



Investigation Report On the Death of Philip S.

**State of Connecticut
Fatality Review Board for Persons with Disabilities**

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INTRODUCTION

On February 8, 2002, Governor Rowland issued Executive Order # 25 in an effort to bring a greater degree of independence and oversight to the process of reviewing and investigating the deaths of people who receive services from the Department of Mental Retardation in Connecticut. Executive Order # 25 requires that the Department of Mental Retardation report all deaths of persons placed or treated under the direction of the Commissioner of the Department of Mental Retardation to the Office of Protection and Advocacy.

The Executive Order also established a Fatality Review Board for Persons with Disabilities, which is chaired by the Executive Director of the Office of Protection and Advocacy. The purpose of the Fatality Review Board is to investigate the circumstances surrounding those deaths, which, in the opinion of the Executive Director, warrant a full and independent investigation.

On October 9, 2002, as per Executive Order # 25, the Executive Director of the Office of Protection and Advocacy (OPA) received a letter from the Commissioner of the Department of Mental Retardation (DMR) referring the death of Mr. Philip Sampson* for review by the Fatality Review Board (FRB). On January 27, 2003, after reviewing a preliminary summary of the facts of the case, the Executive Director formally referred the situation to the FRB to initiate a full investigation into the circumstances leading up to and surrounding Mr. Sampson's death.

Mr. Sampson, who was thirty-six years old at the time of his death, resided in a group home operated by Seacorp, Inc. (hereafter referred to as "Seacorp"), a private provider in southeastern Connecticut. Prior to his death, he had lived at the group home for almost one year. Records show that on July 2001, while away on vacation with his mother, Mr. Sampson was possibly bitten by an insect. He was started on an antibiotic and on August 14, 2001, during his annual physical examination, his primary care physician noted that he had mild cellulitis - an inflammation of the skin due to a bacterial infection - of his right lower leg. On August 15, 2001, Mr. Sampson was diagnosed with acute cellulitis and admitted to a local hospital for treatment with intravenous antibiotics. On Wednesday, August 29, 2001, Mr. Sampson was discharged from the hospital and admitted to a local nursing home. He was not discharged directly to his group home because his bedroom was on the second floor and at the time of his discharge, August 29, 2001, he was unable to manage the stairs. The plan was for him to receive physical therapy to increase his strength and mobility, which would enable him to return to the group home within a short period of time. Mr. Sampson had been a patient at the nursing home for a little over one week, when he was re-admitted to the hospital in critical condition on September 5, 2001, and never regained consciousness. Mr. Sampson eventually died of respiratory failure and pneumonia on September 10, 2001.

* The names of all service recipients are pseudonyms.

The DMR Commissioner's letter identified several care issues relating to Mr. Sampson's death, the most significant of which include:

- Inadequate communication that occurred following Mr. Sampson's discharge from a local hospital to a nursing home, including the issuance of incomplete physician's orders; and
- Quality of care issues at the nursing home.

The investigation conducted by the FRB included interviews with professionals employed at the nursing home, staff with the DMR and Department of Public Health (DPH), and staff who supported Mr. Sampson at his group home. In addition, Mr. Sampson's medical records and reports of other investigating agencies were reviewed.

The purpose of the FRB investigation was to examine the specific events leading up to and surrounding Mr. Sampson's death, to identify relevant issues and concerns regarding his care and treatment during the course of his stay at the nursing home, and to determine whether any lessons can be learned to help improve systems that care for others who are similarly placed.

BACKGROUND INFORMATION

Philip Sampson was born in 1965 in New London, Connecticut. One of six children, he maintained close relationships with his family. Mr. Sampson had mild mental retardation. He was also legally blind and, according to his records, lived with a series of chronic medical problems, many of which followed from a cancerous tumor of the optic nerve that was discovered when he was six years old, or from the resulting surgery and cobalt radiation treatment he received. Mr. Sampson moved to his group home in southeastern Connecticut in October 2000. Prior to that, he had lived at a residential school for the blind in Massachusetts, a group home in northwestern Connecticut, with his parents in California, and several community training homes.¹

In addition to the lifelong implications of that childhood tumor, Mr. Sampson had a number of other medical conditions that were notable. According to his medical records, Mr. Sampson's diagnoses in August 2001 included: diabetes insipidus (a disease marked by excessive urination); hyperglycemia (elevated blood sugar); disaccharidase deficiency (a digestive enzyme deficiency); hypernatremia (elevated concentration of sodium in the blood); panyhypopituitarism (a condition resulting from a diminished secretion of pituitary hormones); hypothyroidism (a condition resulting from inadequate levels of thyroid hormone in the body); cardiomyopathy (a disease that diminishes cardiac performance); hypoxia/hypercarbia (deficiency of oxygen and elevated levels of carbon dioxide in the blood); cortical adrenal insufficiency (resulting from a diminished secretion of adrenal hormones such as testosterone); hyperlipidemia (increased level of

¹ A community training home (CTH) is a private family home in which three or fewer adults with mental retardation reside and which is licensed by the Department of Mental Retardation (DMR). According to the DMR licensing regulations a CTH "provides a nurturing home environment where adults can share responsibilities, develop mutual relationships, be independent, and make their own choices."

fatlike substances in the body); gastroesophageal reflux disease (GERD) (tendency toward regurgitation of stomach acid and other contents into the esophagus); hydrocephalus (accumulation of excessive amounts of cerebrospinal fluid within the brain); and congestive heart failure (CHF) (insufficient cardiac capacity, resulting in an accumulation of abnormal amounts of fluid in the blood vessels surrounding the heart). Other pertinent history noted in Mr. Sampson's medical record includes periodic episodes of aspiration pneumonia, a type of pneumonia that is caused by the inhalation of gastric contents. In 1998, treatment for an episode of pneumonia included a short-term gastrostomy, which is the surgical opening of a passage through the abdominal wall for the purpose of introducing food directly into the stomach, and a short-term tracheostomy, which is the surgical opening of the trachea to provide and secure an open airway, which was followed by the onset of adult respiratory distress syndrome. According to Taber's Medical Dictionary, adult respiratory disease syndrome is a condition of respiratory insufficiency marked by decreased oxygen concentration in the blood. Additionally, Mr. Sampson's records indicate that he had experienced cellulitis in 1998 and 1999, and deep vein thrombosis in 1991.

In February 2001, Mr. Sampson was hospitalized with bilateral pneumonia, and was seen by a pulmonologist while in the hospital. Although congestive heart failure and pulmonary edema are not listed in the final diagnoses from this hospitalization, and Mr. Sampson was not referred for follow-up by a pulmonologist or cardiologist, the Discharge Summary states, "left lower lobe pneumonia with less extensive right lower lobe pneumonia. This also was probably superimposed with CHF (congestive heart failure) and pulmonary edema."

Following Mr. Sampson's hospitalization for pneumonia in February 2001, he began receiving oxygen therapy at the group home. A nurse from the local Visiting Nurse Association (VNA) came to the group home every week to monitor his oxygen saturation levels.² Every other week, or as necessary depending upon his medical needs, a nurse from the VNA also checked Mr. Sampson's blood pressure, pulse, blood sugar (glucose) levels³, respiration and lung sounds, and his legs for signs of edema (swelling). Every three weeks, a nurse from the VNA came to the group home to administer an injection of Depo-testosterone.

Mr. Sampson was prescribed numerous medications to treat his chronic medical conditions and to replace the hormones that his body did not produce naturally. It is important to note that Mr. Sampson was also required to drink one to two liters (or 64 ounces) of fluid a day to prevent dehydration. (*NOTE: Group home staff indicated that encouraging Mr. Sampson to drink and monitor the sufficiency of his fluid consumption were essential to promoting his health.*) In addition to scheduled visits by nurses from the VNA, Mr. Sampson received care and treatment from community-based practitioners, including an endocrinologist, an ear, nose, and throat specialist, a team of primary care

² The saturation of the arterial blood with oxygen, expressed as a percentage. It is normally greater than 96%. An oxygen saturation level of 90% is generally considered minimally acceptable.

³ In healthy people, normal blood glucose (sugar) levels are maintained at about 70 to 115/130 mg (milligrams) per dl (deciliter).

physicians, and a podiatrist. Group home staff coordinated the care provided by these practitioners, following plans developed by an interdisciplinary team that included the agency's nurse consultant.

Despite his numerous medical diagnoses and somewhat fragile health, Mr. Sampson lived quite successfully in his community residence. In fact, during the course of this investigation, those who knew him well consistently described him as an interesting, personable and remarkably spirited man – one whose life was defined not by his health care needs, but by his many interests, contributions and relationships.

Consistent involvement and frequent contact with family members no doubt contributed to the fullness of Mr. Sampson's life. But so too did the efforts and understanding of his group home staff. They administered most of his medications, checked his blood sugar level every morning, monitored his fluid intake, took him to medical appointments and ensured that health information was communicated appropriately. In deference to his history of aspiration pneumonia, they also ensured that his meat was cut up into small pieces, that he drank thin liquids, and that he sat up straight while he ate. Although he was legally blind, Mr. Sampson had some peripheral vision. He used a cane for mobility, and was able to get around on his own in locations that were familiar to him. Staff respected and encouraged this autonomy, while, at the same time ensuring that he could exercise it in a safe environment. Although much of their time was spent on physical care and health support, group home staff clearly held Mr. Sampson in high regard, seeing him as a unique and interesting human being.

During an interview with the FRB investigator, the group home manager described Mr. Sampson as an outgoing person who loved to talk, and didn't like being alone, preferring instead the company of other people. He liked to listen to tapes, especially ones that told stories about dogs, going for rides and shopping. Mr. Sampson was partial to magnets, keys, and key chains. He loved to walk on the beach and collect rocks. He also liked to wade and swim, if someone was around to support him. Mr. Sampson was the type of person who would try just about anything. He liked to work and collect a paycheck. He was very close to his family and spoke with at least one family member daily. Mr. Sampson could use the phone independently. He liked to cook and was learning to use the stove and oven. He also did his laundry independently. Mr. Sampson loved to help. He was always very helpful and kind. He didn't like the snow, because he used a cane and the snow could be slippery. When the weather was nice, he liked to go for walks around the neighborhood. Mr. Sampson would go to his sister's house every couple of months or so. He liked jokes and had nicknames for all of the staff. Mr. Sampson could be demanding at times, not for attention, but to have his needs filled, like any of us would if we were in similar circumstances. He was always very respectful and polite.

HOSPITAL ADMISSION AUGUST 2001

In August 2001, Mr. Sampson was hospitalized at Lawrence and Memorial Hospital in New London, CT for two weeks for the treatment of cellulitis. According to his medical records, Mr. Sampson presented at the hospital with a fever, pain, swelling, and redness of his right lower leg. In July 2001, he had visited his mother in California where records indicate that he was possibly bitten by an insect. A sore developed on the side of his right ankle. Two days prior to Mr. Sampson's hospitalization, a sore developed around the bite site, which was not responsive to outpatient antibiotic treatment. In the hospital, Mr. Sampson's leg was kept elevated and he received intravenous antibiotic therapy. He responded well to this treatment. At the time of his admission, the cellulitis had extended up to the right knee, but with the IV antibiotics, it rapidly diminished. By the time he was discharged, there was minimal swelling, his ankle was not tender, and there was a small scar at the site of the bite. Mr. Sampson still reported pain upon walking.

During this hospitalization, Mr. Sampson was noted to have shortness of breath and tachycardia, which is an accelerated heart rate. He was seen by a pulmonologist and cardiologist and tests were performed which revealed further evidence of an enlarged heart and congestive heart failure. He was started on digoxin, a beta blocker, and an ACE inhibitor, which are medications designed to treat congestive heart failure and other cardiopulmonary problems. Mr. Sampson's oxygen saturation level was depressed during the course of his hospitalization, and he continued to require supplemental oxygen. Complications related to his hypernatremia (elevated concentration of sodium in the blood) were also noted. In response, he was seen by a nephrologist (kidney specialist) and one of his medications (DDAVP) was adjusted. No other medication changes were made.

While hospitalized, Mr. Sampson was also tested for methicillin-resistant staphylococcus aureus (MRSA), which are organisms that are resistant to the antibacterial action of penicillin-type antibiotics, and was found to have "colonized" MRSA present in his nostrils. According to the National Centers for Disease Control and Prevention, approximately 25% of the population in the United States has colonized MRSA present in nasal passages. The vast majority of these individuals are asymptomatic. The same source indicates that no special precautions or restrictions beyond standard hygiene are generally required.

On August 29, 2001, fourteen days after his admission to the hospital, Mr. Sampson was discharged to a nursing home for physical and oxygen therapy to stabilize and improve his condition prior to his return to the group home. In an interview with the FRB investigator, the group home's nurse consultant reported that at the time of his discharge from the hospital, Mr. Sampson's need for medical care and monitoring exceeded what could be provided to him at the group home. The nurse consultant stated that, due to the severity of Mr. Sampson's episode of cellulitis and the resulting decline in his physical abilities, he required skilled nursing evaluation and assessment on an hourly basis following his hospitalization, as well as physical therapy to restore his mobility. The nurse consultant also reported that while Mr. Sampson had received oxygen therapy at home in the past, this circumstance was different in that he was now not ambulating, and

required a wheelchair or walker for assistance. Because his bedroom was located on the second floor of the group home, it was felt that Mr. Sampson would need to be able to increase his strength and mobility in order to negotiate the stairs before returning home.

The nurse consultant further stated that, based on her professional experience, planning for Mr. Sampson's discharge to the nursing home conformed to established practices. These practices include the following components: the patient's physician documents the discharge diagnoses, medical orders, and current medication regime on the Inter-Agency Patient Referral Report (W-10); and the hospital's case manager (also known as discharge planner) completes the patient's discharge paperwork, with the assistance of secretarial staff, and confers with the receiving facility. The nurse consultant indicated that all of the case managers at the hospital are registered nurses, and that planning for a patient's discharge begins at the time of admission. Initially, consideration was given to discharging Mr. Sampson to the hospital's in-house rehabilitation facility. He had a rehabilitation consultation at the hospital but it was determined that, due to his lack of motivation and cooperation, he would not be a candidate for transfer to that unit. *(NOTE: Admission requirements for the hospital's rehabilitation unit stipulate that patients must be able to participate in close to three hours of combined therapies, such as physical, occupational, and speech therapy, per day.)* Following this determination, the case manager turned her attention to locating a nursing home offering rehabilitation services. Because Mr. Sampson's placement was anticipated to be for short-term (less than 30 days) rehabilitation only, pre-admission screening by the DMR was not required. *(NOTE: Pre-admission screening by a designated state authority is required by federal Medicaid law prior to long-term placement of an individual with mental retardation into a long term care facility. This requirement, established in 1987, is designed to prevent inappropriate institutionalization of individuals whose health care needs do not warrant admission to a health care facility.)*

The group home's nurse consultant stated that neither Mr. Sampson's family nor group home staff members were personally familiar with the particular nursing home identified for him. The decision to admit Mr. Sampson to the nursing home was based primarily on its location, which was in close proximity to the group home and his family members, and its open-bed availability. The nurse consultant reported it is generally assumed that a nursing home's acceptance of an individual for admission to its facility is predicated on its ability to meet that individual's medical and other needs.

Mr. Sampson's discharge diagnoses, which are listed on the Inter-Agency Patient Referral Report (W-10), included right lower extremity cellulitis, hypernatremia, cardiomyopathy/congestive heart failure, panhypopituitarism, hypoxia/hypercarbia, hypothyroidism, optic nerve glioma @ (at) age 6, hydrocephalus, legally blind, cortical adrenal insufficiency, diabetes insipidus, hyperlipidemia, and disaccharidase deficiency.

Medications upon discharge (twelve of them) included Tylenol for fever or pain and oxygen @ 2 liters to maintain his saturation levels at or above 90%. Mr. Sampson's therapeutic goal upon discharge from the hospital was "to return to more ADL (activities of daily living)." Discharge services requested for Mr. Sampson by the hospital were nursing care, occupational therapy and physical therapy.

The hospital's Discharge Nursing Assessment indicated that Mr. Sampson was alert and oriented, that he could not bear weight on his right foot, that he ate 85% of his diet, that he needed physical assistance with bathing, dressing, transfer, toileting and ambulating, supervision with administration of his medications, and that he ate independently. The Discharge Nursing Assessment also notes that Mr. Sampson was given his last dose of Tylenol #3 prior to physical therapy for pain in his right foot, and that his oxygen saturation level was 94% at the time of discharge.

There is no information on the Inter-Agency Patient Referral Report (W-10) or Discharge Nursing Assessment regarding monitoring Mr. Sampson's fluid intake and output, his requirements for fluid intake, or other dietary requirements.

NURSING HOME PLACEMENT

The following chronology of events is taken from local hospital, nursing home, DMR, and DPH records and reports. The FRB investigator also conducted interviews with professionals employed at the nursing home, DMR, DPH, and Seacorp, the private residential provider.

Hamilton Rehabilitation and Healthcare Center, the facility to which Mr. Sampson was discharged, is a single-story, 160-bed, Medicare and Medicaid-certified, for-profit nursing home located in Norwich, Connecticut.

DAY 1 August 29, 2001 (Wednesday)

Mr. Sampson was transported to Hamilton Rehabilitation and Healthcare Center (hereafter "Hamilton") by ambulance. According to Hamilton's Director of Nursing, who was interviewed by the FRB investigator on April 2, 2003, notations made by Hamilton staff on the hospital transmittal form indicate that nursing home personnel spoke directly with Lawrence and Memorial Hospital on the day of Mr. Sampson's admission.

Mr. Sampson's group home manager was at the nursing home when Mr. Sampson was admitted. He remembers the ambulance attendants bringing a packet of information with them from the hospital. According to the group home manager, all of this information was passed along to Hamilton's social worker, who also functioned as the group home liaison. The group home manager spoke with Hamilton's social worker at length about Mr. Sampson's medical conditions and needs. He shared with her the names of Mr. Sampson's family members and group home staff, and let her know that a staff member from the group home would be visiting Mr. Sampson at least once a day during the course of his stay at the nursing home. The group home manager accompanied Mr. Sampson to his room. Before leaving, he helped Mr. Sampson unpack his belongings and get settled. The group home manager reported that he had no concerns about Hamilton during that first visit. The nursing home appeared to be very clean and the residents seemed happy. He indicated that Mr. Sampson seemed "okay" with the placement. Although Mr. Sampson wanted to come home and didn't really want to be

there, he wasn't ready yet to do his exercises. The group home manager stated that everyone working at Hamilton seemed very busy.

Upon his admission to Hamilton, Mr. Sampson received a number of standard screening assessments. According to a Nursing Admission Assessment, completed by a licensed practical nurse (LPN), Mr. Sampson was admitted to Hamilton at 5:00 PM. His vital signs were: Temperature (T) 98.1, Pulse (P) 80, Respiration (R) 20 and Regular, Blood Pressure (B/P) 118/80, Weight 146.6 Comments pertaining to his skin condition include, "pink with edema [swelling], no open areas." His breath sounds are described as "normal." Mr. Sampson's functional status assessment notes that he requires a one-person assist to transfer, ambulates with the assistance of a walker, and is unable to bear weight on his right leg. It is noted that Mr. Sampson has pain in his right ankle. His sleep pattern "varies," he is described as being "continent" and using the toilet. It is noted that Mr. Sampson has his own teeth, eats independently, has a regular diet, and requires assistance with his shower, oral hygiene, and shaving routines. Mr. Sampson is described as "cooperative, oriented, alert, and obeys commands." His motivation towards rehabilitation is described as "good," and it is noted that he has been provided with an explanation of his plan of care.

A Problem/Skilled Needs List indicated that the following were to be addressed on a daily basis: monitor for falls, cardiac assess, monitor for signs/symptoms of infection, diabetes management, assess for pain, monitor oxygen saturations, assess for cognitive changes.

A Fall Risk Assessment, completed by a registered nurse (RN), assigns Mr. Sampson a summary score of 11, which places him at moderate risk. Categories of risk that apply include a sensory deficit (visual), being on a significant medication, walking and transferring with the assistance of caregivers, having a cardiovascular weakness, using an assistive device for walking and transfers, and having a recent decrease in mobility.

A Pain Assessment, not dated or signed, states that Mr. Sampson does have a diagnosis that would give reason to believe he would be in pain, which is listed as cellulitis. It is also noted that Mr. Sampson is capable of verbalizing pain, and gives the date of pain onset as July 2000. No other information is provided on the Pain Assessment.

A Bladder Retraining Assessment, not dated or signed, describes Mr. Sampson as "alert, oriented, slow comprehension, very demanding, and time-consuming." His mobility status is listed as "independent with minimal assistance with walker."

A Dehydration Risk Assessment, completed by a RN, assigns Mr. Sampson a 1 out of a possible score of 8 for potential risk for dehydration. A score of 8 indicates a person is at high risk. *(NOTE: This is a questionable score. Mr. Sampson's diabetes insipidus created significant risk of dehydration and was the principle reason he had previously been placed on a fluid intake regime requiring him to drink 64 ounces of liquid per day.)*

A Braden Scale-For Predicting Pressure Sore Risk, completed by a RN, assigns Mr. Sampson a summary score of 18 out of a possible score of 23, placing him at low risk for developing pressure sores. Risk factors noted for Mr. Sampson include limited physical activity, probably inadequate nutrition, and a potential problem with his skin sliding against surfaces when moving or being helped to move.

A Nursing Care Plan developed for Mr. Sampson, which is signed by three LPNs and one RN, summarized his presenting problems, goals and objectives of the nursing care provided for him, and the treatment approaches or activities required to achieve those goals. Problems identified included his cellulitis, vision impairment, diabetes insipidus, impaired cognitive ability, activities of daily living skill deficits, nutritional status, and functional mobility.

Activities required of nursing personnel to address Mr. Sampson's health care needs included observing his affected leg for swelling and other symptoms of cellulitis, accommodating his visual impairment and cognitive disability by modifying the physical environment, instructional methods, and interactions of staff members, monitoring his fluid intake and output, and observing him for signs of excessive thirst, observing him for signs of respiratory distress or changes in his mental status, observing him for signs of an increase or decrease in blood glucose (sugar), offering him a regular diet, monitoring the percentage of meals eaten and offering another option if less than 50 % is consumed, and completing physical therapy evaluation and follow-up.

The only nurse's entry made on Day 1 states* :

2415 hrs [2:15 AM] Arrived at 1700 hrs [5:00 PM] no problems. MD [physician] and family aware. Meds [medication] will arrive tomorrow. Will not stand on RT [right] ankle. Very fussy eater. Continent of bowel and bladder.

DAY 2 August 30, 2001 (Thursday)

A Physical Therapy Evaluation was completed for Mr. Sampson on Day 2 and Day 3, for a total of two hours over the two-day time period. It states that the goal for therapy is "to return home." Mr. Sampson is described as "alert, lucid, pleasant, and follows commands well." There is a note indicating that "patient reluctant to move right lower extremity due to pain."

Mr. Sampson's group home manager, wrote the following note after an interaction with nursing home staff on Day 2:

I called Hamilton rehab center at 12 noon to see if Philip was evaluated by the physical therapist. I talked to [the physical therapist] (director of the rehab department). I asked him how Philip was doing; he had a good night and a good morning. I asked him if he [Philip] had a plan for rehab. [The physical therapist] stated that Philip would be working on strength training in his legs. They will

* Indented sections included in the body of the report represent direct quotes from witnesses or language taken directly from documents reviewed.

also work on balance and his gait. Pain is playing a big part in Philip's therapy; Philip is unable to put pressure on his right foot. First they will work on the pain; then they will start with assisting him on transferring from his bed to a chair and so on. I asked [the physical therapist] if he had a rough estimate of time that Philip might be in therapy; he stated anywhere between 2 to 4 weeks. [The physical therapist] feels that Philip should be able to walk independently after the therapy. [The physical therapist] then stated this would all begin when Philip's infection is treated. I asked [him] if he meant the cellulitis, he stated no the MRSA. I told him that Philip's MRSA is not being treated. He told me that Philip's MRSA is contagious and at this point Philip is isolated in his room. I told him that I was unaware of this. I asked him how is Philip going to get his therapy, [the physical therapist] stated when he is able to leave his room his therapy will start. I asked [him] how is Philip using the telephone; [he] stated he is not allowed to use public phones because he could spread the MRSA through his ear canals. [The physical therapist] also stated that whenever they enter the room they wear gowns, masks, and gloves. I told [him] that yes, Philip has MRSA in his nose BUT it is colonized and NOT infectious. [He] stated that maybe I should talk to his charge nurse. I agreed.

The charge nurse for Philip's wing is [...]. After introducing myself [to the charge nurse], she asked me if she could call me back because she was at lunch. I told her NO I've got questions that I need answered. I asked [her] if Philip is colonized, she stated yes. I asked her why is everyone entering Philip's room in gowns and masks. She stated they should not be. They only need to use universal precautions. I asked her about the telephone, she stated Philip could use the telephone no problem. I asked her if Philip is confined to his room, she stated no. I told her what I was told by [the physical therapist], she stated he must not have received all of Philip's paper work. I expressed to her that all of the people working with Philip should know that his MRSA is colonized. I very strongly expressed to her that I did not want Philip treated like an outsider, I want him treated like all the others, she agreed. I proceeded to ask her about Philip's roommate. She stated his roommate is in the hospital. I asked her if this gentleman has MRSA, she stated NO. I questioned what would happen when he returns; she stated it would be fine if they shared a room. I told her that our nurse stated to me that people with MRSA should either room alone or with someone with MRSA. She stated that maybe I should call their infectious control nurse, I told her I would. I ended the conversation by telling her that I'd be calling every day for an update. I also told her that someone from the group home would be there every day to visit Philip, she stated OK.

Nurse's entries made on Day 2 state:

0600 hrs [6:00 AM] T P R 93 – 70 – 20. Alert/verbal. Playing music, talking [with] staff, ringing call light throughout the shift. Did not sleep soundly. No c/o [complaints of] discomfort.

1400 hrs [2:00 PM] Pt [patient] very demanding, on light frequently. Very verbal. Fussy about food - Verbalized doesn't like what is being served. Seen and evaluated by PT (physical therapist). Up on w/c [wheelchair] – on the phone [unable to read]. Stable V/S [vital signs] T P R 100 – 70 –18. P.O. [by mouth] fluid encouraged. [Unable to read] [with] assist and walker.

Continue on antibix [antibiotics] [without] ill effect for cellulitis. [Unable to read] T = 99

2245 hrs [10:45 PM] T P R 99.2 – 80 – 20. [No] c/o [complaints of] pain or SOB [shortness of breath]. O2 [oxygen] sat [saturation] 94 [%]. RT [right] ankle pink [no] open areas. Continent of bowel and bladder. Ambulates with walker assist but will not put weight on RT [right] ankle. Very fussy about food and drink taken poorly. Brother in to visit. Very friendly and encouraged pt [patient] to eat.

(NOTE: There is no record of Tylenol being administered for pain, and there are no entries recording Mr. Sampson's urinary intake or output. The Glucose Monitoring Log also contains no entries.)

DAY 3 August 31, 2001 (Friday)

An Occupational Therapy Evaluation was completed for Mr. Sampson on Day 3, for a total of 45 minutes. It states that the goals for occupational therapy are, “to be able to get dressed, I have to walk.” Treatment precautions listed are “legally blind, oxygen-dependent, and MRSA – nares.”

The attending physician completed Mr. Sampson's admission medical history, physical examination, and physician's orders on Day 3. The physician's orders stated that Mr. Sampson was to have a regular diet. They do not address requirements for fluid intake, nor do they stipulate that Mr. Sampson's intake and output be monitored. The physician's orders include Tylenol 650 mg by mouth every 4 hours (as needed) for pain or elevated (100 oral/timpanic (ear) – 101 rectal) temperature.

The group home manager recorded the following entry on Day 3:

I talked to [...], the infectious [disease] control nurse at Hamilton rehab center. She was in [Philip's] room when I called. She told me that the charge nurse told her that I called yesterday with a lot of questions. I asked her if Philip's MRSA is colonized. She said yes. I told her what I was told by the [physical] therapist. She stated the only orders that were put in place for Philip is universal precaution. I asked her about his roommate. She stated when possible people with MRSA should have their own room, but if the person is colonized and not showing any signs of infection related to their MRSA then they can share a room. She stated that if Philip shows sign of discharge from his nose then they would re-evaluate his living arrangements. I was reassured that Philip is able to go anywhere in the rehab center. She told me to call with any questions. I thanked her for her time.

Nurse's notes made on Day 3 state:

0600 hrs [6:00 AM] T P R 98.9 – 72 – 20 O2 [oxygen] sats [saturation] 94% and O2 @ 2L/min. [2 liters/minute]. RLE [right lower extremity] pink, slightly edemous. Pt stated, "it only hurts when I walk on it." Alert/verbal, ringing call bell often – sometimes just to talk to staff. Playing CDs. Only sleeping for short periods of time.

1230 hrs [12:30 PM] T P R 98.6 – 80 – 20 Alert, cooperative. O2 [oxygen] Sat [saturation] 90% on RA [room air]. Phoned group home. Denies any pain, discomfort.

2300 hrs [11:00 PM] T P R 97 – 80 – 20 O2 Sat 98% on RA [room air] while awakening. Denies pain. Verbal, asking for attention often very picky about food and drink. [...] [attending physician] to visit. [Decrease] Accu-Chek [test to measure the level of sugar in the blood] to BID [twice a day] on Monday only and then to p.r.n. [as needed]. RT [right] ankle pink with slight edema.

(NOTE: There is no record of Tylenol being administered. There are also no recordings for fluid intake or output. The Glucose Monitoring Log records a reading of 86 at breakfast and 96 at dinner.)

DAY 4 September 1, 2001 (Saturday)

The group home manager recorded the following entry on Day 4:

I went to see Philip at about 12:30 PM. Upon my arrival he was eating his lunch, [...] from [his vocational program] was with him. I sat with Philip while he finished his lunch, after we went outside. Philip wanted to show me all the money he won playing bingo, all in all he won 50 cents, he was very happy. I sat and talked to Philip, I asked him how his day was going and he said fine. He told me that today he was going to play blackjack (Philip wanted to win more money). I asked him if he has been walking, he stated yes. Philip said he is walking with the physical therapist in the mornings. I asked him what kinds of exercises he has been doing, he stated just walking. Philip told me that he walks the halls. Philip was happy that the group home was coming to [see] him. Overall Philip was in a good mood, he was positive about his walking. He stated he wanted to walk to the van [when he goes] home. I visited with Philip for 3½ hours.

Nurse's notes entered on Day 4 state:

1400 hrs [2:00 PM] Remains on Augmentin [antibiotic] for R [right] extremity cellulitis. Fair po [by mouth] intake. Alert/active. O2 sat 92%. Lungs clear [without] cough. Cont [continent] of bowel and bladder. Visitors [after] lunch. 97.2 – 78 – 20

2300 hrs [11:00 PM] T P R 98.4 – 72 – 20 Up, ambulatory in wheelchair from 1900 – 2200 [7-10 PM]. Called group home x 1 [once], attempted to call sister but was not home. Became very angry after this and wanted to call sister's friend to see if she was there. Told res. [resident] to wait a little while and try sister's home again. Very angry until taken outside for a walk. [Right] ankle remains pink. Denies discomfort. No obvious reaction to ATB [antibiotic].

(NOTE: There is no record of Tylenol being administered. Fluid intake is recorded as 1140cc, and output is recorded as 400 cc. It should be noted Mr. Sampson was up to the bathroom to void, so input and output records may not be accurate. The Glucose Monitoring Log records a reading of 85 at breakfast and 174 at dinner.)

DAY 5 September 2, 2001 (Sunday)

The group home manager recorded the following entry on Day 5:

I went to see how Philip was doing. Upon my arrival he was in his room sitting in his wheelchair. I asked Philip if he had walked yet. He stated yes a little while ago. I asked him how his leg was doing. He stated it still hurts. He told me that his brother [...] was in yesterday, he enjoyed the company. Overall Philip looks fine and his spirits are high. I told him the group home would be in later to see him. Philip told me he liked [...] (a new sub) [substitute staff] and wanted to see her again. We talked for about an hour and a half.

Nurse's notes entered on Day 5 state:

0500 hrs [5:00 AM] T P R 99 – 74 – 20 Slept well. No c/o [complaints of] discomfort.

1600 hrs [4:00 PM] T P R 97.6 – 72 20 Amb [Ambulates] in w/c [wheelchair]. Visitor from group home. [Right] ankle pink. Denies discomfort. Remains on ATB [antibiotic].

(NOTE: According to the nursing home Medication Administration Record, Mr. Sampson's antibiotic was discontinued, per doctor's orders, on Day 3. There is no record of Tylenol being administered. Fluid intake is not recorded, and output is recorded as 250 cc. It should be noted Mr. Sampson was up to the bathroom to void, so the output recorded may not be accurate. The Glucose Monitoring Log records a reading of 93 at breakfast. There is no dinner reading recorded.)

DAY 6 September 3, 2001 (Monday and Labor Day)

The following entry was recorded by the group home manager regarding events that were reported to him by group home staff on Day 6:

[At approximately 6:00 PM] [...] [a staff member at the group home] received a call from [...] a staff member [who was visiting Mr. Sampson] at Hamilton stating that she was worried about Philip. She stated he is mumbling and slurring

his words. While talking to him she stated he was falling asleep. [...] [The staff member at the group home] got on the phone with Philip to confirm this. She [the staff member visiting Mr. Sampson at Hamilton] went to the nurse's station and notified them. She [this same staff member] suggested it could be his blood sugar. At this point [the staff member at the group home] called our agency nurse [consultant] and updated her. [The group home's nurse consultant] stated to call the nursing home and tell them that this is not normal. She instructed [the staff member at the group home] to remind them [Hamilton nursing staff] about his blood sugar issues and that his DDAVP [medication used to treat the level of sodium in Mr. Sampson's blood] had been changed prior to leaving L&M [Lawrence and Memorial Hospital]. [The staff member at the group home] called Hamilton rehab center back and spoke to [...] (2nd shift nurse). [This same staff member] updated her [the 2nd shift nurse] concerning Philip. He told her about the sugar issues, diabetes insipidus and the recent change in his DDAVP. [The 2nd shift nurse] seemed unaware of any of this. [The staff member at the group home] told her that Philip was slurring his words; [the 2nd shift nurse] stated she hadn't noticed. She [the 2nd shift nurse] at this point checked his blood sugar, 275, she stated normal. [The staff member at the group home] told her he [Mr. Sampson] normally runs low. She [the 2nd shift nurse] then proceeded to ask the staff member at the group home if there was anything else he would like her to check. He stated no. She stated she would re-check his blood sugar in one hour.

Nurse's notes entered on Day 6 state:

1450 hrs [2:50 PM] [T P R] 97 – 72 – 22 AP [apical pulse, which is heard over the heart with a stethoscope] 92, [BP] 92/62 Alert/oriented. Lungs clear. [No] cough, lung SOB [shortness of breath] noted. Abd [abdomen] soft, non-tender. BS [bowel sounds] (+) times 4 quads [in all four quadrants]. Cont [continent] of B/B [bowel and bladder]. App [approximately] 25% at breakfast. Refused lunch, throwing fit did not like lunch. Offered alternative, refused. Stated, "I don't want anything." One person transfer. [No] c/o [complaints of] leg pain. Self-mobile in w/c [wheelchair] from hallway to room [without] incident. No s/s [signs/symptoms] of diabetic reaction.

2245 hrs [10:45PM] 98.6 – 80 – 20 BP 112/68 Alert, verbal. W/C [wheelchair] as per norm. Tired tonight. Not as bright as usual. BS [blood sugar] at 1630 [4:30 PM] is 120. O2 [oxygen] sat [saturation] 99 % on RA [room air] at 1630 [4:30 PM] at 2000 [8:00 PM] 88 [%] on RA [room air] O2 [oxygen] put on 92 on 2L [2 liters]

According to nursing home records, Mr. Sampson received 30 minutes of physical therapy on Day 6.

(NOTE: There is no record of Tylenol being administered. Fluid intake is recorded as 940 cc, and output is recorded as 700 cc. It should be noted Mr. Sampson was up to the bathroom to void, so input and output records may not be accurate. The Glucose Monitoring Log records readings of 107 at breakfast and 120 at dinner. There is no

notation of a blood glucose reading of 275 in Mr. Sampson's record. Nor is there a record of an additional reading being obtained an hour after the nurse's discussion with group home staff at approximately 6:00 PM. It should also be noted that the LPN (2nd shift nurse) referred to by group home staff members as being unaware of Mr. Sampson's medical condition and medication changes, was responsible for completing Mr. Sampson's Nursing Admission Assessment and signed off on his Nursing Care Plan when he was first admitted to the nursing home. In an interview with DPH investigators, this same LPN stated that while she could recall speaking with group home staff members on one occasion about Mr. Sampson being tired, she could not recall ever being told about slurred speech. She also reported that she did not observe Mr. Sampson with slurred speech and stated that each time the group home staff asked about Mr. Sampson's condition, she would find nothing wrong. There is no indication in Mr. Sampson's records that either the RN supervisor or attending physician was informed by the LPN of the group home staffs' concerns.)

DAY 7 September 4, 2001 (Tuesday)

The group home manager recorded the following entry after a visit to Hamilton on Day 7:

[At approximately 11:00 AM] we [group staff members] went to Hamilton rehab center to visit Philip. Upon arrival as we walked to his room we could hear him calling for help. We rounded the corner and saw him getting up out of his wheelchair and walking over to his bed, no supervision in the room by the nurses. As Philip sat on his bed, we noticed that his air hose was under the wheel of his wheelchair. We asked Philip how long he was sitting in his wheelchair. He did not know. Philip was waiting for [...] [the physical therapist]. He had not done his exercises yet. We also noticed that Philip's bed was unmade, he had no pillowcases or sheets. When I asked Philip how he was feeling he stated okay, I am tired. While we were talking to Philip his words were slurred, he was also leaning over to the side to lie down. We encouraged Philip not to lie on the unmade bed, he did anyway. Philip was also back on his oxygen 3 liters. I asked him why, he stated that they put him on it this morning. At this point I went to find [...], the charge nurse, she is not available, and [...] (charge nurse) will be in to talk to us. [...] [charge nurse] came into the room. She stated to us that she was on vacation when Philip arrived. We asked her to check his blood sugar (this may be why he is sleepy and slurring his words). His blood sugar level was 181. We expressed our concerns about Philip's condition. [...] was not updated on Philip's medical conditions. She had no background information on Philip. [...] was asked to make an appointment with [...] [Philip's endocrinologist]. She wrote this request down and stated she will call his office. Once an appointment is set up she will call the group home and let us know when it is. She told us that [...] [attending physician] is [Philip's] doctor while in the rehab center. If [...] [Philip's primary care physician] or [...] [Philip's endocrinologist] prescribes medication, will the orders be followed by this facility? She stated as long as [...] [the attending physician] signs off on them, this should not be a problem. We told her that it was not normal for Philip to fall asleep mid-conversation. Philip usually stays up late and talks all day. I asked her why he was back on oxygen.

She stated his sats were low this morning. His pulse ox [oxygen] is 91 on 3 liters. I asked her for Philip's current medication list. She copied the Kardexes for me. I told her that he might be due for his Depo-Testosterone. I will call them with a date. I explained to her that when he gets sick or if his meds change his electrolytes will need to be monitored. We asked [...] [the charge nurse] to complete blood work on Philip. She said yes. We questioned his physical therapy. We told her that he has been waiting since this morning for [...] [the physical therapist]. She told us that he is down the hall with someone. She went to get him. [...] [the physical therapist] entered the room. We talked to him about Philip's progress and we told him that Philip was waiting for him. [...] [the physical therapist] stated that he feels Philip is already making progress, pain continues to be a problem. I told [...] [the charge nurse] that Philip was on Neurontin the last time he had cellulitis. She said she would talk to [...] [the attending physician]. We asked [...] [the physical therapist] to please set a specific time for Philip's therapy, as this will help Philip regulate his day. On the way out we stopped in to talk to [...] [the nursing home's social worker]. Again we expressed our concerns. [...] [the social worker] seemed upset to hear that Philip was sleeping on a mattress with no sheets. She called the Nursing supervisor to the office. Once she arrived she was updated about Philip. The above information was given to her. We explained that Philip's blood sugar should be monitored more often. I told her that in the year that I have known him he has NEVER slurred his speech. She was told that Philip is a reliable reporter. If he says something hurts, it does. She was told that something is wrong and it needs to be addressed. A meeting with his team is set for Friday, the [...] [Day 10], at 11:00 AM.

The group home manager's supervisor, who is the Director of Residential Management, accompanied him to the nursing home on Day 7 because of the concerns that had been raised by group home staff regarding Mr. Sampson's condition. According to her account:

When we entered the unit we could hear Philip's voice raised in frustration. He was saying over and over, "help me, I'm tired of waiting." Philip's room was beside the nurse's station, from the doorway we could see him struggling to raise out of the wheelchair, his oxygen hose was caught under the wheel and his feet were tangled in the footrest. When Philip would try to stand, the chair would move and he would fall backwards. We reassured Philip that we were there and helped him out of the chair. Philip stumbled to the bed and attempted to lie down, we were trying to help him sit up as the plastic mattress was bare, but he was unable to sit upright. We summoned a nurse at that point.

Nurse's notes entered on Day 7 state:

1600 hrs [4:00 PM] [T] [P] [R] 97.8 – 108 – 20 [BP] 98/63 AP [apical pulse] 84 Alert/forgetful at times. [No] acute respiratory distress noted. Sats [saturation] 92% on O2 [oxygen] @ 2L [2 liters] via N/C [nasal cannula] abd [abdomen] soft, non-tender. App [appetite] O-25%. Fluids enc [encouraged]. [No] s/s

[signs/symptoms] diabetic reaction. Spoke with caregivers. N.O. [new orders] per [...] [attending physician]: 1) may consult with [...] [endocrinologist] will schedule an appointment in AM 2) Accu-Cheks [test to measure the level of sugar in the blood] BID [twice a day] x [times] 7 days 3) Neurontin [pain medication] 600 mg PO [by mouth] TID [three times a day].

2300 hrs [11:00 PM] BS [blood sugar] at 1600 [4:00 PM] 135, O2 [oxygen] sat [saturation] on RA [room air] 88 on 2L 92 % no problems

According to nursing home records, Mr. Sampson received 75 minutes of physical therapy and 45 minutes of occupational therapy on Day 7.

(NOTE: There is no record of Tylenol being administered. According to the Medication Administration Record, Philip received one dose of Neurontin at 1700 or 5:00 PM. Fluid intake is recorded as 1010 cc, and output is recorded as 100 cc. It appears unlikely that Mr. Sampson was able to use the bathroom independently at this point, given the group home staffs' description of his condition when they visited earlier in the day. It may be that Mr. Sampson only voided 100 ccs of fluid as recorded by the nursing home staff. The Glucose Monitoring Log records a reading of 86 at breakfast and 135 at dinner. It should also be noted that the nurse (LPN) referred to by group home staff members as having no background information on Mr. Sampson and being unaware of his medical condition, signed off on his Nursing Care Plan.)

In interviews with the FRB investigator, the group home's nurse consultant, confirmed that she had been informed of Mr. Sampson's elevated blood sugar level on Day 6 and the fact that "he was not himself" on Day 7 by group home staff members. According to the nurse consultant's running notes, Hamilton was asked to draw electrolytes in light of Mr. Sampson's diabetes insipidus. Her notes also indicate that a nursing supervisor at Hamilton agreed to follow-up with that and consult with Mr. Sampson's endocrinologist.

The nurse consultant stated that she had no direct contact with nursing home personnel during the course of Mr. Sampson's admission.

DAY 8 September 5, 2001 (Wednesday)

According to nurse's notes entered on Day 8:

[no time noted] Resident [Mr. Sampson] has been asleep on hourly rounds. Resident hard to arouse this morning for his 0600 [6:00 AM] Synthroid. Unresponsive to sternal rub.⁴ Blood sugar this AM is 117. Resident did not respond to this stimuli. Updated next shift and to find resident's morning routine. Again attempted to arouse.

0740 hrs [7:40 AM] Patient [not] responding to painful or verbal stimuli. VS [vital signs] [BP] [P] [R] 124/64 – 66 –24. [No] resp [respiratory] dif [difficulty]

⁴ A sternum rub is administered by vigorously rubbing the sternum with the second knuckle of the middle finger in an effort to evoke a physical response on the part of a victim during a medical emergency.

noted. O2 [oxygen] on a 2L [2 liters] N/C [nasal cannula]. O2 [oxygen] sat [saturation] unobtainable. Lungs clear. [...] [attending physician] called. Send to ER for evaluation. Mother called message left. [...] [Group home manager] called will meet at hospital. Sister [...] notified of transport to Backus [William W. Backus Hospital in Norwich, CT.] Report called to ER. Pt transferred via 911 @ 7:50 AM.

1200 hrs [12 noon] resident [Mr. Sampson] adm [admitted] WWBH [William W. Backus Hospital] Dx: resp [respiratory] failure, sepsis, and pneumonia.

1500 hrs [3:00 PM] late note. On Day 7 at 1515 [3:15 PM] at nurse's station playing with beads. Layed down for nap at 1600 [4:00 PM]. Rang for Teddy Bear at 1700 [5:00 PM]. LOC [level of consciousness] as per norm at 1730 [5:30 PM]. Ate 75% of meal and drank 360 [cc] of fluids taken. LOC [level of consciousness] as per norm. Resting, meds [medications] given at 2130 [9:30 PM]. No problems.

EMERGENCY HOSPITAL ADMISSION

William W. Backus Hospital records reflect the following information as dictated by Hamilton Rehabilitation and Healthcare Center's attending physician:

PHYSICAL EXAM

On admission [September 5, 2001] revealed an unresponsive young male intubated with vital signs on arrival of temperature 101.8 rectally, blood pressure 56/palp, heart rate 126, respiratory rate 41, pulse oximetry 78% on nonrebreather mask, patient comatose. Right pupil enlarged, left pupil smaller but did not respond to light, posturing, unresponsive even to noxious stimuli.

ASSESSMENT AND PLAN ON ADMISSION

Is of a young white male presenting in septic shock and acute respiratory failure, acute renal failure with hypernatremia, hypermagnesemia, and severe anoxic encephalopathy and aspiration pneumonitis. Patient pancultured upon admission, started on IV fluids wide open, then started on dopamine and Levophed for pressor support, started on Primaxin and Levaquin IV. Cardiac enzymes were done to rule out for an MI [myocardial infarction]. From a cardiac standpoint we got an echocardiogram which read left ventricle normal size and systolic function, otherwise unremarkable. We also went ahead and did a Doppler ultrasound of the legs which was negative for DVT. Cardiology was consulted, Dr. [...]. Also endocrine was consulted, Dr. [...], and renal consult with Dr. [...] obtained and pulmonary intensivist consult obtained with Dr. [...] and Dr. [...]. The patient was given stress doses of steroids given his diagnosis of adrenal insufficiency and panhypopituitarism. Accu-Chek coverage was done and prior to intubation code status was discussed with the mother and initially everything was done according to their wishes. During the hospital course the patient started with some myoclonic movements, becoming very spastic, posturing. We repeated the CAT

scan of the head which showed new extensive bilateral low attenuations in an MCA distribution, no definitive evidence of hemorrhage and it was read like an extensive bilaterally involving ischemia and infarction of the MCA distribution new when compared to a study of 9/5/2001. On this basis neurology was consulted. Neurology consult felt that this was definitely not an infarct, it was just severe anoxic brain injury. Prognosis was discussed with the family. Any chances of returning to a reasonable life if he made it was poor. It was the opinion of the neurology consult, Dr. [...], that he might remain in a chronic vegetative state. The family did not want this so they decided to withdraw support. Before that they considered organ transplant. Hartford Transplant Unit, Dr. [...], came. This was not possible. Eventually the patient expired on 09/10/2001.

FINDINGS OF OTHER INVESTIGATING AGENCIES

Department of Public Health (DPH)

On Day 9, the Office of Protection and Advocacy Abuse Investigation Division (OPA/AID) received a complaint concerning the alleged neglect of Mr. Sampson by the Hamilton Rehabilitation and Healthcare Center. Based upon the nature of the complaint, the allegations received by the OPA/AID regarding the care and services provided to Mr. Sampson by Hamilton were referred to the DPH, Division of Health Systems Regulation, for investigation. *(NOTE: Both the OPA/AID and DPH are signatories to a multi-agency memorandum of understanding which established a protocol for referring allegations of abuse/neglect of people with mental retardation for investigation by the agency with primary jurisdiction over regulated facilities.)* The purpose of the DPH investigation was to determine whether the nursing home was deficient in providing appropriate care and services to Mr. Sampson prior to his death, as determined by regulatory requirements.

According to their survey report, the DPH investigation included a review of Mr. Sampson's medical records, interviews with nursing home personnel, review of the nursing home's policies and procedures, tour of the nursing home, and review of personnel files. Representatives of the DPH Division of Health Systems Regulation also made unannounced visits to the nursing home during the early part of 2002 for purposes of investigating the complaint. A review of Mr. Sampson's hospital records was also completed.

The DPH review of nurse and nurse aide staffing for a two-week period from mid-December 2001 through the beginning of January 2002 revealed that staffing met the minimum requirements of the Regulations of State of Connecticut Agencies.

As a result of the DPH investigation, it was determined that a number of program requirements were out of compliance or not met prior to Mr. Sampson's death. Deficiencies pertaining to Mr. Sampson's care and treatment cited by DPH investigators included the following:

1. The facility did not immediately inform the resident's physician when there was a significant change in the resident's physical, mental, or psychosocial status on Day 8 prior to his being transferred to the emergency room.
2. The facility failed to ensure that the resident's respiratory status was assessed for changes as identified in the resident care plan and in accordance with acceptable standards of practice on Day 8 prior to his being transferred to the emergency room.
3. The LPN (who first noticed that Mr. Sampson was unresponsive on the morning of Day 8) conducted no other assessment of the resident and did not consult with the RN supervisor regarding the resident's condition. The facility policy for emergency care identified that if the resident's condition had changed, emergency care was to be initiated and the physician was to be notified.

A referral was made to the practitioner's unit of DPH (regarding the LPN who first noted that Mr. Sampson was unresponsive on the morning of Day 8) for action as deemed appropriate. As a result of this referral, a reprimand was issued. According to Hamilton administrators contacted by the FRB investigator at the time of this investigation, this same LPN is no longer employed at their facility.

Office of Protection and Advocacy Abuse Investigation Division (OPA/AID)

The OPA/AID monitored the investigation completed by the DPH. Based on the facts of the case presented, the OPA/AID concluded that neglect was confirmed in this case, and made the following recommendation:

The Department of Mental Retardation should ensure that all of the DPH recommendations (related to the aforementioned investigation) are implemented.

Department of Mental Retardation (DMR)

The DMR completed a review of the circumstances of Mr. Sampson's death. Following this review, DMR wrote a letter to Mr. Sampson's primary care physician noting that there were no specifications for diet or fluid intake on the Inter-Agency Patient Referral Report (W-10 Form), despite Mr. Sampson's diagnosis of diabetes insipidus, which DMR believed impacted Mr. Sampson's care.

Mr. Sampson's primary care physician responded that DMR was correct in noting that there was no diet order on the W-10. The physician noted that he appreciated DMR bringing this matter to his attention and hoped that he could improve on the care for patients like Mr. Sampson in the future.

FATALITY REVIEW BOARD FINDINGS

In addition to the findings reached by the DPH, OPA/AID, and the DMR mortality review, the FRB also concludes the following:

1. Philip Sampson was a thirty-six year old man with mental retardation who, despite living most of his life with a number of complex medical conditions, tenaciously found ways to assert his presence, enjoy his life, and make meaningful contributions to the lives of others. He was involved with his family and well supported by staff from a DMR licensed group home, who understood his needs, ably managed his complex health care needs, and demonstrated great commitment to his happiness and welfare.
2. On August 15, 2001, Philip Sampson was admitted to an acute care hospital for intravenous (IV) antibiotic treatment of cellulitis in his left leg. Following completion of a course of IV therapy, he still complained of pain in his leg and was unable to walk independently. On August 29, 2001, Mr. Sampson was discharged from the hospital to the Hamilton Rehabilitation and Healthcare Center, a nursing home located in Norwich, Connecticut. Because the nursing home admission was for short-term rehabilitation purposes, Medicaid pre-screening (commonly referred to as “OBRA” or “PASSAR” screening) was not required.
3. While planning for Mr. Sampson’s discharge from the hospital followed an established, customary routine, it did not include research into whether the particular nursing home identified for him was able to meet his specific needs. Those needs stemmed from Mr. Sampson’s complex, chronic health problems as well as his visual impairment and mental retardation. In addition to competent medical management and constant monitoring, he needed considerable attention, reassurance, encouragement and redirection.

Although Hamilton had been previously cited by DPH for breakdowns in quality of care similar to that which was experienced by Philip Sampson, this information was not readily available to his discharge team. A review of DPH investigation findings shows that resident care plans were frequently not implemented as written, facility staff who were responsible for providing residents with care and treatment were unfamiliar with their medical conditions and needs, residents were frequently left unattended, and physicians were not promptly notified of accidents that resulted in injuries or significant changes in a resident’s condition. Mr. Sampson experienced virtually all of these problems while at Hamilton.

4. The DPH investigation conducted in response to Mr. Sampson’s death concluded that minimum staffing requirements were met for the time period surveyed by DPH in December 2001 and January 2002. However, the FRB’s review of actual staffing patterns for the period of Mr. Sampson’s admission revealed that nursing coverage barely met minimum staffing standards, and at several times may have fallen below those standards. As reported by Hamilton’s Director and Assistant of Nursing in interviews with the FRB investigator, these standards are:

- During the day shift, two LPNs are assigned to each of the three units, with a full capacity of 160 residents, for a total of 6 LPNs on duty. If two LPNs for each unit are not available, the RN supervisor or charge nurse is assigned to provide nursing coverage.
- During the night shift, one LPN is assigned to each of the three units, for a total of 3 LPNs on duty. If one LPN for each unit is not available, the RN supervisor or charge nurse is assigned to provide nursing coverage.

The FRB review of facility records revealed numerous absences or uncovered shifts at the unit level, meaning that RN supervisors or facility charge nurses were frequently responsible for providing nursing coverage to those units in addition to performing supervisory duties. On both Day 4 (Saturday) and Day 5 (Sunday), a RN supervisor or charge nurse worked “double duty” by covering a full twelve-hour shift. Two of the nurses working on Day 5 (Sunday) worked fourteen-hour shifts. It also appears that there may have been a two-hour gap during the day shifts on Day 4 (Saturday) and Day 5 (Sunday) where one of the units had only one nurse on duty for a two-hour period, whereas there should have been at least two nurses working. In addition, the use of split shifts and pool nurses was evident in an attempt to arrange coverage due to numerous “call outs”, particularly over the Labor Day holiday weekend. These conditions appear to have contributed to a lack of adequate and consistent staffing over the period of Mr. Sampson’s admission.

On Day 7, a Tuesday, group home staff arrived at the nursing home at approximately 11:00 AM to find Mr. Sampson alone in his room, his voice raised in frustration, calling for assistance as he attempted to transfer out of his wheelchair into his bed. Despite the fact that his room was next to the nurse’s station, there didn’t appear to be anyone available to assist him. His oxygen hose was caught under his wheelchair, and his feet were tangled in the footrest. Although it was late morning when the group home staff arrived, Mr. Sampson’s bed had been stripped of bed linen but not re-made. As a result he lay down on an unmade bed.

As previously indicated, Mr. Sampson was able to live successfully at the group home, in spite of his complicated medical condition and fragile health, due to the consistent monitoring of his physical condition by people who knew him well and recognized and understood the subtle signs of potential problems. The nursing home’s inconsistent staffing patterns placed Mr. Sampson at increased risk of having changes in his medical condition go unnoticed, as no one knew him well enough to understand what was “normal” behavior for him, and to detect and respond to important changes.

5. Mr. Sampson’s hospital discharge and nursing home admission was marked by unclear, inadequate, incomplete and, in some respects, inaccurate communications. Specifically, the Interagency Patient Referral form (W-10) signed by the physician who discharged Mr. Sampson from the hospital contained no information about fluid intake or dietary needs. Nor did the Dehydration Risk Assessment prepared by Hamilton shortly after his admission there. In fact, that assessment erroneously

determined that Mr. Sampson's risk of dehydration was minimal. But perhaps the most troubling communications lapses involved attempts by group home staff to communicate vitally important information. Information concerning Mr. Sampson's complex medical conditions and care needs was provided by group home staff to the Hamilton social worker and nursing staff, but there is little evidence that these individuals further communicated or followed up on the information.

Since Mr. Sampson's death, Hamilton has attempted to address this problem. According Hamilton administrators interviewed for this investigation, the nursing home now employs a nurse liaison, who is responsible for assessing every nursing home referral in order to ensure that the facility is able to meet the individual's needs. Once a patient is admitted to the facility, information about care needs are now communicated to a designated contact person. Depending on the patient, the designated contact person would be either the Director of Nursing, the Utilization Coordinator, or the Director of Social Services. However, Hamilton administrators indicated that the Director of Social Services would still be the most likely designated contact person if the patient to be admitted were a resident of a group home or similar program. The implications of this are that communications from experienced, concerned caregivers regarding the person's health care needs may still be routed through an individual who is not trained to evaluate or accurately communicate clinical information, and who has neither the authority nor professional responsibility to ensure it is appropriately acted upon.

The Inter-Agency Patient Referral Report (W-10 Form), which was completed by Mr. Sampson's primary care physician upon his discharge from the hospital, failed to include specific instructions for nursing home staff to follow regarding Mr. Sampson's fluid intake and output, dietary needs, and mealtime instructions. Both were important considerations: Mr. Sampson had a diagnosis of diabetes insipidus, a disease characterized by excessive urination and attendant risk of dehydration. It was critically important to continuously offset this fluid loss by drinking sufficient amounts of liquid. If Mr. Sampson became dehydrated, the balance of electrolytes and various medications within his body could change, leading to potentially life-threatening complications. In addition to the risk of dehydration, Mr. Sampson had a history of aspiration pneumonias. To reduce his risk of aspirating food, caregivers needed to cut up his food – particularly meat – into small pieces, ensure that he drank thin liquids, and ensure that he was sitting fully upright when he ate or drank. Information concerning these needs should have been noted on the Inter-Agency Patient Referral Report (W-10 Form) .

It is doubtful, however, that failure to include information on the W-10 concerning fluid monitoring and food preparation had a significant impact on Mr. Sampson's care in the nursing home. Following his admission to Hamilton, he was examined by the facility's physician and a comprehensive Nursing Care Plan was developed as required. The Nursing Care Plan specifically recognized the need to monitor Mr. Sampson's fluid intake and output. In addition, the plan called for: 1) assessing Mr. Sampson for pain and providing pain medication as needed; 2) monitoring his oxygen saturation levels; 3) monitoring the percentage of meals eaten and offering an alternative if 50% or less was consumed; and 4) assessing him for cognitive or

functional changes. Failure to follow this plan, and in some cases, manifest ignorance of its provisions on the part of nursing staff did significantly affect the quality of Mr. Sampson's care. These failures included the following:

- Mr. Sampson's fluid intake and output was not consistently monitored. Over the course of Mr. Sampson's eight-day admission, records reveal that his fluid intake was recorded on only three occasions and his urinary output on four. If "intake and output" – "I&O" in medical slang – were being correctly monitored, multiple entries would be expected on a daily basis. It probably did not help that the Dehydration Risk Assessment prepared when he was admitted did not accurately reflect Mr. Sampson's status. That assessment (which is a routine screening applied to all newly admitted patients) scored Mr. Sampson as independently mobile although he was using a walker and a wheelchair. In addition, it listed him as eating and drinking independently (whereas he needed a great deal of encouragement to drink liquids in sufficient amounts), and as having no risk factors for dehydration (although he had a history of refusing liquids), and as having only one predisposing condition, which was listed as the presence of an infection (cellulitis), when, in fact, he also had diabetes insipidus – a condition that carried a major risk of dehydration. Finally, as a dietician or nutritionist did not see Mr. Sampson over the period of his admission, his fluid intake requirements were never determined.
- A Pain Assessment for Mr. Sampson (another routine screening instrument applied to all patients) was not fully completed, although pain was one of his primary complaints upon admission. In addition, in the actual implementation of Mr. Sampson's physical therapy plan, there are several references in the medical record that Mr. Sampson was having difficulty participating in physical therapy because his leg hurt. Reluctance to put weight on his right ankle and complaints of pain are identified on Days 1, 2, 3, and 5. Even though pain was an identified problem, and there was a doctor's order for "Tylenol, 650 mg po [by mouth] every 4 hrs as needed," there is no record of pain medication being given to Mr. Sampson until Day 7 (when he received Neurontin). The delay in addressing this identified problem may have negatively impacted on his ability to participate in physical therapy, which was the primary reason for the nursing home placement.
- According to the nursing home records, there were no oxygen saturation readings recorded for Mr. Sampson from 2:00 PM on Day 4 until 10:45 PM on Day 6. It is important to note that it was during this time period that changes in Mr. Sampson's functional and cognitive status were first evident.
- Mr. Sampson was frequently noted to be a "fussy eater" in the nurse's notes and although not consistently documented, his appetite is noted to be poor on several occasions, yet only one alternative meal was offered. This is significant because group home staff reported that he frequently needed encouragement to eat and drink.
- The Nursing Care Plan also called for an assessment of cognitive changes. However, when cognitive changes were noted, as evident in a nurse's note on Day 6, and as reported to nurses by group home staff on Days 6 and 7, nursing home staff members failed to completely document and address these concerns by reporting them to the RN supervisor or attending physician. Although Mr.

Sampson's condition is clearly deteriorating by Day 7, the resolution to this problem was to arrange a team meeting for three days hence, rather than requesting that he be assessed by the attending physician as soon as possible.

Lastly, in conversations with group home staff, two LPNs who were responsible for providing Mr. Sampson with nursing care and treatment reported that they were unfamiliar with Mr. Sampson's medical condition and needs. Yet these nurses had signed the Nursing Care Plan. According to Hamilton's Director of Nursing, a nurse's signature on a Nursing Care Plan means that they have reviewed the Plan and will implement it as written. If the nurses involved in discussions with group home staff claim to have been unaware of Mr. Sampson's medical condition and needs, it is questionable whether they could properly carry out the Nursing Care Plan themselves and/or whether they could provide instruction and supervision to the nurse aides, who were also responsible for implementing it.

6. Medication Administration Records reviewed by FRB for the time period of Mr. Sampson's nursing home admission do not include the corresponding month and year, his diagnoses, allergies, his physician's name, or the initials and signatures for the nurses dispensing his medication.
7. Deviations from the Nursing Care Plan and continuing lapses in communications amongst facility nursing staff resulted in failure to identify and respond to a dramatic deterioration in Mr. Sampson's cognitive status on the sixth, seventh and eighth days of his admission.

In response to the urging of visiting group home staff who were alarmed at Mr. Sampson's uncharacteristic mumbling, slurring his words, and sleepiness on Day 6, a nursing home LPN obtained his vital signs and checked his blood sugar level. A facility RN did not assess Mr. Sampson's apparent change in condition at that time.

In response to the urging of visiting group home staff who were distressed at the apparent further deterioration of Mr. Sampson's condition on Day 7, a nursing home LPN obtained Mr. Sampson's vital signs, spoke with the facility physician regarding the group home staff members' concerns, and noted that an appointment with Mr. Sampson's endocrinologist would be arranged for later that same week. Mr. Sampson's condition was not assessed by a facility RN at that time.

(NOTE: During this time period, group home staff communicated their concerns regarding Mr. Sampson's changes in condition to their agency's nurse consultant, who directed them to request that the nursing facility arrange a consult with his endocrinologist. According to the nurse consultant's nurse's notes, "the skilled nursing facility was asked to draw electrolytes in light of the diabetes insipidus and the nursing supervisor agreed to follow-up with that and consult with Mr. Sampson's endocrinologist." In an interview with the FRB investigator, the nurse consultant reported that she had no direct contact with the nursing facility – that this information had been communicated through the group home agency's direct care staff. The nurse consultant indicated that in her role as nurse consultant to the group home agency she did not provide clinical nursing services to the agency's clients.

Her responsibilities involved ensuring that care plans were appropriate, and advising direct care and administrative staff on issues related to the coordination of clients' health care. Because her role was limited to consulting with the group home agency, and because Mr. Sampson was a patient in a health care facility at the time, the nurse consultant indicated that it was not agency practice for her to become directly involved in communicating clinical information to health care facility personnel.)

When a facility LPN found Mr. Sampson to be non-responsive on the morning of Day 8, she administered a sternum rub. Although Mr. Sampson failed to respond to the sternum rub, this same LPN left him alone for over an hour and a half before she notified the facility's RN supervisor, who then assessed his condition and called the facility's physician.

8. Facility nursing notes and group home staff members' observations concerning Mr. Sampson during the sixth and seventh days of his stay report inconsistent information concerning his status.

Observations of Mr. Sampson on Day 7, which were recorded in a late note entered by a facility LPN on Day 8, describe a different picture of Mr. Sampson's level of consciousness and behavior, and stand out as inconsistent with group home staff members' descriptions for the same time period.

9. Two of the admission screening assessments (Pain Assessment and Bladder Retraining Assessment) completed upon Mr. Sampson's admission to Hamilton were not dated or signed. In addition, the Nursing Admission Assessment was completed and signed by a LPN. It is not clear whether this assessment was performed independently by the LPN or completed under the direction of a RN, as required by the LPN Practice Act, C.G.S. §20-87a(c).
10. On the morning of Day 8, a little over one week after Philip Sampson was admitted to the nursing home, he was transported to a local hospital emergency department, "unresponsive even to noxious stimuli." Diagnostic studies completed at the hospital revealed the presence of septic shock, acute respiratory and renal failure, and severe anoxic brain injury.
11. Although it is not possible for this investigation to definitively determine that negligence on the part of the Hamilton Rehabilitation and Healthcare Center caused Mr. Sampson's death, there is sufficient evidence to conclude that multiple lapses in the quality of his care at the facility and recurrent failures in communicating critical information occurred during his stay there, and that these lapses and failures constituted significant neglect of his needs.

RECOMMENDATIONS

Recommendation 1

The Department of Mental Retardation should require that its residential service providers carefully consider all available alternatives to nursing home placement for short-term rehabilitative care. The Fatality Review Board is aware that obstacles may exist to returning individuals to their home environments. These obstacles may include the time and resources needed to complete nursing delegation tasks, the purchase of special equipment, mobility issues, the availability of residential support staff, and the coordination and provision of skilled nursing services. However, whenever possible, preference should be given to returning individuals to their home environments and providing whatever additional resources are necessary to meet their needs.

Although the quality of nursing home care is known to vary considerably between specific facilities, it is generally recognized that nursing homes are not appropriate long-term placements for people with mental retardation and other disabilities, except when a person's medical needs predominate. This is partly because opportunities for intensive, individually relevant habilitative programming are not readily available in these types of settings, and partly because both the needs and abilities of individuals who have cognitive limitations or communication issues often get lost in any congregate facilities. Nursing homes are organized around paradigms for economical and efficient physical health care, and facility staffing patterns typically do not allow for sustained, close working relationships of the type most needed by people with mental retardation. For these reasons, federal Medicaid laws require that all persons with mental retardation receive a comprehensive evaluation prior to being permanently placed in a long-term care facility in order to ensure that care in such a facility is, in fact, necessary. While nursing homes offering short-term rehabilitation present many of the same limitations, short-term admissions are not reviewed.

In assessing lessons learned from Philip Sampson's death and the deaths of other individuals with mental retardation receiving care in similar settings, the Fatality Review Board is discovering that short-term nursing home placements may be especially problematic for persons with mental retardation. While our findings indicate that Mr. Sampson received poor care at this particular nursing home, the experiences of others and independent studies suggest that nursing homes in general are neither organized nor staffed to meet their treatment needs.

Federal and state laws require that nursing homes develop an individualized plan of care for every resident and employ sufficient staffing to provide all of the care which is listed in the care plan. However, as our findings in this case indicate, severe staff shortages, staff turnover, and insufficient staff training frequently prevent treatment approaches identified in the plan of care from being properly implemented and reinforced. The consequence of this for Philip Sampson was that there was not one person who was consistently responsible for looking after him, staff who were responsible were not

always familiar with his physical condition and medical needs, and no one person was accountable for monitoring and coordinating his care.

The Fatality Review Board does not have sufficient information to determine whether the lapses in care experienced by Philip Sampson at the Hamilton Health Care Center are characteristic of all, or even most, long-term care facilities. However, there is enough evidence of lapses and deficiencies in the care afforded to Mr. Sampson and others whose deaths have been reported to the FRB to conclude that people with mental retardation are particularly vulnerable in long-term care facilities, even when their admission is for short-term rehabilitative care. Accordingly, the FRB recommends that both acute care hospitals and the mental retardation service system view nursing homes as rehabilitation placements of last resort. Prior to being discharged from acute care settings, every effort should be made to explore alternatives to nursing home care, and to arrange supports so that persons with mental retardation can experience rehabilitation in their own homes with people who know and care about them.

Discharge planning should begin early on in the person's hospital stay. Individuals with mental retardation and their caregivers need to take an active part in the discharge planning process. They need to be aware of community-based agencies that provide home care and outpatient services including visiting nurses, home health aides, personal care assistants, physical, occupational, and speech therapists, nutritionists, and other in-home healthcare services and how to access them. If necessary, the Department of Mental Retardation should allocate additional resources, including staff resources, to meet the individuals' new and emerging medical needs.

When planning a discharge to home, caregivers should receive adequate information and training in care procedures, the potential impact of caregiving on the caregivers, recognition of symptoms requiring medical or nursing intervention, and other important aspects of the person's care. In addition, individuals involved in the discharge planning process need to know that discharge decisions made by professionals in acute care settings can be appealed if the individual or his or her caregivers feel that the discharge plan is not appropriate.

Recommendation 2

The Department of Public Health should work with the Department of Mental Retardation to ensure that nursing homes admitting persons for whom the Department has direct or oversight responsibility designate a licensed nurse to coordinate the intake process and to interface with involved caregivers on an ongoing basis. Public and private residential providers should also designate a licensed nurse to be the primary liaison for any hospital and/or nursing home admission. In situations where a private provider agency does not have a licensed nurse on staff, the DMR Regional Health Services Director should be contacted.

Ideally, the transfer of an individual from an acute care setting to a long-term care facility should be well organized and thoughtful. Understanding the person's identity and needs involves more than having an understanding of the person's medical issues and needs. Caregivers, residential staff, and family members often have important anecdotal information regarding the person's likes, dislikes, strengths, and challenges. They also may be able to suggest ways to elicit the person's cooperation. One of the responsibilities of the liaison should be to familiarize themselves with this information, along with pertinent medical information, and disseminate it to appropriate facility staff. One of the problems in nursing homes is that rarely is there one individual or team of individuals who assumes responsibility for a person's care. Impermanent staff assignments and inconsistent schedules mean that people don't really get to know the individuals with whom they work. Very often, many of the nursing home's administrators work during the week from 8 to 4 or 9 to 5, and direct care staffing patterns are more like a "patchwork quilt." In addition, nurses are often assigned separate functions, such as infection control and medication administration, which have little to do with providing direct care. This means that service provider representatives, friends, and family members often lack an accessible, established contact who is knowledgeable about medical issues to whom they can convey concerns and ask questions of regarding the individual's medical care and treatment.

In Philip Sampson's case, even with his group home manager advocating for him, and he was a very strong and competent advocate, it was alarming to see that his efforts appeared to hold no sway. There was no one in a position of authority at the nursing home with knowledge of Mr. Sampson's medical condition and apparent deterioration to receive and effectively respond to his concerns until it was too late. In addition, it was not the practice of the group home's Nurse Consultant to have direct contact with the nursing home once Mr. Sampson was an admitted patient under their care. In order to ensure that other individuals do not experience similar risks, it is critical that permanent channels of communication, along with the assignment of permanent liaison positions, be established whereby provider representatives, family members, and other involved caregivers can express concerns, share observations and information, and have questions answered regarding the individuals' care and treatment. It is also essential that nursing homes and provider representatives assign alternate liaisons, who are also knowledgeable about medical issues, to be available to respond to caregivers' concerns when the persons permanently occupying these positions are not available. Finally, people working in the residential service system need to be taught how to effectively advocate for individuals who are temporarily placed in a nursing facility. Staff need to be provided with information regarding how to best communicate their concerns regarding an individual's health or physical condition, steps they can take if an individual doesn't seem to be responding to treatment, and who to approach with suggestions, questions, or concerns regarding treatment approaches identified in the individual's plan of care.

Recommendation 3

The Department of Mental Retardation, in conjunction with the Department of Public Health and Department of Social Services, should develop a preferred list of long-term care facilities, which meet basic requirements for the provision of short-term rehabilitative care for people with mental retardation. These requirements should include:

- **The assignment of a licensed nurse to coordinate the intake process and act as a permanent liaison between persons with mental retardation and their caregivers.**
- **A demonstrated history of safely and effectively providing rehabilitative services to persons having developmental disabilities. Those facilities lacking a demonstrated history in this regard must have an expressed interest in working as part of a team for persons with developmental disabilities.**

In the absence of these conditions or expressed interest, facilities should not be considered suitable for placement.

As indicated previously, federal Medicaid laws require that persons with mental retardation who are being considered for long-term placement in a nursing care facility undergo a comprehensive evaluation to determine whether the nursing facility is the most appropriate place for them to receive services and whether additional specialized services are required. Although no such evaluation is required for short-term nursing home admissions, the overriding issues and concerns of people with mental retardation for whom placement in a nursing home may be warranted, are often the same. Individuals in fragile health with cognitive limitations or communication issues who may be unable to articulate their feelings and needs may get lost in congregate living environments where they are not known to their caregivers. In addition, severe staff shortages and high turnover rates experienced by many nursing homes may affect the quality of services being provided.

The Department of Mental Retardation, in conjunction with the Departments of Public Health and Social Services can greatly assist consumers by developing a list of preferred long-term care facilities that have a proven track record of success in supporting persons with developmental disabilities who have been referred for short-term rehabilitative care. Although data regarding regulatory compliance and various indicators regarding the status of residents of licensed facilities has recently become available on government websites (<http://www.dph.state.ct.us>; <http://www.medicare.gov>) it does not include information concerning the experience of people with developmental disabilities.

Recommendation 4

DMR should make residential service providers and case managers aware of the process to follow if the nursing home care being provided to one of their participants is cause for concern and efforts to resolve these concerns have been unsuccessful. The role of “nurse-consultants” within the mental retardation service system should be reassessed with an eye toward any regulatory, contractual, or resource changes that may be necessary to ensure that nurse consultants function to

follow and advocate for coordinated, high quality care when agency clients are admitted to health care facilities.

People working in the residential service system need to be taught how to effectively advocate for individuals who are temporarily placed in a nursing facility. Staff need to be provided with information regarding how to best communicate their concerns about an individual's health or physical condition, steps they can take if an individual doesn't seem to be responding to treatment, and who to approach with suggestions, questions, or concerns regarding treatment approaches or interventions identified in the individual's plan of care.

APPENDIX

In addition to examining the specific events leading up to and surrounding Mr. Sampson's death, this investigation sought to understand what might have been occurring for other residents in the nursing home prior to and following the period of his admission. In order to take the overall context of Mr. Sampson's experience into consideration, the FRB reviewed citations and regulatory actions concerning the Hamilton Rehabilitation and Healthcare Center, which were issued by the Department of Public Health (DPH) from 1999 to date. It should be noted that the information summarized below was taken directly from the documents reviewed and redacted to protect the privacy of the individuals.

According to information provided by DPH, the following citations and fines were issued during this time period:

1. Year 1999 – A resident was able to leave the facility unnoticed after the resident's family had informed facility staff that the resident had been able to unlock a secured door by punching in an access code. The facility became aware the resident was missing after receiving a call from the local police department informing them that the resident had been discovered approximately one mile from the facility. The resident was found with abrasions on the face and reportedly sustained a probable nasal fracture. The facility was not able to determine how the resident left the unit or was able to leave the building without being noticed. A monetary penalty was imposed.
2. Year 1999 – A resident whose interventions called for observing for signs and symptoms of depression, hallucinations and/or delusions reportedly made a statement to facility staff expressing an intent to commit suicide. While the nurse's notes revealed that a psychiatric nurse and nursing supervisor were informed, there was no evidence that the physician had been consulted. Subsequent nurse's notes recorded that four days later, the resident was observed by a facility nurse aide walking and screaming in the hallway with a plastic bag around the neck. The notes further described the resident twisting the bag into a tight knot, which was removed by staff. Following notification of the physician, the resident was transferred to a hospital psychiatric unit.
3. Year 2000 – (A and B) Two residents had bowel regimes identified on their Plans of Care and physician's order sheets that directed that various laxatives be administered if they failed to have a bowel movement for three consecutive days. A review of clinical records by DPH revealed that their bowel regimes, which had been ordered by their physicians, had not been followed. Subsequent to the failure to carry out physician's orders, both residents were transferred to the hospital with diagnoses that included fecal impaction. (C) One resident's Plan of Care identified a risk for skin breakdown related to incontinence. Intervention included perineal care after each occasion of incontinence, repositioning, and checking for incontinence every two hours. Constant observation by a DPH

surveyor revealed that the resident was seated in a wheelchair for a total of three hours and five minutes, without the benefit of repositioning or assessment for incontinence. During an interview with DPH the Director of Nursing stated that residents are to receive incontinent care every two hours. (D) A resident's Plan of Care included an intervention for staff to transfer the resident using a Hoyer Lift and the assistance of two staff members. Nurse's notes documented that a x-ray of the resident's right leg revealed a fracture of the right tibia, which is the bone between the knee and ankle. A review of facility documentation by DPH revealed that a nurse aide transferred the resident to the bed alone without a Hoyer Lift, stating she was "strong enough." The nurse aide was terminated from employment following the incident for failure to transfer the resident according to the nurse aide assignment and for disregarding the safety of the resident. A monetary penalty was imposed.

4. Year 2001 – (A) A resident with diagnoses including diabetes and congestive heart failure was described in nurse's notes as having labored breathing, dry mucus membranes and a flushed face with an elevated temperature of 101.8, despite being on antibiotic treatment and Tylenol. The physician was not contacted regarding the resident's condition until [almost 18 hours later], at which time an order was obtained for a chest x-ray, blood and urine cultures, and to start a different antibiotic treatment. It should be noted that the resident's Plan of Care identified the problems of fluid volume deficits with a potential for dehydration secondary to diuretic therapy, frequent episodes of pneumonia and urinary tract infections. An interview with the charge nurse by DPH revealed that although a message had been left with the physician that the test results were available, the physician was not contacted and made aware of the test results, or that current antibiotic treatment was inappropriate to treat the resident's symptoms, until the [following morning]. The nurse's notes further identified that the resident was admitted to the hospital with diagnoses that included urosepsis, pneumonia, and dehydration. (B) A resident diagnosed with emphysema and chronic obstructive pulmonary disease was identified as having vomited a moderate amount of yellow fluid, having an elevated temperature (100.1 rectally), elevated blood pressure (160/80), rapid pulse (116) and respiration of 32 (resident's respiration typically ranged from 18-22). The physician was notified and an order for compazine was obtained and given with good results at [½ hour later]. The nursing notes further identified that although the resident had increased respiration of 40 and pulse rate that continued at 116 [4 ½ hours later], the physician was not re-notified. At [4 hours and 45 minutes later], the resident was noted as congested with labored breathing, vomiting green liquid, had ashen color and cyanotic lips. The resident vomited and was turned onto the side. At [close to 5 hours later], the resident was without respiration or pulse, was suctioned, oxygen administered and CPR initiated. The ambulance arrived [about 10 minutes later] and transported the resident to the hospital where the resident later died. A monetary penalty was imposed.

5. Year 2001 – Inspections conducted by DPH revealed the following: (A) A resident’s Plan of Care identified a toileting deficit, with direction to approach toilet every two hours and to provide as needed pericare after each incontinent episode. Observation by the DPH surveyor between [a 2 hour and 45 minute time period] revealed that the resident remained in his/her wheelchair without the benefit of repositioning or incontinent assessment. Upon the intervention of the DPH surveyor, the resident was repositioned and provided with incontinent care at [that time]. An interview conducted by DPH with the resident’s daughter revealed that when she arrived at the facility [later] that same day, upon her request, the resident was to stay up in the wheelchair. The resident’s daughter further stated that the facility is short staffed with only three nurse aides on the dementia unit to provide care for 53 residents. An interview with a nurse aide by the DPH surveyor revealed that she was a pool aide working without an assignment and receiving her direction from the regular aide and worked [a 12-hour shift] that same day, and there were two aides for the residents and “we finally got all of the residents up by 2:30 PM.” (B) A resident’s Plan of Care identified nutrition altered with approaches of need to be fed up in a customized wheelchair for lunch and supper meals, and to have meals in the North Solarium daily. On the same date as the above observation, the resident was observed by the DPH surveyor to have his/her supper fed to him/her in bed. An interview conducted by the DPH surveyor with a facility nurse revealed that all residents on the dementia unit haven’t been toileted or repositioned since 3:00 PM and that by the time residents get to the dining room and fed, staff don’t have time for other care issues. (C) A resident’s Plan of Care identified a problem of altered nutrition with approaches to seat in the dining room during meals. The care plan also identified a problem of impaired skin integrity with approaches to reposition every two hours and to provide incontinent care every two hours. On the same date as above observations, the resident was observed by the DPH surveyor in the same position on his/her back [for 2 ½ hours] without the benefit of repositioning or incontinent assessment. The resident was also observed to have his/her supper meal fed to him/her in bed. (D) A resident’s Plan of Care identified a problem of impaired physical mobility with approaches to turn and reposition every two hours. On the same date as above observations, the resident was observed by the DPH surveyor in the same position on his/her back [for 2 ½ hours] without the benefit of repositioning or incontinent assessment. (E) A resident’s Plan of Care identified a problem of toileting deficit with approaches to provide incontinent care every two hours. On the same date as the above observations, observation by the DPH surveyor revealed the resident’s diaper to be saturated with a large amount of urine. An interview conducted by the DPH surveyor with a facility nurse on the dementia unit revealed that all residents had not been toileted or positioned since 3:00 PM that same day. (F) A resident’s Plan of Care identified a problem of skin integrity with approaches to turn and reposition every two hours. On the same date as the above observations, the resident was observed by the DPH surveyor in the same position on his/her back [for 3 hours] without the benefit of repositioning or incontinent assessment. A monetary penalty was imposed.

6. Year 2002 – (A) A resident’s Plan of Care identified extensive assistance for transfers and for walking in the corridor and inability to walk in the room. The Care Plan also identified the problem of potential for trauma related to a history of falls and decreased safety awareness. Approaches identified in the Care Plan included use of a modified wheelchair with a laptray for positioning, check every ½ hour and release every two hours for repositioning and incontinent care. Constant observations by the DPH surveyor identified that the resident was up out of bed in a wheelchair with a laptray (four hours and ten minutes) seated in the dining room. The restraint was not released by staff and the resident was unable to self-release the restraint. During this period of time, the resident was noted to be rocking his/her upper torso back and forth. (B) The same resident’s Plan of Care [dated the previous year] identified the problem of trauma potential related to a history of falls, unsteady gait, and cognitive impairment. Interventions included the use of a wheelchair with a laptray when out of bed. A restraint assessment identified that the resident removed the lapbuddy [a soft laptop cushion that fits between the person and wheelchair frame to facilitate upper body positioning and prevent falls] from the wheelchair frequently, tried to get up on his/her own, and needed a wheelchair with a laptray in place. A physician’s order completed on the same day as the restraint assessment identified a change from use of a lapbuddy to a laptray due to the resident’s decreased cognitive awareness and safety. Review of the nurse’s notes revealed that the lapbuddy continued to be used after the date of the physician’s order for the use of a laptray instead. Approximately two months later, nurse’s notes identified that the resident released his/her seatbelt and fell to the floor from his/her wheelchair. The resident sustained a fractured right hip from the fall. There was no physician’s order and/or assessment for the use of a seatbelt with the wheelchair. (C) A resident’s Plan of Care identified the use of a wheelchair when out of bed with a laptray for proper positioning. Constant observations by the DPH surveyor revealed the resident to be seated out of bed in a customized wheelchair with a laptray for (four hours and thirty minutes) without incontinent care and/or repositioning. During this period, the resident was left in the dining room [for 3 hours and 40 minutes]. In the dining room he/she was observed after lunch by the DPH surveyor to call out several times “come here” or “you know me.” When in his/her room [for the following ½ hour] he/she was calling out “Help me please.” He/she was also slumped over in his/her chair. The charge nurse went in the room and tilted the resident’s chair up, but no other care was given. At this time the DOH surveyor questioned the charge nurse about the resident not receiving care and she stated that she was unaware that the resident was not given incontinent care and/or repositioning since he/she was up out of bed. [Ten minutes later] when the resident was returned to bed, his/her incontinent brief was soaked with urine and his/her left buttock was deep red. (D) This violation concerns the care provided to Philip Sampson when he was discovered by a facility nurse to be unresponsive to stimuli including a sternal rub. The facility’s policy for emergency care identified that if the resident’s condition had changed, emergency care was to be initiated and it was not. A monetary penalty was imposed.

7. Year 2002 - (A) A resident's Plan of Care identified potential for trauma related to a history of falls and cognitive impairment. Review of the nurse's notes identified that the resident released the seatbelt on his/her wheelchair and fell to the floor. The resident was sitting in front of the nurse's desk at the time. The resident sustained a skin tear on the right upper arm but neurological signs and range of motion were noted to be within normal limits. The resident was put back into his/her wheelchair and remained up [for 4 hours and 45 minutes], during which time he/she was very restless with constant movement and frequent verbal outbursts. Tylenol 650 mg was given for possible discomfort. Then the following morning the resident yelled "no" when asked to turn on his/her side. Physical Therapy was notified to check the resident, but the physician was not notified until [late morning]. An order was received to transfer the resident to the hospital for an evaluation, and [the resident] was admitted to the hospital with a fractured hip. (B) This violation concerns the care provided to Philip Sampson when he was discovered by a facility nurse to be unresponsive to stimuli including a sternal rub. When interviewed by a representative from DPH, the facility nurse stated that she did not notify the supervisor or doctor of Mr. Sampson's condition. A monetary penalty was imposed.
8. Year 2003 – Multiple investigations of the facility concluded in February 2003 revealed the following: (A) Based on interviews and a review of clinical records, it was revealed that a resident who required extensive assistance with transfers and ambulation was found on the floor and a facility investigation revealed a faulty alarm; [approximately 2 weeks later] the same resident was found on the floor and the wheelchair alarm was not working at the time; [not quite a month later] the same resident was again found on the floor. The nurse aide assigned to the resident stated that the bed alarm was in place but was not sounding when she discovered the resident sitting on the floor. The resident was sent to the emergency department and admitted with a diagnosis of a fractured left hip. The facility's Director of Nursing stated that the facility maintenance department had a practice of inspecting all alarms on a weekly basis and the alarms used by this particular resident were not included on the list and had not been inspected. (B) A resident's Plan of Care indicated that the resident was transferred with extensive assistance of two or more persons and a gait belt. A nurse's note noted that the resident and a nurse aide fell to the floor while the nurse aide was transferring the resident. The resident sustained a non-displaced fracture of the surgical neck of the humerus. The nurse aide stated that while transferring the resident from wheelchair to bed, the resident leaned into her and both of them fell to the floor. The nurse aide stated that she had not referred to the resident assignment card and was unaware of the requirement for a two-person assist with transfers nor the requirement to utilize a gait belt since she usually worked the night shift. (C) A resident identified as severely cognitively impaired, having periods of restlessness and totally dependent on staff for all care fell from the bed onto the floor during morning care and sustained a 3x2 cm laceration to his/her forehead and a 1 cm laceration to his/her right ear. The resident was transported to the emergency department for an evaluation and returned to the facility with 10 sutures to his/her

head. The nurse aide responsible for providing his/her care reported that although the resident's bed had bolsters in place, she removed them in order to provide his/her care. The resident was agitated and restless during care, flailing his/her arms, twisting and turning, and attempted to reach for the basin of water when he/she fell out of bed. Further review of the resident's clinical record by DPH revealed that the resident had also fallen out of bed on two other occasions. One fall resulted in the resident falling headfirst to the floor during morning care, sustaining a "star-like" laceration. The investigation revealed that the side rail was down and the resident's bed was in the high position. A report of the other event revealed that the resident was found on the floor next to his/her bed. There were no witnesses to the fall and no injuries were sustained. The report identified that the resident had bolsters in place and the resident had fallen in the space between the bolsters. DPH identified that although the resident had three falls from the bed, two that occurred during care, the only change to the Care Plan directed staff to leave the bolsters in place during care. The facility's Fall Prevention policy states a reassessment will be performed after every fall, and that interventions should be immediate after every fall. A review of the resident's Care Plan revealed that the resident's falls that were related to his/her behavior during care were not identified in the Care Plan. (D) A resident's change of status assessment identified the resident as severely cognitively impaired, full loss of range of motion bilaterally of lower extremities, totally dependent on staff for activities of daily living, and required two or more persons to assist with bed mobility. A nurse's note noted the resident rolled off the bed onto the floor while being provided care by a nurse aide. The resident was subsequently transported to the hospital and diagnosed with a left tibia-fibula fracture. (E) A resident was identified as severely cognitively impaired, resistive to care and totally dependent on staff for toilet use. The resident's Plan of Care identified the resident with a potential for trauma related to falls and a toileting deficit related to confusion. Interventions included a personal alarm when in the wheelchair and toileting the resident as mood allows. The nurse's narrative identified that the resident, who was crying and agitated, was brought to the nurse's station for 1:1 monitoring. The resident requested to use the bathroom and during transport via the wheelchair, the resident lurched forward and fell to the floor. The resident was transported to the hospital where he/she received three staples to the left forehead. Physical therapy notes [dated approximately 5 months earlier] stated that if the wheelchair alarm was insufficient, that a lap belt would be utilized. Psychiatry notes [dated approximately 1 month earlier] recommended a lapbuddy for safety. Although the resident had six falls when the alarm failed or the resident fell from the wheelchair, a lapbuddy for the wheelchair was not added to the resident's Care Plan until a day after [the] fall from the wheelchair when the resident sustained a head injury. A monetary penalty was imposed.

9. Year 2003 – A resident's significant change assessment dated [early December] identified diagnoses of congestive heart failure and dementia. The physician's orders dated [2 months later] identified the resident received Lasix 80 mg every day. The resident's Plan of Care identified the problem of a fluid volume deficit.

Interventions included to observe for decreased fluid intake, poor skin turgor and dry mucous membranes. The nursing notes dated [early March] identified the resident did not receive medications because of increased lethargy. The nursing notes further identified that the physician was notified of the increased lethargy, poor intake and holding of medications. Blood work was ordered and some of the resident's medications were discontinued. The nursing notes from [early March] until [early May] continued to document poor intake, and dry mucous membranes. On the morning of [in early March] the physician was notified and an order to send the resident to the hospital was obtained. The hospital discharge summary dated [1 week later] identified the resident was admitted with a BUN (blood urea nitrogen) of 180 and diagnoses that included dehydration, renal failure and urosepsis. An interview and review of the resident's intake and output record with the Director of Nurses by DPH revealed that the resident's intake [for 3 days prior to the hospital admission] was less than 500 cc in 24 hours. A monetary penalty was imposed.

10. Year 2003 – A resident's diagnosis included quadriplegia. An assessment identified that the resident was alert, totally dependent on staff for all activities of daily living and had full loss of body movement. The resident's Plan of Care identified alteration in skin integrity with interventions that included a pressure relief air mattress, reposition every two hours and two full siderails while in bed. Nurse's note revealed that the resident fell out of bed landing on his/her face and abdomen and was immediately sent to the emergency department for evaluation. An interview with the nurse aide by DPH identified that in an attempt to reposition the resident, one siderail was lowered, the resident was pulled to the edge of the bed and at this time, the resident requested that the inflation status of the air mattress be checked. The nurse aide stated that as he/she reached for the button at the bottom of the bed, the resident slipped off the bed headfirst and landed on the floor. Review of inservice identified that siderail use was reviewed with facility staff regarding this type of bed. Review of the manufacturer's instructions directed that the bed rails should not be in the down position while the mattress is in use or the patient left unattended with the bed rails down. The resident was admitted to the hospital for a right hip fracture. A monetary penalty was imposed.
11. Year 2003 – (A) This violation concerns the care provided to the resident identified above, whose diagnosis included quadriplegia. Review of a nurse's note identified that the resident had returned from the emergency room following an evaluation for possible injury from an earlier fall [which is described above] and documented oxygen saturation of 88% on room air (normal saturation [is] 95% to 100%). An interview with a facility LPN and RN conducted by DPH identified that oxygen at two liters per minute was administered [to the resident] with a subsequent oxygen saturation of 98% on the two liters of oxygen. During an interview with the facility RN she stated that although her respiratory assessment was not documented in the clinical record, she observed on the [3rd] shift that the resident was hyperventilating with shallow breaths and that air

movement was heard in all the lung fields. An interview with the same RN identified that the attending physician was not made aware of the oxygen saturation, the respiratory assessment and/or the application of oxygen therapy. A DPH review of the facility policy for change in condition identified that the physician and the resident's responsible party would be notified with changes in condition. The procedure for oxygen administration included checking the physician's order for liter flow and method of administration. An interview with the physician conducted by DPH [revealed] that he was not notified of the resident's respiratory changes during the identified period and he would expect to be notified with changes in resident condition and that the resident was [re]-admitted to the hospital with diagnosis inclusive of pneumonia, sepsis and a fractured right femur. (B) A resident identified as having no memory deficits and as being able to make his/her needs known to facility staff complained of nausea, was given Mylanta [2 ½ hours later], and began "dry heaving." Nurse's notes from [the next 12 hours] that same evening identified that the resident complained of nausea off and on during the night, had diarrhea twice, and was pale. Nurse's notes at [early afternoon] the following day identified that the [same] resident's appetite was poor and she complained of nausea. The physician was not notified until [mid-afternoon that same day] when the resident complained of severe nausea and an order was received for medication to be given every four hours as needed for nausea. A monetary penalty was imposed.

It is important to note that the DPH also made unannounced visits to the Hamilton Rehabilitation and Healthcare Center over the course of a two-month period in 2002. Violations noted during the course of these visits include:

- a resident was not protected from asphyxiation due to neck compression;
- the facility failed to release a waist restraint and reposition one resident in accordance with the plan of care for one of fifteen residents and failed to accurately assess for restraints with documentation to reflect the appropriate utilization of the devices for five of fifteen residents in the [DPH] sample survey;
- the facility failed to revise the resident care plan subsequent to identifying behaviors that affected the resident's seating position in the wheelchair;
- based on review of the clinical record, observations, and staff interviews for one of five residents in the [DPH] sample survey, the facility failed to provide incontinent care and repositioning in accordance with the plan of care; and
- based on clinical record review, the facility failed to ensure that one patient who had experienced decline in physical condition and who was also utilizing a self-releasing seatbelt was provided with adequate supervision. Subsequently, the resident expired due to asphyxiation due to the restraint causing neck compression.

In 2002, as a result of these violations, a monetary fine was imposed. In addition, a Consent Agreement between the DPH Division of Health Systems Regulation and the Hamilton Rehabilitation and Healthcare Center was executed, which stipulated, among other measures, that the facility contract with a registered nurse, acceptable to DPH, to serve as an Independent Nurse Consultant for a minimum of five months. The responsibilities of the Independent Nurse Consultant included, but were not limited to, being at the facility twenty-eight hours per week, conducting and submitting to DPH an initial assessment of the facility's regulatory compliance and areas requiring remediation, submitting weekly written reports to DPH identifying the facility's efforts to comply with applicable federal and state statutes and regulations, and making recommendations as necessary to ensure the facility's conformance with applicable state and federal statutes and regulations. The facility also agreed to establish a mechanism whereby every resident who is restrained and/or provided with a self-releasing belt is assessed on an ongoing basis for the need for such devices. The facility also agreed that it would employ sufficient personnel to meet the needs of the resident population at all times, and that it would appoint a free-floating Nurse Supervisor on each shift whose primary responsibility is the assessment of patients and the care provided by nursing and ancillary staff.

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