that an on-call nurse was notified. There is also no notation that the PCP was ever notified of the change in the client's condition, as per his written request. The client was eventually admitted to a local hospital, but never recovered from the condition.

Status: The OPA/AID investigation substantiated neglect. Recommendations were issued to DMR.

34. Nature of allegation: possible neglect by facility staff. Age: 52. Residence: Southbury Training School (STS). DOD: 6/12/05. (OPA/AID intake: 6/13/05). The client choked on hamburger while on an outing in a shopping center parking lot. Three staff members were responsible for watching a total of six clients in two vehicles. The client who choked while eating a hamburger was supposed to be receiving one-to-one supervision at the time of the incident.

Status: The OPA/AID investigation substantiated abuse and neglect. Recommendations were issued to DMR.

35. Nature of allegation: possible neglect by facility staff. Age: 43. Residence: CLA. DOD: 6/24/05. (OPA/AID intake: 6/22/05). The client choked on a peanut butter sandwich while attending her day program. Three staff members were present at the time of the incident. Two staff members were assisting another participant approximately twenty feet away and the other staff was retrieving a puzzle in a different room. A staff assignment log indicated that the Day Program Manager was assigned to provide client care and supervision. However, the Day Program Manager was not present during the incident but rather was at another location attending a meeting. Food is kept in a refrigerator, which is supposed to be kept locked. However, the refrigerator was not locked during this incident which resulted in the client gaining access to the food, with an end result of choking. The client had supervision guidelines, which indicated that she needed line-of-site supervision at all times. The client was apparently left alone and out of site for approximately 2-5 minutes. Apparently, there had been numerous team meetings and memos to address the client's issues with stealing food and attempting to stuff food into her mouth. Two staff members changing another participant discovered the client with a peanut butter sandwich in one hand and a ham sandwich in the other hand. These two same staff members noticed the client was choking and that her lips were turning blue. The staff members began the Heimlich maneuver and called 911.

Status: The OPA/AID investigation substantiated neglect. Recommendations were not issued, as the provider effectively addressed issues brought to light as a result of this incident.

HEALTH CARE: AN EMERGING CHALLENGE AS DMR
CONSUMERS BECOME MORE INDEPENDENT

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*A Policy Analysis Requested by the Connecticut Office of Protection and Advocacy for
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HEALTH CARE: AN EMERGING CHALLENGE AS DMR CONSUMERS BECOME MORE INDEPENDENT

“Compared with other populations, adults, adolescents, and children with MR [Mental Retardation] experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care (U.S. Department of Health and Human Services, 2002, p. xii).” This was the premise of a symposium convened in December 2001 by then-Surgeon General of the United States David Satcher. The symposium brought together approximately 150 experts from the public and private sectors, including researchers, doctors, leaders of disability networks, family members, and self-advocates. Dr. David Coulter, a neurologist from Boston’s Children’s Hospital, was one of several speakers who emphasized that promoting good health among this population required doctors to respect self-determination and recognize the desire of patients with intellectual disabilities to set their own goals.

In Connecticut, the need to find a path that respects self-determination while encouraging good health outcomes has taken on increased urgency. In the brief span of time since a Fatality Review Board for Persons with Disabilities (FRB) was established in Connecticut in 2002, investigations into the deaths of consumers of the state’s Department of Mental Retardation (DMR) service system have led to serious concerns about health care. Does the state have an obligation to step in when consumers with intellectual disabilities¹ are unable to effectively manage their own health supports independently due to functional limitations related to their disabilities? If so, how can this be done without compromising the personal autonomy and choice-making that are at the heart of self-determination?

¹ In this report, we adopt the phrase “intellectual disabilities” and avoid the lexicon of “mental retardation,” “mentally retarded,” and the abbreviation MR in crafting our own prose. This follows the example of many agencies in our home state of Connecticut and elsewhere. However, when we cite research or reports, even when not quoting verbatim, we use the lexicon the authors used when we think it is required for clarity.

As in many other states, a growing number of consumers in Connecticut are living in homes of their own choosing, with only a few hours per week of supports. A smaller but growing subset of consumers negotiate their own budgets and select their own staff. If we are witnessing preventable deaths due to lack of proper health care management among consumers who are still tied closely to the state service system, will such grave outcomes become even more common as consumers move farther away from the established infrastructure? Must persons with disabilities and their allies accept increased morbidity as one of the costs of self-determination? The purpose of this report is to highlight the problems that the FRB investigations have unearthed, to review the literature relevant to health care and independent living for persons with intellectual disabilities, and to search out policy options.

The policy context that gave rise to this inquiry is crystallized well by Galantowicz et al. (2005, p. 8):

All people, disabled or not, take risks. However, people with disabilities and the elderly may be more vulnerable to negative outcomes, as well as more vulnerable from the effect of negative outcomes. This is due not only to poor health status, but also to the inability of some to make informed decisions about risky behaviors and their consequences. Health experts also recognize that low literacy negatively impacts an individual's ability to make informed decisions, as do factors such as adequate vision, concentration, working memory, and the ability to process information... (Dubow, 2004). Balancing a...right to make choices, including potentially unhealthy or unsafe ones, with the State's need to assure...health and welfare... is an over-riding concern.

In order to inform readers of the seriousness of this issue, we begin by spotlighting two cases investigated by the FRB of individuals who died in 2004. (We have fictionalized the names in order to protect confidentiality.)

VIGNETTE #1: SUSAN

Susan, aged 30 years, lived alone in her own apartment with support from a private provider contracted by Connecticut's Department of Mental Retardation (DMR). She had Down Syndrome and a documented heart condition that was never repaired, leaving her more susceptible than others to serious illness and infection. She took daily medication for her heart condition. She also was visiting a psychiatrist regularly and taking an anti-depressant medication.

When she first began feeling ill and made her support agency aware of this, a staff member brought her cola and crackers (according to the agency log) and encouraged her to take Tylenol. The next day, they noted that she vomited her daily medications in the morning; consequently, a staff member brought her to an ambulatory care facility. Neither Susan nor the staff member informed the physician there of her heart condition. The doctor diagnosed her as having a virus, and discharged her with instructions to rest and use Tylenol. He gave additional instructions related to a diarrhea problem (restricted diet and Imodium) and his most detailed instructions were in regard to pain she was experiencing due to a left knee sprain.

Two days later, Susan persisted in her complaints and the staff log indicated they thought she was “exaggerating her aches and pains.” Two additional days passed. Susan walked to a friend’s house but called for a ride home from her agency because she could no longer stand. She weighed 173 pounds, and it required three staff to carry her into her apartment and help her into bed. When the staff member who remained in the apartment observed her after a while looking yellow and unable to move, she called an ambulance. By the time Susan was admitted to a hospital, the infection that caused her illness had apparently reached her heart and other organs. She survived for one more week and died in the same hospital. The cause of death was cardio-respiratory failure as a result of an infection.

VIGNETTE #2: LOUIS

Louis, aged 20 years, was excited about a new living arrangement and new job; records indicated that he was well regarded and thriving in both venues. Louis was frustrated with having to rely on agency staff to assist him daily with his diabetes care. He openly stated that he wanted to manage it himself. However, it was well documented that his diabetes was volatile, with drastic fluctuations in his glucose levels. The label he carried from school was “mild mental retardation.” The consensus among caregivers was that he needed help to get his diabetes more stable.

Over a period of five months, Louis’ roommate or staff found him hypoglycemic (unresponsive and losing consciousness due to having an excess of insulin in comparison to the amount of sugar in his bloodstream) on eleven separate occasions. On the twelfth occasion, just five days after the eleventh incident, emergency responders rushed Louis to the hospital and attempted without success to resuscitate him en route. He was pronounced dead upon arrival.

CONCERNS ARISING FROM THESE VIGNETTES

Susan’s Individualized Service Agreement (ISA) called for 23 hours per year of nursing care, but after her death, investigators could find no record of her receiving any recent nursing appointments or supports. The question arises in her case as to whose responsibility it should have been (or could have been) to make sure Susan was getting the nursing care that someone knew she needed when they wrote the plan.

Additional questions in Susan’s case have to do with why there was a failure to inform the physician at the ambulatory care facility about Susan’s heart condition, and why the agency staff seemed to consistently underestimate the seriousness of her symptoms—right up to the time they carried her home, rather than taking her straight to a medical facility.

Louis, on the other hand, was receiving regular nursing support; his ISA authorized 9.5 hours per week and according to his records, he was receiving it. A question arises in Louis’s case as to whether the amount of nursing time should have been increased, given the frequency of the episodes of hypoglycemia. Aside from that, was there anything else that could have been done—helping him, for instance, to better regulate his sugar levels through diet or exercise? However, Louis was already chafing against the involvement of caregivers in managing his diabetes. What kind of intervention would have been feasible?

Susan and Louis were each receiving support services from DMR in community settings of their own choosing. Each had well documented health issues that led to their untimely deaths. It is easy enough to criticize Susan's caregivers. However, it is possible that her psychiatric issues in combination with her cognitive impairment made it difficult to accurately assess her distress signals. "People with intellectual disability often have a range of problem behaviors, which may be learned, or symptomatic of a psychiatric or physical disorder. While demanding the provision of health care, the problem behaviors may paradoxically make health care difficult to access" (Lennox & Kerr, 1997, p. 368).

In Louis' case, no specific error or misjudgment by a caregiver emerged from the FRB investigation. The main question is whether a red flag should have gone up at some point: how many episodes of hypoglycemia would it have taken to generate some kind of an intervention designed to change the pattern? Should the service system have provided a sturdier safety net to sustain an energetic young adult—even one with volatile diabetes who resisted help?

Could any state policy consistent with the principles of self-determination have improved the health prospects for Susan or Louis? What about other individuals whose health issues are equally grave but who are self-directing their supports? Is it realistic to think about state policies that would avoid—or at least reduce the likelihood—of such disheartening outcomes?

Connecticut is not the only state that has these concerns. Oregon reviewed the deaths of persons with developmental disabilities over a recent period of eight years and found that they were highly correlated with medical issues. The four most common causes of death were (in order): aspiration, constipation, seizures, and dehydration (Galantowicz et al., 2005, p. 11).

BACKGROUND: DRAMATIC IMPROVEMENTS IN LONGEVITY

It is well to begin with the good news. Until quite recently, the life span of persons with intellectual disabilities—especially those with Down Syndrome, for whom data are the most accurate--was much shorter than that of their peers. "Average age at death in the 1920s was 9 years for this group. According to Janicki, it rose to 30.5 years in the 1960s and to 55.8 years in 1993" (Braddock, 1998).

Although they have not reached parity in longevity with their peers, current studies tell us that the life expectancy of "older adults with MR" is 66 years and growing (Fisher & Kettl, 2005, p. 26). (The mean age at death for the general population is 70.4 years [Braddock, 1998]). The generation that has been educated in neighborhood schools and offered increasing opportunities for normalization will do better still: Former Surgeon General Satcher testified to the U.S. Senate that, "Life expectancy of people with mental retardation has increased to the extent that younger adults with mental retardation are expected to demonstrate little disparity in longevity" (Satcher, 2001).

This dramatic increase in life span is a consequence of both social and medical changes. Hayden and Kim (2002) reviewed 18 studies conducted from 1998 to 2001 concerning health issues for individuals with intellectual disabilities and reported that movement of persons previously institutionalized into community settings has in most cases contributed to their health and well-being. Among 10 studies that compared use of

medical services by those who stayed in and those who left residential institutions, "overall health... [of] counterparts who lived in the community was unchanged or improved after leaving institutions. Access to services was considered timely and appropriate. Medical services received were rated as being either better or unchanged" (p. 7).

A comparison study of 366 individuals with MR to other patients with more typical cognitive functioning receiving their health care services in the same settings found that those with MR were doing relatively well as a whole, and attributed their status both to the effects of improved health care and deinstitutionalization (McDermott et al., 1997).

We begin this policy inquiry, therefore, with the recognition that protective mechanisms devised by well-meaning state authorities of previous generations failed to assure the well-being of large numbers of persons with intellectual disabilities. Social connections, physical activity, a meaningful place in one's community: these have turned out to be as important as seeing a doctor regularly. With history in mind, we approach with caution the question of what state policies ought to be put in place today, to protect the many people like Susan and Louis whose health and lives seem at times to be unnecessarily jeopardized by circumstances associated with their independence.

HEALTH CHALLENGES FACING PERSONS WITH INTELLECTUAL DISABILITIES

What health challenges do people with intellectual disabilities face? "Health promotion, disease prevention, early detection and universal access to care are the cornerstones of a balanced community health system. Yet, in each of these areas, individuals with mental retardation face barriers" (Satcher, 2001). In spite of these obstacles, many individuals with intellectual disabilities maintain good health. As a group, however, they experience some chronic illnesses and adverse health conditions more frequently than their peers.

Chronic conditions that have been found elevated among adults with intellectual disabilities include dental disease (Beange et al., 1995; Turner & Moss, 1996), hearing or visual impairment (Beange et al., 1995; Kapell et al., 1998; McDermott et al., 1997; Turner & Moss, 1996), dietary disorders and obesity (Aronow & Hahn, 2005; Beange et al., 1995; Turner & Moss, 1996), hypothyroidism (Kapell et al., 1998), non-ischemic² heart disease (Kapell et al., 1998; Turner & Moss, 1996), and seizure disorders (Beange et al., 1999; McDermott et al., 1997; McDermott et al., 2005). There has also been documentation of an increased frequency of mental health challenges (Aronow & Hahn, 2005; Beange et al., 1999; Turner & Moss, 1996) and central nervous system conditions (McDermott et al., 1997).

However, evidence that patients with intellectual disabilities have a more robust profile in certain respects than their peers has also emerged. Kapell and colleagues (1998, p. 272) concluded that "the prevalence of chronic medical conditions that are common in the

² Non-ischemic heart conditions are those not associated with blood flow but with congenital or developed physiological anomalies such as heart murmurs, valve problems, and abnormally slow heartbeat.

general population, such as diabetes, ischemic heart disease³, stroke, and ulcers were not elevated” among either of two groups of patients with intellectual disabilities (one group had Down Syndrome and the other did not). McDermott et al. (1997), found that patients with MR had lower rates of the following conditions and behaviors inimical to optimum health: hypertension, migraines/chronic headaches, diabetes, depression or anxiety, obesity, substance abuse, and smoking.

Research has furthermore demonstrated the fallacy of lumping together all persons with intellectual disabilities when it comes to anticipating their likely health risks. McDermott et al. (1997) found that adults with Down Syndrome (but not others with MR) displayed significantly lower rates of hypertension, indicating they were at lower risk than the general population for atherosclerosis. In the Kapell (1998) study, conversely, the profile of the Down Syndrome cohort was significantly more adverse than the other MR subjects in three areas: visual impairment, hypothyroidism, and non-ischemic heart disease. McDermott et al. (2005) found that epilepsy was present in under 14% of adult patients with Down Syndrome but in over 25% of those with other varieties of MR and in 40% of patients who had MR combined with cerebral palsy.

Interaction Between Functional Impairments and Health Care

Some of the health challenges facing individuals with intellectual disabilities originate along with the disabilities. The congenital (non-ischemic) heart conditions associated with Down Syndrome are a good illustration of this. Other health problems develop as the intellectual disability influences decisions about when and where to seek care, the ability to effectively communicate one’s symptoms and one’s history to physicians and other providers, and the ability to understand and adhere to a treatment plan (Edgerton et al., 1994). An illustration of this phenomenon is the prevalence of hearing impairment. Beange and colleagues (1995) examined 200 individuals with intellectual disabilities in Sydney, Australia, and found hearing loss in 25% of their sample, as against only 2% of the general population. They reported that the buildup of impacted earwax contributed substantially to this problem (Beange et al., 1999). As more individuals with intellectual disabilities are educated alongside their peers and achieve greater functional capabilities compared to persons with similar cognitive challenges in the past, we may find that some of these adverse health trends diminish or disappear--like the shortened life spans of earlier generations.

POLICY OPTIONS: WHERE DO WE GO FROM HERE?

Galantowicz and colleagues (2005) conducted an investigation into state policies on behalf of the Centers for Medicare & Medicaid Services (CMS), with the aim of discovering methods of managing and reducing risk among those who receive support through home and community-based services (HCBS) waivers.⁴ They carried out their

³ Ischemic heart problems are those characterized by a decrease in the blood supply to a bodily organ, tissue, or part caused by constriction or obstruction of the blood vessels.

⁴ The waiver is a mechanism through which service recipients in many states have been able to receive supports without being lodged in institutional settings.

research in 11 states that represented a range of waiver types and geographic areas. (Connecticut was not among the states investigated.⁵)

Health risks are one of three kinds of risks that Galantowicz et al. (2005, p. 1) address, but the other two risk categories they describe also contribute to health problems. For instance, they define the second category, behavioral risks, as including “poor decision-making about safety and health issues as a result of a brain injury or cognitive limitation.” Their third category, risks to personal safety, includes inattention by caregivers. This could extend to an inadequate response by a caregiver to illness or injury. We can readily see that all three of these categories of risk contributed to the demise of both Susan and Louis.

Galantowicz et al. (2005, p. 2) state: “The responsibility for addressing these risks is not new to state waiver programs. States already address risk proactively through individual assessment and service planning processes.” This statement is not true only for service recipients receiving their support through waivers. It is in principle true for everyone who enters a service system. Policies and procedures already in place are supposed to address health problems of individual service recipients (as well as their other needs) on a case-by-case basis.

In Connecticut and many other states, the service system requires the drawing up of an individualized service plan. When someone’s health problems require a change in approach (such as Louis) or when someone is not receiving services that the plan enumerates (such as seemed to be the case for Susan), mechanisms do exist within agencies such as DMR to address these issues through the revision of the plan or the performance review of the staff members engaged with the individual. How fluid, flexible, and responsive the system can be in doing this in a timely fashion is another question. In Connecticut, a failure of the service system (or of families) to address health problems that threaten someone’s well-being can also be flagged by filing an allegation of abuse or neglect with the state’s Office of Protection and Advocacy.

Pro-active state policies

Galantowicz et al. (2005) identified among the 11 states they examined a variety of specific policy measures that go beyond the standard individualized service plans to strengthen the safety net for those individuals that are considered at unusually high risk (whether due to health challenges or other reasons). Several state service systems have introduced tools that are used to rate the level of risk of individuals receiving services. For instance, Pennsylvania officials introduced a tool prior to relocating large numbers of people from institutional to community settings, and continues to use it for community residents.

In Kentucky, case managers are required to meet face-to-face every two weeks with any client receiving services through a brain injury waiver because the state considers these

⁵ The only states in the northeast that were investigated were Massachusetts and New York. Massachusetts policies were reviewed with respect to waivers for people with mental retardation and/or developmental disabilities, and New York waiver policies were reviewed with respect to individuals with brain injury.

individuals to be at higher risk. In Oregon, for the same reason, case managers must make a face-to-face visit monthly to developmental disabilities waiver recipients.

In New York, each recipient of waiver-based services who has a brain injury must sign a document agreeing to specific activities and responsibilities related to enumerated risks. Medication management is one of the activities that can be covered in such a plan. Such activities have always been included within New York's individualized service plans, but in the past, they were buried among the other documentation. Now they are highlighted in a "Plan for Protective Oversight."

Ohio tracks all "unusual incidents" among its participants in developmental disabilities waiver services. When three or more incidents are recorded, regulations require the drawing up of a prevention plan.

Enlisting Consumers and Health Care Providers in Voluntary Solutions

Most of those who are thinking about health care for persons with intellectual disabilities are not proposing policy mandates but rather seeking solutions that can take place either within the health care system or in other arenas where health and wellness can be promoted. The participants in the symposium convened by the Surgeon General (U.S. Department of Health and Human Services, 2002) with the intention of "closing the gap" in health care between those with mental retardation and other Americans gave a ringing endorsement to the development of creative and voluntary efforts that tie together health care providers, individuals with intellectual disabilities, residential facilities, and other stakeholders. They developed a "Blueprint" comprised of six goals.

Goal 1: Integrate Health Promotion into Community Environments

Goal 2: Increase Knowledge and Understanding

Goal 3. Improve Quality of Health Care

Goal 4. Train Health Care Providers

Goal 5. Ensure Effective Health Care Financing

Goal 6. Increase Sources of Health Care

The blueprint spelled out and detailed action steps for each of the goals, and highlighted "creative program" responses to illustrate the action steps. One example of the latter was the Center for Oral Health for People with Special Needs at the University of the Pacific School of Dentistry. The Center initiated a coalition embracing dental professionals, hospitals, and Regional Centers (units that fund services for people with developmental disabilities in California) and funded a dental services coordinator (usually a dental hygienist) to reach out to individuals with intellectual disabilities and agencies in the community to assure that dental care became more widely available and also to offer training and support to general dentists and others to help them become more adept and more confident at serving this population. Another example was the Oregon Healthy Lifestyles for Persons with Developmental Disabilities Program, which offered a combination of workshops and mentoring for individuals with intellectual disabilities and education for health care providers-in-training to prepare them to better address the health challenges of adolescents with developmental disabilities.

Practitioners and researchers are testing a variety of approaches to draw those living independently into more conscientious choices about healthy lifestyles and appropriate use of health care services. For example, Aronow & Hahn (2005) and a companion study (Hahn & Aronow, 2005) found in pilot studies that low-cost interventions voluntarily embraced by consumers could be effective in helping them to take measures to improve their health. In the two studies, participants were visited at home for a comprehensive health interview, either by a trained layperson or by a nurse. (All of the patients lived independently or in group homes where there were no medical staff on-site.) The interview was followed soon after by written feedback providing information to each participant about her or his individual health strengths and risks, and recommendations on how to reduce the risks. Participants generally rated the interview and the feedback as meaningful and helpful, and early indications were that many took the recommendations seriously.

REVISITING OUR CONNECTICUT VIGNETTES

Could Susan or Louis have benefited from some of the creative and voluntary efforts such as those described above? If Louis had the opportunity to attend workshops in which he was asked to reflect on his own health risks, and then offered a chance to be paired with a mentor, might this have motivated him more than the feedback he apparently was receiving from group home staff and from nurses? If Susan had a stronger relationship with a primary care physician and a community-based medical facility, would she have received better care and advice in her critical days and hours of need than she got from visiting a walk-in clinic where nobody knew her history? One is certainly tempted to answer both questions in the affirmative. At the same time, we have to recognize that the dissemination of such practices to a large majority of individuals with intellectual disabilities is nowhere on the horizon.

What about the more pro-active approaches that state government could take? It is not clear how this might have changed the circumstances for Susan. But a procedure for tracking unusual incidents or events as presently practiced in the state of Ohio (for waiver recipients only) would certainly have flagged Louis after his third, fourth, or fifth episode of hypoglycemia. What then? What intervention would have put this young man back on the path to wellness, so that he could continue to enjoy his new home, his new job, and the new taste of independence?

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