



DISABILITIES RIGHTS CENTER, Inc.

**EXAMINING PREVENTABLE DEATHS IN
THE DEVELOPMENTAL SERVICES SYSTEM**

**A Call to Action—Keeping Vulnerable Citizens
Safe from Harm**

A White Paper

The Disabilities Rights Center

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**The Disabilities Rights Center is the designated federal protection and
advocacy system for New Hampshire and is a member of the National
Disability Rights Network**

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I. Executive Summary¹

A. Introduction

People with significant disabilities are many times more likely than the general population to become victims of violence, abuse, or neglect.² Residential settings which are isolated, have poorly trained caregivers and/or receive suboptimal support or supervision are especially risky for people with disabilities. Those who live in such settings tend to have less control over their environment, and abuse and neglect can occur and go unnoticed or unreported. Medically fragile individuals, or those with behavioral challenges, are especially vulnerable.

The Disabilities Rights Center (DRC) is the designated protection and advocacy agency for New Hampshire. It has the authority to conduct investigations in cases of suspected abuse and neglect and advocate for changes to redress individual or systemic deficiencies and violations of rights of individuals with disabilities.

In 2009 and 2010, DRC investigated the deaths of two individuals who were served by the New Hampshire Department of Health and Human Services/Area Agencies (hereinafter sometimes referred to as the “DHHS/AA system”).³ DRC found that these deaths were preventable. DRC also reviewed the circumstances of four earlier deaths and found that they were caused by the same or similar failures on multiple levels. Moreover, most if not all of the contributing factors to these two recent deaths have been the subject of repeated findings and recommendations of prior government reports. However, most of the critical recommendations have gone unimplemented.

The overarching purpose in focusing attention on all of these deaths and the antecedent and contributing conditions is to create an urgency and impetus for additional needed changes so as to prevent future deaths and other tragedies.

All six deaths (involving five separate incidents) are briefly summarized below and described more fully in Section II.⁴

¹ This Summary as well as the full reports are available at www.drcnh.org/deaths.html.

² http://www.cdc.gov/traumaticbraininjury/pdf/VictimizationTBI_Fact%20Sheet4Pros-a.pdf

³ The Bureau of Developmental Services (BDS) is the bureau in DHHS with chief operational responsibility for developmental services and oversight and supervision over the 10 area agencies. Ultimate responsibility for oversight and supervision rests with the DHHS Commissioner under RSA 126-A:4 and RSA 171-A:2. At the regional level, each Area Agency, and its executive director, has responsibility for provision of services in his/her catchment area and for the clients they serve.

⁴ The complete reports of the 2010 and 2009 reports are attached as Appendices A and B respectively. They, along with the reports of the other deaths, are available at www.drcnh.org/deaths.html.

B. 2010 and 2009 deaths

The 2010 death was of a 33 year old man, ST. ⁵ **He died in February 2010.** He had cognitive, physical and behavioral impairments, and a mental health diagnosis. One of his behaviors involved abnormal eating patterns in which he put a large and unsafe amount of food in his mouth. ST resided in Penacook, N.H. with an enhanced family care provider (hereinafter sometimes referred to as an “EFC provider”). He died after getting into and choking on some brownies while the EFC provider was asleep at approximately 5:00 a.m. He died after waking her up. This was not the first time he had choked on food. The Medical Examiner determined ST’s death was **“a result of upper airway obstruction by...brownies...stemming from abnormal eating patterns due to an organic brain disorder....”**

The second death, which occurred in June 2009, was of JH, a 26 year old woman, who was nonverbal and had significant cognitive disabilities. She was provided day services by a vendor who contracted with an Area Agency. Her mother also was certified and received funding to provide services to her in the family home, a second floor rented apartment. JH died in a fire in the family home that started shortly after her mother left for work at 5:00 a.m. Her father, with whom she was left, panicked upon seeing the fire and exited the burning apartment without her, and subsequently returned in what was a futile attempt to save her. In the attempt, he died as well.

As stated, these tragedies were preventable and were the result of multiple failures at the provider, vendor, Area Agency and state level, including:

- The failure to follow basic practices in care and service provision in accordance with professional standards and legal requirements under federal law (Medicaid) and state law (RSA 171-A). These include failing to:
 - Arrange for staffing coverage or residential models based on the needs of the client.
 - Conduct adequate onsite inspections of homes prior to clients moving in and on a periodic basis thereafter to ensure that the homes met the fire and other safety needs of the clients and were otherwise suitable.
 - Select, properly train, support and supervise the actual residential provider in supporting an individual with complex or significant medical and/or behavioral issues generally, as well as in addressing potential emergency or acute issues.
 - Conduct adequate clinical and personal safety assessments to determine the necessary services and strategies to address complicated or significant medical or behavioral issues.

⁵ For privacy reasons, neither the name nor the real initials of this or the other deceased victims mentioned in this report are being used. The actual names are being disclosed to individuals and officials who have the need and authority to know their identities, e.g. DHHS, Area Agency officials, vendors.

- Implement appropriate services and strategies to address behaviors or risks that may result in harm to the individual or to others.
 - On the part of Area Agencies and service coordinators, in particular, to actively advocate for their client's rights and needs, including seeking outside advocacy when necessary.
 - Follow proper incident reporting **and** remediation requirements so that strategies can be put in place to prevent greater or fatal tragedies later, and
 - At all levels, to ensure an effective quality assurance system that proactively identifies and corrects deficiencies and at the same time promotes and rewards quality services and outcomes.
- The failure to learn and apply lessons from at least three other similar incidents resulting in four client deaths in 2000, 2004, and 2006.
 - The failure of DHHS and at least the AAs involved, as well as the Legislature and Governor, to implement many of the findings and recommendations from committees and commissions that the Legislature/Governor previously convened.

The death of someone who receives significant support, even when everyone is doing his or her job, is always difficult. Deaths that are a result of derelictions in care are far more difficult. Those deaths that are part of a pattern of similar circumstances are even more tragic and disturbing. This is the case here.

The first legal, ethical, and moral tenet of any system of care is to “*do no harm.*” This is certainly the case with the legislatively-created DHHS/AA system. It is a principle that has historical roots, given the vulnerability of the clients the system serves, it is fundamental. The circumstances leading up to and causing these recent deaths, as well as the previous ones, violate that fundamental tenet.

To a large extent, the problems leading to these deaths still exist. There is one notable exception, however. Significant system improvements were made following the 2006 fatal fire in Tilton. As a result of joint efforts of the State Fire Marshall's Office, DHHS/BDS, AAs and local fire officials, major actions were implemented to improve the life safety in EFC homes and other certified residences in the system. That type of commitment and urgency needs to be brought to bear on the other systemic problems that have been exposed in prior studies and by the deaths that are the subject of this paper.

C. Brief Summary of Previous Deaths

VH, a 70 year old woman, died on December 18, 2004 in Milton, NH. VH had intellectual, physical, and mental health disabilities and increasingly complex medical issues. She had recently moved in with an EFC provider, a single 20 year old woman and her two young children. VH was found dead by her home provider following a 24-hour period of decompensation. The provider had allowed VH to sleep on VH's bedroom floor overnight while she entertained a date with whom she drank heavily through the evening. The Medical Examiner determined "[t]he mechanism of death was likely cardiac arrhythmia **due to electrolyte imbalance due to dehydration due to refusal of food and water** during an acute exacerbation of chronic schizophrenia."

CJ, a 49 year old man, died on September 12, 2000, in West Danville, VT.⁶ CJ had intellectual, physical and mental health disabilities, and like the others, was on multiple forms of behavior medication. CJ used a walker. He had recently moved in with an EFC provider (along with another client). The home was not properly certified. According to the Medical Examiner, CJ died as a result of "**dehydration with contributory...pneumonia.**" In the brief 10 days between his placement with this provider and his death, CJ was subjected to various forms of neglect and mistreatment, including the provider leaving him outside at night and on the floor in his own urine for hours and days at a time.

Two Women, BB, age 50 and MD, Age 55, died on February 28, 2006, in Tilton, NH. These women were two of three clients with developmental disabilities living with an EFC provider who died in an early morning fire at the home. The State Fire Marshall's investigation found that life and fire safety deficiencies existed in the EFC home. The Area Agency policies and procedures regarding inspection, assessment, and oversight of the home were found to be inadequate. Similar to JH's case, the provider left the three women in the care of her male companion in the home when she left for work at about 5:00 a.m. Shortly thereafter, the fire occurred, killing BB, MD, and the EFC provider's companion.

D. Recommendations

Recommendations to prevent avoidable deaths and other tragic incidents are set forth in Section V. Many of the recommendations are a reiteration of unimplemented recommendations from reports of commissions and committees convened by the Legislature and/or Governor.

⁶ While CJ was placed in a home in Vermont, he was a resident of New Hampshire and the responsibility of DHHS/BDS and his Area Agency.

II. Description of Circumstances Leading to Each Death and Findings

A. Introduction

To fully understand both the deficiencies in care and management that contributed to each death and the similarities among the deaths, a more detailed summary of the facts of each case is provided. Subsection B summarizes the facts in the 2010 death of ST and the 2009 death of JH. A summary of the facts in the 2006 Tilton fire deaths, the 2004 death of VH, and the 2000 death of CP are contained in subsection C.⁷

Part III of this report, relying in large part on the findings already made in each investigation and several New Hampshire government reports, then categorizes and describes the patterns of deficiencies contributing to the deaths.

Brief Synopsis of Each Death

Initials/ Age	Location of Death	Yr. of Death	Disabilities/Diagnosis	Area Agency	Cause of Death
ST, 33	Penacook, NH	2010	Cognitive, Physical, Mental Health and Behavioral Impairments	Moore Center (Region 7)	Upper airway obstruction from brownies; abnormal eating patterns
JH, 26	Pittsfield, NH	2009	Cognitive and Communication Impairments	Community Bridges (Region 4)	Smoke inhalation under accidental circumstances
BB, 50 and MD, 55	Tilton, NH	2006	Cognitive Impairments, Others not Determined	Lakes Reg. Community Services Council (Region 3)	Smoke inhalation
VH, 70	Milton, NH	2004	Mild Cognitive, Mental Health, and Medical Impairment	One Sky Community Services (Region 8)	Cardiac arrhythmia from dehydration/ refusal of food or drink; possible gastro-intestinal bleeding.
CJ, 49	W. Dan- ville, VT	2000	Cognitive, Mental Health, and Physical Impairment	Northern Human Services (Region 1)	Dehydration w/con- tributory pneumonia

⁷ As noted, DRC conducted investigations of the 2009 and 2010 deaths, which are attached as Appendices A and B. The investigations are being released for the first time concurrent with this paper. DRC also completed an investigation of the 2004 death of VH which was provided to DHHS and the Incapacitated Adult Fatality Review Committee previously. The findings in this paper are based on that investigation as well as one conducted by the Area Agency. DRC did not conduct investigations of the 2006 Tilton fire deaths or the 2004 death, but relies on investigations completed by the NH State Fire Marshall's office (for the 2006 deaths) and an investigation by DRC's counterpart in Vermont, the Vermont Protection and Advocacy Agency (for the 2000 death). The earlier 2004 and 2000 investigations and the 2006 investigation from the State Fire Marshall's office are available at www.drcnh.org/deaths.html. DHHS conducted either sentinel reviews or investigations of some of these deaths, but was unwilling to provide them to DRC.

B. 2010 and 2009 deaths

1. **ST, a 33 year old man, died on 2/4/10 in Penacook, NH** (DRC full investigation report is attached as Appendix A and is available at www.drcnh.org/deaths.html).

a. Background and Relevant Facts Leading up to ST's Death

ST, who was 33 when he died, had a significant cognitive disability, psychomotor (physical) impairments, post-traumatic stress disorder (PTSD) and a behavior disorder, including a dangerous eating behavior in which he put a large and unsafe amount of food in his mouth. While he had some verbal ability, his communication was very limited. He walked independently but with a very unsteady gate.

ST received services through the Moore Center, an Area Agency, which contracted with an Independent Service Network who in turn contracted with an EFC provider. The EFC provider and ST lived in an apartment in Penacook, and had been since 2007 when ST was placed there. A staff person from ISN provided day services.

For at least 10 years prior to 2007, ST had received residential services directly or under the auspices of the Moore Center. From 1997-2000, he resided in a 24/7 staffed group home because his parents were no longer able to handle his needs at home. In 2000, he was transferred to an EFC provider where he remained until 2006, at which time and through 2007, he experienced an increase in frequency, severity and duration of aggressive behavior, yelling, and severe agitation. These behaviors resulted in multiple hospitalizations and increased and frequently changing psychotropic and other behavior-changing medications.

Because his then EFC provider could no longer handle him, he was ultimately placed through Moore Center and ISN with the EFC provider under whose direct care he ultimately died in 2010. This EFC provider reportedly had considerable experience in working with individuals with disabilities and behavioral issues.

While reportedly ST's behaviors improved immediately, by late 2007, his negative behaviors were again steadily increasing, including yelling, experiencing severe highs and lows, and sleeplessness. During this time, because of his limited understanding of danger, the EFC provider also worked with ST on trying to understand the dangers of moving vehicles and heat from cooking.

The EFC provider, ISN and Moore Center staff also became aware that ST had issues due to his lack of coordination and difficulty governing the amount of food he put in his mouth, putting him in danger of choking on food. For example, ST experienced two choking incidents prior to the choking incident that caused his death. The first, in July 2007, occurred when ST was choking on a

lunch meal. His day program staff stopped the choking by manually removing the food from ST's mouth. According to this day program staff person, he then developed his own precautionary strategy, which included prohibiting submarine sandwiches, a particularly problematic food item. This incident was not documented in an incident report or otherwise.

Another choking incident occurred in December 2008. The EFC provider bought ST a "sub" while she was at a hairdresser's appointment. She did not observe him while he was eating, and he began to choke on the sub. Because the EFC provider was physically unable to perform the Heimlich maneuver on ST, primarily due to ST's size, a 911 call was made and a person ran over to a veterinarian's office for help. The veterinarian came over, positioned ST over a chair and successfully performed the Heimlich maneuver. While the EFC provider notified both Moore Center and ISN of the incident, ISN did not make a record of the incident, and Moore Center case notes provide only some limited factual details of the incident. The follow-up was completely inadequate to prevent ST from choking again.

The EFC provider's own remedy to address this dangerous behavior was to only leave out soft foods such as bananas that ST would not choke on and also to rely on childproof latches on her kitchen cabinets, installed by a prior tenant. The problem with the latches was that they left a gap between the door and the cabinet frame. ISN did not have any specific requirements or protocols in place as to these food-based behavioral issues.

There were also two other behavioral/safety issues of relevance that put ST at risk of harm and at times caused him injury. One was ST's lack of coordination, which caused him to fall three or four times a month at the apartment, including over coffee tables, in the small confines of the bathroom, and between the home provider's bed and the wall, where he was not able to get up on his own or with her assistance. Verbal and written reporting of these incidents through ISN and to the Moore Center was inadequate.

The second issue related to ST's general difficulty sleeping, which resulted in him being awake and unsupervised in the middle of the night. Although the home provider would get up at night to check on him, she needed her sleep because she worked during the day at another Area Agency. The combination of ST's nighttime wakefulness, eating and choking issues, lack of coordination and falling presented real risks. They were not sufficiently assessed through a proactive risk assessment process or through incident reporting and remediation and, ultimately, became a deadly combination.

b. ST's Death

ST's death occurred at approximately 5:00 a.m. on February 4, 2010. Before the EFC provider went to bed, she gave ST Temazepam (a prescribed sleep medication). It was the second night that ST had been on Temazepam to help him sleep. As the medication left him "dazed and confused" on the first night, the provider reported that she called the Moore Center to see if she should take him off the pill. She was told to try it for another night. The Moore Center disputes that she called, and feels that the call may have been made to the community mental health center in Manchester. In any case, the provider gave him the pill and ST fell asleep on the couch at about 9 p.m.

However, ST did not sleep through the night. A neighbor, while walking her dogs at 4:00 a.m., heard ST talking to himself inside the provider's apartment. At about 5:00 a.m., the provider awoke when she heard a "thud" in her room. The thud was the sound of ST falling to the floor next to her bed. The provider told ST to get up himself. She said that she would be back to help him up if he was not able to get up himself. The provider's explanation was that she thought that ST liked to be babied and that she did not think it was good to encourage that behavior. The provider then went into her kitchen to smoke a cigarette and may have used the bathroom. The exact time lapse is not known. The provider stated that it was possibly between four to six minutes.

When the provider returned to her room to check on ST, she found him with his eyes rolled back in his head and "stuff" coming out of his mouth. The provider was unable to locate her phone. She ran to her neighbors for help. Her neighbor called 911 and followed the 911 operator's instructions, but the neighbor was unable to revive ST.

It was later determined that ST had choked on brownies. The brownies had been given to the provider the day before. She thought she had put them in one of the cabinets with the childproof latch. She speculated that ST might have gotten to the brownies through the gap that existed between the door of the cabinet and the childproof latch even, when the latch is engaged. As to the brownies, there was a partially eaten brownie by ST's side and a gallon size Ziploc bag with brownies on top of the hope chest that was at the foot of the provider's bed. There were also considerable brownie crumbs in the bedroom and leading into the bedroom.

The Chief Medical Examiner, Thomas Andrew, MD, after conducting an autopsy, concluded that ST died **"as a result of upper airway obstruction by food bolus (brownies) stemming from abnormal eating patterns due to an organic brain disorder of unspecified etiology."** (Emphasis added.)

c. **DRC's Findings, Conclusions, and Recommended Corrective Actions from the ST death** are contained in the report, Appendix A, pp. 14-19 and are highlighted below in Section IV.

2. **JH, a 26 year old woman, died on 06/08/09 in Pittsfield, NH** (Full DRC investigation report attached as Appendix B and is available at www.drcnh.org/deaths.html .)

a. Background and Relevant Facts Leading up to JH's Death

JH was a 26-year-old woman with developmental disabilities, who lived with her mother (who was her guardian) and father, in a second floor apartment in Pittsfield, N.H. JH required 24-hour supervision and assistance with all activities of daily living, including personal hygiene. JH was able to walk without assistance and used a combination of some vocalization and simple sign language signs for communication.

JH's mother was her certified provider under the State He-M 521 program regulations. Under this program, JH was able to live with her family, which was certified to receive Medicaid funding. In return, the home and provider (JH's mother) were required to meet minimum standards upon initial, and then annual inspection, by the area agency, Community Bridges. He-M 521.07 required Community Bridges to visit JH at home at least quarterly to determine, among other things, whether her services met her individual "environmental and personal safety needs."

JH received 30 hours a week of one-to-one residential and day services through Lutheran Social Services (LSS), with whom Community Bridges contracted. Service coordination was provided by Community Bridges. Funding was provided through the Medicaid Waiver. Even though LSS' responsibility included "residential services," LSS largely provided its support to JH outside the home.

Between 2005 and 2009, there were 35 incident reports prepared primarily by JH's LSS direct care provider concerning poor personal care by JH's parents and lack of sanitary conditions in the apartment. There were also concerns about medication management. In April of 2008, several LSS employees filed an anonymous complaint to BEAS regarding JH's hygiene as well as the conditions of JH's home. Jennifer Cook, the service coordinator supervisor from Community Bridges, also subsequently called BEAS to report possible family neglect.

The BEAS investigator, after meeting with JH, her parents, staff at LSS, JH's primary care physician, and reviewing the available records, determined that the complaint was unfounded. DRC's investigator interviewed the BEAS investigator as part of its own investigation. From that interview, it was learned that the BEAS investigator did not enter or visit the family's residence or speak with JH's direct care staff person, the author of most of the incident reports. Due to DHHS/BEAS

regulations, which require that records of unfounded cases, including the original report, be completely expunged after six months,⁸ the records of this investigation were no longer available when DRC performed its investigation after the fatal fire. Based on her recollection, however, the investigator believed that the complaint was solely focused on JH's hygiene and did not include the conditions of the residence. The overall evidence obtained during the DRC investigation indicates, however, that the investigator was made aware not only of JH's personal hygiene issues, but the housing conditions and other incidents that may have occurred in the home. The investigator also never considered whether there might be evacuation issues for JH in the event of an emergency, even though she lived in a second floor apartment, nor is this something that is routinely checked.

After receiving BEAS' determination, LSS continued to have concerns about JH's hygiene and living situation, but were resigned to the fact that "in reality nothing was going to change." Community Bridges had an obligation to "promote the health and safety" of JH as its client and to affirmatively "safeguard her rights."⁹ However, there is no indication that at any time before, during, or after the BEAS investigation, either Community Bridges or LSS considered addressing the guardianship issue and possible conflict, seeking a co-guardian or an outside advocate for JH. Nor was JH's ability or her parent's ability to safely evacuate her from the premises considered or discussed by any agency, let alone addressed.

On February 9, 2009 JH's parents notified Community Bridges that they were being evicted from their apartment. They requested assistance from Community Bridges; none came. In March, 2009, the family had given up finding a new apartment because the family had no money for a security deposit. On April 30, 2009, Community Bridges conducted an annual He-M 521 Certification Review of the family home as required. There was no comment on the condition of the home, nor was there any check on JH's or her family's ability to evacuate in the event of an emergency. Certification was renewed for another year.

On June 2, 2009, (six days before the fire), when the family's phone had been turned off, the family inquired of Community Bridges whether there was funding to help them pay bills. Although internal records indicate that Community Bridges decided it was unable to help with funding, there is no indication that the family ever received any response to its request, including information about the possibility of other funding sources.

On June 5, 2009, a team meeting was held to discuss JH's services and budget. The focus was on reducing JH's services for budget reasons. During this meeting, JH's father asked if he could

⁸ He-E 704.10.

⁹ He-M 505.03 (d)(4) & (w)(5)

appeal the decision to cut his daughter's budget. The response from the aforementioned service coordinator supervisor was that he could, but he "couldn't get blood from a turnip." Neither at or prior to the meeting did Community Bridges offer any assistance with regard to the payment of phone bills, or address the pending eviction and possibility of homelessness for the family. Had Community Bridges addressed the family's request for assistance, which the family started making in February, the family, including JH, may have been out of the home before the fatal fire on June 8th. While Community Bridges could not have foreseen the June 8th fire, its failure to act in assisting in the eviction situation is in conflict with its multiple obligations to address JH's needs.

b. Fire and JH's death

On June 8, 2009, JH's mother left the apartment around 4:50 a.m. for work. At about 5:45 a.m., she received a phone call from her son, informing her of the fire.

According to the State Fire Marshall's report, the son, who then lived next door, had been awoken by his father banging on his apartment door at about 5:10 a.m., stating the apartment was on fire. The son (also JH's brother) asked his father where JH was and then told his father that he had to get JH out of the apartment. Both he and his father returned to the family's apartment where fire and smoke were visible at that time. JH's brother reported seeing flames coming from the refrigerator. He saw his father re-enter the apartment, turn right and disappear into the living room area. JH's brother was then forced back down the building stairs and onto the street because of the intense heat and smoke.

JH's father and JH both perished in the fire. JH was found lying on her left side in a fetal position in the master bedroom wedged between the bed and wall, directly under a window. An overturned dresser was on top of her head. **JH's cause of death according to the Medical Examiner was "smoke inhalation under accidental circumstances."**

Despite legal requirements, Community Bridges never conducted an adequate assessment of JH's safety and other related needs. Staff also did not develop plans to address the risk of fire in JH's residential environment and the need for an evacuation plan and drills. Had there been a rehearsed fire evacuation plan, JH's father may have acted differently and removed JH before going to his son's apartment for help.

It should be noted that the governing regulations issued by DHHS are also not explicit in requiring that safety needs and assessments encompass an evacuation plan and drills when an individual is receiving state services or is living in a He-M 521 certified home.¹⁰

c. DRC's Findings, Conclusions, and Recommended Corrective Actions from the JH Death are contained in the report at Appendix B, pp. 21-36 and are highlighted below in Section IV.

C. 2006, 2004 and 2000 Deaths

1. Tilton Fire— 2/28/2006 Resulting in Deaths of Two Residents and One of the Two Caretakers This summary is primarily based on the State Fire Marshall's Investigation reports and records and correspondence between the Fire Marshall and DHHS.

a. Summary of Facts

The home that burned down was owned by an EFC provider who contracted directly with Lakes Region Community Services Council (the Region 3 Area Agency) for residential services for three individuals with developmental disabilities. Two individuals had their own first floor bedrooms. The third, who had the most significant disabilities, slept on the second floor, and as stated in the Fire Marshal report, "would have been resistant to [caretaker] efforts to evacuate her."

On February 28, 2006 at 4:45 a.m., the EFC provider left for her day job at Belknap County Nursing Home. Her male companion, the other caretaker, had begun his day. The clients were asleep. The EFC provider reported nothing irregular, and "nothing out of place in the basement" when she left the home. At 5:23 a.m., the companion reported a house fire in a 911 call.

It was later determined that the fire started in the basement. One of the first floor residents, whose bedroom door led directly to the outside, got out. The other first floor resident, MD, age 55, was found dead in a fetal position. She had a very high carbon monoxide level in her blood. It was the opinion of the State Fire Marshall investigator that she "may have been scared and was hiding or waiting for [the caretaker] to come to get her rather than exiting herself..." The second floor resident, BB, age 50, was found dead in a second floor bedroom (not her own) and "would not have listened to the [caretaker] and may have been attempting to retrieve the dog," according to the investigation report.

¹⁰ By way of comparison, the Department has used more explicit language in regulations governing clients living in enhanced family care or staffed model homes. Prior counsel for BDS, Ken Nielsen, confirmed that DHHS does not have any specific policies or guidance documents which an area agency must follow when conducting routine home checks pursuant to He-M 521 nor are the terms "personal and environmental safety" specifically defined in the regulations. It is DHHS' responsibility, however, to initially certify a home under He-M 521 upon the recommendation of the Area Agency. Attorney Nielsen stated that the Department essentially leaves it up to each individual Area Agency to define these terms as it sees fit. In this case, Community Bridges also had no specific definition or written checklist for its service coordinators to follow when determining if, in fact, a home met the He-M 521 criteria.

While the fire started in the basement, the cause was ultimately undetermined. However, the investigator did note what he characterized as “creative maintenance in regard to electrical, including extension cords running all over the interior and exterior of the house [and] that the possibilities of electrical fire were great.” There was no smoke detector in the basement, but one on the first and second floors.

When the home first became certified in 1989, only one smoke detector would have been required, but by the year of the fire, 2006, one on every level was required, including in the basement, and the detectors had to be interconnected so that if one alarm sounded, all alarms would sound. As the investigator concluded, if there had been an interconnected smoke detector in the basement “and it was working properly, the caretaker would have been alerted to the fire much sooner than he was.”

b. Steps Taken in the Aftermath of the Tilton Fire Fatalities

As a result of the fire, a joint effort was undertaken by DHHS and the Office of the State Fire Marshall’s Office of the Department of Safety, which included a *Joint Report on the Status of Life Safety Code in Licensed and Certified Community Residences, 6/15/06*. As a result of this effort and report, a number of measures were taken to improve the life safety of EFC homes and other certified community residences housing 3 or fewer residents to bring them into compliance with current life safety code requirements. (The report is attached as Appendix C.) These are also summarized and discussed in Section V (A) (2).

2. VH—Died on 12/18/04 in Milton, NH (Full investigation report is available at www.drcnh.org/deaths.html.)

a. Background and Relevant Facts Leading up to VH’s Death

VH was a 70 year old woman diagnosed with a mild intellectual disability, schizophrenia, drug induced Parkinsonism, hypothyroidism, and bladder control issues.

One Sky, the Area Agency for Region 9, was responsible for VH’s services at the time of her death and for years before it. One Sky in turn contracted her care to Options for Independent Community Living (OICL), a vendor then licensed to provide DD services. OCL contracted with an EFC provider for both residential and day services. OCL is no longer in business.

In March 2004, eight months before her death, VH had been living with the same OCL contracted EFC provider for 10 years. In or around March 2004 VH began deteriorating significantly, experiencing a higher incidence of hallucinations, forgetfulness, confusion, and increased difficulty

or inability in eating, resulting in choking at times. The choking incident prompted a change of her diet to ground or pureed foods.

In 2004, as a result of this marked deterioration and two incidents requiring emergency medical care, VH's primary care physician, psychiatrist, and the Exeter Hospital made recommendations for increased care, including VNA services, occupational therapy, social worker services, and physical therapy. VH's psychiatrist also twice recommended care in a nursing home.

With the exception of physical therapy, neither the Area Agency, nor OCL or its nurse, implemented any of the recommendations, including the relatively simple recommendation for ground or puree food to reduce the risk of choking.

In September 2004, OCL notified One Sky that VH's budget was "far too low to provide [VH] with the types of supports she need[ed] [and] that Ms. H had decompensated significantly over the past year both mentally and physically." OCL also indicated that VH was "far less independent and require[d] hands-on hygiene assistance as well as closer supervision at home and in the community, including at times...physical support when walking. Her medical diagnoses [were] numerous and irreversible."

In late September or early October 2004, the EFC provider terminated her contract with OCL due to her inability to meet VH's increased need for care, stating that there were insufficient funds to provide VH with the care she needed for her deteriorating condition.

In late October 2004, OCL placed VH in respite care and then placed her more permanently with the EFC provider in whose care she ultimately died.

The new EFC provider was a 20-year old single mother raising two children, ages 1 and 2. She was the sister of the OCL coordinator who, at the vendor level, was responsible for VH's care. The EFC provider was inexperienced and untrained in providing in-home, one-on-one care.

Despite VH's condition and recommendations for considerable health and nursing supports, there was no documentation of identified health supports, including supervision by a nurse or nurse trainer. In fact, within 9 days after placement, the nurse trainer went on a month-long vacation, with no provision made for nurse presence or oversight during that period. OCL refused onsite services of the VNA despite medical orders authorizing it.

b. Events Leading up to and Circumstances Surrounding VH's death

In the 24-hour period before VH's death, VH failed to eat or drink, was leaning over as she sat, and was having extreme difficulty with mobility. Rather than obtaining emergency care for VH, the EFC provider, after consultation with the OCL nurse trainer, Nurse Pare, took VH with her as she ran her errands throughout the day. Nurse Pare, as the vendor's Nurse Trainer, was responsible for

coordinating care and advising providers on how to address the health issues of clients. Nurse Pare did not advise the home provider to obtain emergency care, nor did she assess VH in person. Rather, Nurse Pare merely advised the home provider to have VH drink fluids. The EFC provider was unable to get VH to eat or drink during the day or to get into her bed that night. She put VH to sleep on the floor of VH's bedroom and spent the evening drinking wine coolers with her boyfriend. The next morning the EFC provider found VH dead, still on the bedroom floor. The police report said VH had been unable to take fluids and that she had difficulty swallowing chicken nuggets and French fries from McDonald's. As noted, her food was supposed to be pureed or ground.

The Deputy Chief Medical Examiner, Jennie Duval, MD found that VH died of "complications of schizophrenia"¹¹ and that "[t]he mechanism of death was likely cardiac arrhythmia **due to electrolyte imbalance due to dehydration due to refusal of food and water** during an acute exacerbation of chronic schizophrenia." (Emphasis added.)

c. DRC's and Consultant's Findings, Conclusions, and Recommended Corrective Actions from the VH death are contained in the investigation report available at www.drcnh.org/deaths.html and discussed further below in Section III.

3. CJ, a 49 year old male, died on 9/12/2000¹² in Vermont

a. Background and Relevant Facts Leading up to CJ's Death

CJ was a 49 year old male at the time of his death. He had cerebral palsy, and though he had the ability to walk, he was quite dependent on others to help him and used a walker. He was also diagnosed with a mild intellectual disability, schizophrenia, and depression, was also incontinent and exhibited challenging behaviors. Agency records indicate he routinely let himself fall to the ground, causing injury to himself and potentially others, and he had a hard time adapting to changes. At times, when CJ's behavior deteriorated, he was involuntarily admitted to NH Hospital.

His death occurred in an EFC provider home where he was placed only 10 days previously. The EFC provider had been a service coordinator for the Area Agency and resigned that position to

¹¹ DRC's consultant, after conferring with the Chief Medical Examiner, Thomas Andrew, concluded that VH was experiencing a gastrointestinal bleeding event prior to her death. The consultant concluded, as more fully described in her report, that the nurse trainer, who was in communication with the home provider in the 24-36 hours prior to VH's death, was negligent in assuming that the cause of VH's distress was purely psychiatric. DRC's consultant was Carol Walsh, a nurse practitioner with 30 years of experience in developmental disabilities. She has provided primary care and clinical consultation and developed clinical and educational programs for persons with cognitive disabilities, their families, and support staff and has provided consultations to the U.S. Department of Justice and to the MA Department of Developmental Disabilities Investigations Division.

¹² In addition to the Disabilities Rights Vermont (formerly Vermont Protection and Advocacy Agency) investigation report, a DHHS mortality tracking report was also reviewed, as well as records provided by DHHS' Office of Client and Legal Services (OCLS), including a complaint investigation report by the Area Agency. However, OCLS would not provide the state level investigation it had done.

become CJ and the other gentleman's provider. The home was in Vermont, but the placement was made by Common Ground/White Mountain Mental Health and Developmental Services, which is run by Northern NH Mental Health (the Region I Area Agency), which provided services to CJ. The home was given "temporary certification" for two beds a week before CJ and the other individual moved in. The temporary status was given without an onsite visit by the Area Agency. As discussed below, this was a critical oversight as the home was physically ill-suited for CJ.

Prior to his placement with the EFC provider, CJ had resided in an assisted living facility in Haverhill, NH for two years but was given notice that he had to vacate because of, among other things, his "behavior, hygiene, and attitude." He was upset about having to leave the facility. As noted, he had a hard time adapting to change.

b. Events Leading up to and Circumstances Surrounding CJ's Death

During what turned out to be a 10-day stay with the EFC provider, a series of events transpired which culminated in CJ's death. These included multiple falls in and outside the home and elsewhere, some causing CJ to hit his head, at times followed by as many as 16 hours of CJ remaining on the floor or ground. On one occasion CJ was left outside on a cold September night.

During most of this 10-day period CJ refused to eat. He vomited and his health progressively deteriorated. There was no medical intervention, though many calls were placed by the EFC provider to the Area Agency about the deteriorating situation, primarily to the housing coordinator. No contact was made directly with medical providers.

The following are excerpts/summaries from the Vermont Protection and Advocacy agency report on the chronology from September 3 to September 12, 2000, based primarily on the EFC provider's own progress notes and phone records.

September 3, 2000 – Home (EFC) provider noted that CJ allowed himself to fall several times, including in her small bathroom, where he hit the toilet, tub and sink cabinet. After falling in the bathroom right after lunch, he remained on the floor until 4:30 a.m. the next morning.

September 4 – CJ refused to eat in the morning. The EFC provider brought him to the "Littleton" office for a shower. He fell in the bathroom there, hitting his head. When the EFC provider returned home with CJ, he fell down to the ground as he got out of the car. The provider stated that CJ refused to get up. *** The provider watched him from inside the house. CJ made it to the front door (crawling) around midnight. The provider opened the door and he crawled inside. CJ spent the remainder of the night on the floor.

September 5 – CJ refused to go to the kitchen for breakfast. He vomited multiple times throughout the day, then he went to bed. This was also one of the two days that the day program worker went to the home to provide help in caring for CJ and the other resident for a few hours.

September 6 – CJ spent two nights on the kitchen floor (one span of time), lying in his urine for the entire time. CJ sat up September 8 with assistance. The provider also noted in her notes that CJ was physically weaker at this point. [Multiple phone calls made by home provider to Area Agency.]

September 7– [Multiple phone calls made by home provider to Area Agency.]

September 8– [Multiple phone calls made by home provider to Area Agency.]

September 11– The provider’s notes state that CJ did not get out of bed and that he was being assisted with feeding. He only nodded his head for communication purposes. The notes stated that the provider found CJ to be sweaty but he had no temperature. Multiple phone calls were made by the home provider to the Area Agency. In one call, the acting case manager offered to go to the home, but the provider declined because she had a meeting scheduled with him on September 14 and felt it could wait until then.

September 12 - The provider’s notes indicated that she found CJ had passed away in his bed sometime after 4 p.m.

The autopsy conducted by Vermont’s Chief Medical Examiner **found that CJ died as a result of “dehydration with contributory...pneumonia.”**

c. Summary of Other Findings of Disabilities Rights Vermont Report (formerly Vermont Protection and Advocacy)

1. To obtain temporary certification of the home, the AA Housing Coordinator certified in writing that the residence/day program was in “full compliance with [all applicable] statutes and regulations,” despite the fact that he did not inspect the home before the placement, pursuant to the He-M 1001 regulations, and that the home was physically unsuitable for CJ due to his physical limitations and phobia of stairs. The home also did not undergo a fire safety inspection prior to NH issuing temporary certification.

2. There is no indication that the provider was furnished with any type of manual to help in addressing emergency conditions or challenging behaviors of a client (generally or with respect to CJ). There was also no evidence of a medical services plan or personal safety assessment or plan relative to the home that the provider could access, including but not limited a plan for CJ to evacuate within 3 minutes, as required by He-M 1001.

3. The contract between the AA and the home provider to provide services to CJ was not signed until approximately three weeks after CJ’s death [in] violation of He-M 1001.04(f).

III. Overview of Relevant Legal and Professional Standards

A. Introduction

Typically, in developmental service systems in the United States and certainly in New Hampshire, the law vests with the state, and specifically the state health and human service agency, the responsibility to ensure the health, well-being and safety of individuals with developmental disabilities and to provide opportunities for growth, informed choice, independence, employment, and integrated community living. Above all there is a responsibility to “do no harm.”¹³ In New Hampshire, the Area Agencies share in these responsibilities,¹⁴ though DHHS bears the ultimate responsibility.¹⁵ While to some degree government affords these guarantees to all of its citizens, the legal requirements and professional standards associated with such service systems arise from a long and strongly held belief that most individuals with developmental disabilities require, to varying degrees, lifelong supports and protections from the state beyond those afforded the nondisabled population.

The state laws applicable to these responsibilities and the issues in this paper are set forth below. They also provide the source for more specific regulations. Appendix D contains (1) a more detailed list of the applicable laws, regulations and client rights and (2) describes the principal processes, systems and methods that are needed to ensure that these laws and substantive standards and rights are met.

In these circumstances, federal Medicaid, and in certain situations other federal laws, also apply. Federal Medicaid requirements¹⁶ are very similar to NH state law both in terms of substantive standards of care and services and the need for systems to monitor whether the standards are being met.

B. Relevant State Substantive Standards of Care and Services (Emphasis added to excerpts below are in bold below.)

NH RSA 126-A:4(I)

¹³ As noted in subsection B, multiple sources of law impose these obligations on the part of the State and its surrogates. See for example RSA 126-A:4(I) and RSA 171-A:18 and He-M 503, He-M 310.

¹⁴ RSA 171-A:18 and He-M 505.03

¹⁵ RSA 171-A:4 and RSA 126-A:4(I)

¹⁶ See generally 42 CFR §441.302 and DHHS’ §1915 (c) HCBS Waiver to CMS, 6/1/06, and specifically §3C, Appendix (App) C-2:18; §3D app.D-1:4 &D-2:4; §3G, App G:1-3; and §3H, App H:1-2.

<https://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/itemdetail.asp?filterType=dual,data&filterValue=NewHampshire&filterByDID=2&sortByDID=2&sortOrder=ascending&itemID=CMS1216469&intNumPerPage=10>

There shall be a department of health and human services under the executive direction of a commissioner of health and human services, which department shall be organized to provide a comprehensive and coordinated system of health and human services as needed **to promote and protect the health, safety, and well-being of the citizens of New Hampshire**. Such services shall be directed at supporting families, strengthening communities, and developing the independence and self-sufficiency of New Hampshire citizens to the extent possible.

EXCERPTS FROM NH RSA 171-A

“171-A:1 (V) & (I) Purpose and Policy – The purpose of this chapter is to enable [DHHS] to establish, maintain, implement and coordinate a comprehensive service delivery system for developmentally disabled persons. The policy of this state is that persons with developmental disabilities and their families be provided services that emphasize community living and programs to support individuals and families, beginning with early intervention, and that such services and programs shall be based [in part] on the following:

--Services based on individual choice, satisfaction, safety, and positive outcomes.

--Services provided by competent, appropriately trained and compensated staff.

171-A:4 State Service Delivery System. – The department shall maintain a state service delivery system for the care, habilitation, rehabilitation, treatment and training of developmentally disabled persons. **Such service delivery system shall be under the supervision of the commissioner.**

171-A:13 Service Guarantees. – Every developmentally disabled client has a right to adequate and humane habilitation and treatment including such **psychological, medical, vocational, social, educational or rehabilitative** services as his condition requires to bring about an improvement in condition **within the limits of modern knowledge.**

171-A:18I Area Agency Responsibilities and Operations

*** Each area agency...shall be the primary recipient of funds that may be dispensed by the commissioner for use in establishing, operating or administering such programs and services. The programs and services for which an area agency is responsible include, but are not limited to, diagnosis and **evaluation, service coordination, community living arrangements**, employment and day services, and programs designed to enhance personal and social competence.

EXCERPTS FROM REGULATIONS ISSUED PURSUANT TO RSA 171-A¹⁷

He-M 503.08 Service Guarantees on Services for Which Funds Are Available

(b) All services shall be designed to:

¹⁷ Unless otherwise noted, each provision was in effect as is or substantially so for all deaths reported in this paper.

- (1) Promote the individual's personal development and quality of life in a manner that is **determined by the individual**;
- (2) Meet the individual's needs in **personal care**, employment, adult education and leisure activities;
- (3) Promote the individual's **health and safety**;
- (4) **Promote the individual's right to freedom from abuse, neglect and exploitation.**

He-M 503.09 Service Coordination

(b) The service coordinator shall:

- (1) Advocate on behalf of individuals for services to be provided in accordance with He-M 503.08 (b);
- (4) **Monitor** and document services provided to the individual;
- (5) Ensure continuity and **quality** of services provided;
- (7) **Determine and implement necessary action...when health or safety issues have arisen;**

f. Identifies the individual's safety needs;

g. Identifies any follow-up action needed on concerns and the persons responsible for the follow-up; and

He-M 505.03 Role and Responsibility of the Area Agency

(a) The primary responsibility of the area agency shall be to plan, establish, and **maintain** a comprehensive service delivery system for individuals who are residing in the area. **The area agency shall plan and provide these services according to rules promulgated by the commissioner.**

(b) **Services provided by, or arranged through,** an area agency shall:

- (2) Meet the individual's needs in **personal care**, employment and leisure activities;
- (3) **Protect the individual's right to freedom from abuse, neglect and exploitation;**
- (4) **Promote the individual's health and safety;**

(w) The area agency shall be responsible for assuring that appropriate services are provided in accordance with RSA 171-A and the regulations promulgated there under, including the following...**monitoring** and **safeguarding of rights...**

IV. General Conclusions

A. Introduction

Parts B and C below contain DRC's conclusions regarding the deaths and related issues. The conclusions are generally in addition to the findings made in the 2009 and 2010 investigation reports of JH and ST as well as the previous death investigations.

Parts D and E primarily describe and comment on findings from the previously referenced government reports. Those reports address on a systemic level similar issues raised by these deaths and this paper.

B. General Conclusions

1. The 2009 and 2010 deaths of JH and ST were preventable in multiple ways.
2. There were a number of opportunities as each individual's situation evolved to rectify issues that ultimately caused or contributed to each death. In most situations there were signs and signals of unsafe conditions that led to the fatalities or a history of similar incidents that provided opportunities to change practices. Neither the opportunities were taken advantage of or the signs and signals heeded and addressed.
3. Previous deaths under similar circumstances provided lessons that could have been applied to prevent these more recent deaths. To the credit of responsible officials in agencies such as the Fire Marshall's Office and BDS, some changes were made, but they were not sufficient in scope or depth to address obvious, critical, systemic issues which could have prevented subsequent deaths.
4. Multiple failures of care, service provision, and public administration occurred in the two most recent deaths of ST and JH. These occurred at the direct service level, the Area Agency/vendor level, and the DHHS/BDS level. The failures were strikingly similar to those that contributed to the earlier deaths described above. Indeed, after the very first death (of CJ), there should have been heightened awareness of the multiple and complex needs of other individuals like CJ and the corresponding need for system reform. There was not. While, as noted, there were some later actions taken, they fell far short of what was needed.
5. None of the findings in the investigations or this paper are based on hindsight. The failures in all the deaths violated basic standards of care, service, quality assurance and oversight, as well as Federal Medicaid requirements,¹⁸ state law, and professional standards.¹⁹ The preventative measures and interventions that could have led to different outcomes should have been apparent to those

¹⁸ See note 15.

¹⁹ Council on Quality and Leadership, A Guide to Person-Centered Excellence, (2010) Indicators 2a-e, pp. 9-11; 3e, pp. 13,15; 5a, 5c, 5e, pp.19-21; 6b, pp.23-24; 7a,7b,7d,p.25, and 8b, pp.29-30. www.c-q-l.org

responsible for the care and services in each case, for they are fundamental components of any “comprehensive service delivery system for developmentally disabled persons.”²⁰ The next section categorizes and describes in more detail the major failings.

C. Specific Conclusions/Similarities Between Deaths and Specific Failings²¹

There are a number of highly similar characteristics in the profiles of each victim. These characteristics make each of them particularly vulnerable to the effects of substandard care. All three non-fire related death victims had multiple disabilities and conditions, many of a similar type. They all had cognitive impairments, mental health diagnoses, and challenging behaviors, and were on multiple medications including behavioral medication with significant side effects. Two had limited communication. At least two were prone to choking on food. All three had ambulation, balance or falling issues. Two of the three had incontinence issues. VH definitely presented medical fragility.

The failures, grouped by category, uncovered in the death investigations are:

a. Failure to Select or Arrange a Community Living Arrangement or Staffing Coverage Based on Needs of the Individual

For ST, based on his recent and lengthy history, his behaviors, hospitalizations, and other needs, he required experienced, well-trained and well-supervised staff on duty overnight. This was also the case with VH and CJ, the other two non-fire related deaths. They also all needed various health and clinical supports. Yet each was placed with poorly equipped providers without overnight coverage or clinical enhancements or supports, and, in VH’s case, contrary to the recommendations of independent professionals. In all three cases, they had been with providers who could no longer handle them because of their deteriorating conditions. In these cases, as well as JH’s case, it appears that the AAs gave no consideration to other models of service or supplemental staff in the homes to address safety needs at night, behavioral and medical issues, or environmental factors such as fire safety. For example:

- In the case of ST, who presented multiple challenges, the AA and/or the vendor, rather than consider an alternative residential model, awake staff or other supplemental services, chose to lock him in his room and then tried unsuccessfully to medicate him to make him sleep through the night.
- In the case of VH, despite recommendations for nursing home level of care or supplemental services in the home such as occupational therapy and visiting nurses, VH was placed in an enhanced family care home of a young inexperienced single mother, and supplemental services were refused. As stated by DRC’s consultant:

²⁰ RSA 171-A:1 (Purpose and Policy of the Chapter on Services for Persons with Developmental Disabilities)

²¹ An overview of the similarities across the individuals lives, including the circumstances surrounding the deaths, are depicted in Appendix D.

Given the significant and sentinel events (foot fracture, ER visits, hospitalization) prior to VH's move, **it should have been obvious to all parties involved that VH's care was not consistent with living in the home of a single young mother of 2 children...*****It appears that the "community living imperative," the lack of person-centered health supports needs planning, and funding issues were instrumental in placing VH in harm's way. It is incomprehensible to this consultant how a woman with VH's needs and conditions would be placed in the home of a 20 year old single mother of 2 young children in day care. **[Even t]he possible safety net of a day program (where more monitoring and evaluation could be provided) was discussed but never pursued.**" (Emphasis added)

- Similarly, in the case of CJ, when a 24-7 staffed assisted living facility could no longer handle him, he along with another client, were placed with a provider who was precipitously and unjustifiably provided with emergency certification to operate.
- In the case of JH, at least two factors should have prompted additional or alternative help or housing. The unsanitary and unsafe conditions in which JH was living and the prospect of eviction beginning several months before the fatal fire.

b. Failure to Select, Train, and Supervise the Residential Provider

- In none of the cases examined did the home provider receive adequate preparation, training, guidance manuals or protocols, or supervisory support to deal with and manage the complex or multiple behavioral and safety issues posed by each client. This is the case both in addressing their challenges on an ongoing basis or in anticipation of emergency or acute issues.
 - In ST's case, the consequence was that the home provider was ill equipped to prevent or address choking or falling incidents, to identify emergency situations, perform the Heimlich maneuver, or even promptly summon help.
 - In the case of JH or the earlier Tilton fire related deaths, there was no preparation or training on evacuation or the need for fire drills to prepare for an actual fire or other emergency.
 - In the case of VH, while the provider at times knew enough to call for help, she had none of the training needed to properly care for the individual, causing her to leave VH on the floor unattended at night -- only to find her expired the next morning.
- The findings further show a failure on part of the vendors or AA staff to provide support and supervision, including clinical support. There was a failure to intervene effectively or at all when they were notified of poor conditions, clear signs of deterioration, or risky behaviors hours or days before the death. For example:

- In ST's situation, when the EFC provider contacted the clinical supervisory staff about ST's sleeplessness, and his roaming around the house, she was first given instruction to lock him in his room, and then to medicate him, even after she reported that that strategy did not work. The failure to come up with a solution that was protective of his rights and was effective proved fatal.
- In JH's case, AA staff were unresponsive for years to unsanitary and unhygienic conditions in which JH was living and 35 incident reports by vendor staff.
- For VH, despite her medical and behavioral conditions and recommendations for considerable health and nursing supports, there was no documentation of identified health supports, including supervision by a nurse. In fact within 9 days after placement, the nurse trainer went on a month long vacation, with no provision for nurse presence or oversight during that period. The nurse trainer was also neglectful in failing to assess VH in person or obtain or direct the provider to secure emergency care when notified by the EFC provider of VH's deteriorating condition during the 24 hours preceding her death.²²
- In the case of CJ, AA supervision and oversight, including onsite assessment, was wholly inadequate or nonexistent despite nearly daily reports by the home provider about a client who had a documented history of difficulty in adapting to change, that in his first days of placement was not eating or drinking, was falling, was left outside in the cold or left in his own urine inside for hours and days at a time until he ultimately became bedridden and died of dehydration and pneumonia 10 days after his placement.

c. Failure to Conduct Adequate Clinical and Risk Assessments to Address Significant Medical or Behavioral Issues and to Implement Strategies or Services to Address the Risks

- In all three non fire related deaths there was a failure to conduct personal safety assessments or clinical evaluations (including functional behavior assessments). These were necessary both to identify all high risk behaviors and then to develop and implement effective measures to address the behaviors or their consequences e.g. falling in the case of ST, CJ, and VH. They all suffered injuries; VH fractures. In the case of VH, there

²² As DRC's consultant found, VH's needs warranted a written plan for comprehensive health supports, but this was "utterly lacking." The DRC consultant also made these related findings of the nurse trainer:

- The nurse trainer failed to adhere to BDS regulations/guidelines for administration of PRN medications.
- Assumed clinical activities inconsistent with her role, e.g. dismissing of VNA skilled nursing services (which she was not providing).
- Failed to maintain adequate running and dated progress notes.
- Failed, along with the AA and vendor generally, to provide continuous care management and onsite assessment.
- Demonstrated a complete lack of clinical sophistication manifesting itself in misdiagnosis and failure to obtain needed evaluation and treatment.

was more evidence of risk/clinical assessments by external clinicians who saw VH after falls and illnesses, but their recommendations to address the risks were ignored or not carried out.

- In the three cases examined for fire safety risk assessments (CJ, Tilton, JH), there was a lack of risk assessment and strategies to reduce the risk of fire or resultant injury or death, such as upgraded fire safety features, evacuation plans and drills, and ensuring a first floor location for individuals not capable of self-evacuation.

d. Failure of Area Agencies and Service Coordinators to Advocate for their Client's Rights and that their Needs be Met

- The findings of the investigation reports evidence a failure to (a) make service decisions based on the person's individual needs and (b) affirmatively advocate for and safeguard the rights of the person. Indeed, most of the findings from the investigation and this paper stem from this root cause. Examples which particularly illustrate these issues include:

For JH

- Despite JH living in unsanitary conditions, the AA failed to bring possible guardianship issues before the court, refer JH to an outside advocate, file a report to BEAS (for years), or launch its own He-M 202 investigation. Allowing these conditions to continue for years reflected a cavalier or insensitive attitude on the part of Area Agency staff. Exemplifying this attitude was a statement by an AA supervisor in response to the fact that JH was incontinent and went unchanged for hours—"That is just who JH is."
- When the family was faced with eviction from their apartment, which ultimately burned down, the AA failed to provide assistance which would have enabled them to move out.
- At a team meeting AA staff indicated that JH's funding and services may be cut. When JH's father asked whether that decision could be appealed rather than inform him and the family of their rights and explain the process, the AA supervisor responded with "you cannot get blood out of a turnip."

For ST

- When the EFC provider reported that ST was staying up all night, the AA and/or vendors unconscionable response was to authorize locking him in his room and when the EFC provider objected to that option, they authorized medicating him.

For VH

- Despite the almost 10 year documented need, for a guardian who could have been an independent voice and advocate, and an obligation on the part of the AA to obtain one, no action was taken by VH's AA and no guardianship appointment was made until just prior to VH's death.

- Recommendations and the need for increased levels of funding and care, including VNA, therapies and consideration for a nursing home placement, were ignored or refused. Instead the AA approved VH's placement with a 20 year old single mother of a one and two year old, whose only experience was providing some respite and who was the sister of VH's case coordinator.

For CJ

- When faced with an eviction from 24/7 assisted living, there was no evidence of advocacy or referral to an outside advocate to stop the eviction. Instead with no apparent choice, CJ was placed with an EFC provider of an 18-year employee of the Area Agency whose home the AA did not properly certify.
- Failure to remove the other client from the EFC home until three months after CJ's death, despite obvious evidence of neglect, if not abuse, by the EFC provider toward CJ.

e. Failure to Follow Incident Reporting and Remediation Procedures Designed to Prevent Future Incidents or Fatalities

An incident review process for sentinel, serious or unusual incidents is required by law and industry standards. However, in all five cases, the incident review and remediation process was not followed with respect to the incidents that led, caused or contributed to the deaths in each case. In some instances there was a failure to complete an incident report. In other instances, reports were made through the formal review mechanisms or less formally, but ineffective or no action was taken by management.

- For ST, incident reports were not completed, let alone acted upon, for his previous choking incidents, falls, or sleeplessness, all contributory factors in his death.
- In the case of JH, there were incident reports for unsanitary conditions—35 in total over three to four years - - but no effective action was taken to address the conditions until about a month before JH died. No reports were filed addressing the fire safety issues and risks.
- In CJ's case, the formal incident reporting process was not used. The EFC provider made daily calls to AA staff on serious, reportable behavioral and medical issues as well as inappropriate behavior on her part towards CJ. Yet no incident reports were filed or action taken.
- For VH, the records are devoid of incident reports for VH's many behaviors, e.g. falls, fractures, choking, etc.

f. Failure of Mandated Reporters (e.g. vendor, AA personnel, generic health professionals) to Report Possible Cases of Abuse or Neglect or Other Rights Violations

In addition to the failure to use internal incident review and remediation process, there was a failure to refer suspicions or allegations of abuse, neglect or rights violations to appropriate external agencies. Many of the incidents or conditions which preceded the deaths were subject to mandatory

reporting to DHHS/AA under DHHS/BDS rules (He-M 202) or to BEAS under RSA 161-F:46. All personnel at the provider, vendor or Area Agency level in each case, who had knowledge of those conditions had an obligation to report, yet with one exception in JH's case, no reports were made. In JH's case, it was only years after the conditions were known. In several instances, most notably in VH's case, there was also a failure of generic health personnel such as physicians, general hospital or emergency room staff to exercise their mandatory responsibility to report. If reports had been made, resultant external investigations and corrective actions may have been put in place to prevent the subsequent deaths from occurring.

g. Failure to Learn and Apply Lessons from Earlier Deaths to Later Deaths

Unusual, suspicious or unexpected deaths provide opportunities to learn and take actions to prevent the same or similar incidents in the future.

Based on information made available to DRC, the AAs and DHHS were inconsistent in whether and how they investigated each death and in implementing effective strategies to prevent future deaths. This is evidenced by the subsequent deaths and the contributory factors in each death. The investigations that were done and made available were either significantly flawed or were not fully utilized to address the full scope of the problem.

- In CJ's case
 - The purported He-M 202 investigation hardly constituted an investigation.²³ The AA level "investigation" was initiated over three months after the death. It was characterized as an He-M 202 investigation, investigating whether the right to "be free from abuse, neglect, and exploitation..." was violated. However, the investigation merely recounts some of the facts in a brief, perfunctory, passive form and, contrary to the cited regulations, made no "findings of fact or a proposed determination of whether the allegations are founded or unfounded, [or provided] an explanation of why such determination was made." (He-M 202(m)(3)). It also makes no findings as to whether any of the principals involved e.g. the home provider or AA staff, were deficient or derelict in their duties. It does note that Common Ground (which is part of the AA) terminated the contract with the home provider and moved out the other consumer, though it did not indicate that it was three months after CJ died. It proposed that Common Ground examine areas that should have been subject to findings in the investigation report as they were central to what went wrong.²⁴ In

²³ DHHS' former Office of Client and Legal Services Attorney, Kenneth Nielsen, had serious concerns regarding whether the CJ investigation was a good faith investigation into CJ's death or was more of an attempt to "cover up" the failings that lead to CJ's death.

²⁴ The areas the program were to review were: (1) "how actively the home was monitored during the client's stay, (2) the Home Provider's preparedness in dealing with a consumer with dual diagnoses, (3) whether the home offered a physical environment that was sufficient for CJ's mobility needs, (4) whether a behavior plan may have been of value to the Home Provider in

other words, in this very serious matter, it left it to the program at fault to conduct its own investigation or review, without even a requirement that the program report back as to how they were going to address most of these issues going forward. No recommendation was directed at the more senior management level of the Area Agency. Only the following statement was made: “The Area Director of WMMHDS has reviewed her role and responsibilities around CJ’s placement with the Chief of Operations and the Executive Director of the Agency.”²⁵

- Statewide there did not appear to be any actions taken as a result of CJ’s death or “investigation.” If any were taken, they did not have any tangible effect based on the subsequent deaths and findings of subsequent commission and committee reports as discussed in subsection D below. The Vermont Protection and Advocacy investigation, on the other hand, made a number of salient findings. Had an AA or DHHS investigation been conducted which reached and acted upon the types of findings in the Vermont investigation, some or all these subsequent deaths may have been prevented. This includes the fire related deaths.²⁶
- In VH’s case, an investigation at the AA level of her death did make some findings of neglect and violations of rights under He-M 202. This report in turn helped contribute to some reforms in the region and statewide. However, the reforms were not adequate to address the underlying contributory factors or their effects. They therefore did not act to reduce the risk of harm to individuals and prevent ST’s death, whose situation presented many of the same factors as ST (and CJ).
- In the case of the Tilton fire, a state level investigation conducted by the State Fire Marshall was made available to DRC. That investigation helped lead to the 2006 DHHS-State Fire Marshall Office Joint Report which, as described in Section V(A) below, resulted in the implementation of a number of important life safety measures in community residences. Those measures no doubt reduced the risk of fire or injury or death in those residences. However, in the case of JH, the AA (Community Bridges) did not adopt or adapt those fire safety or life saving measures in JH’s home nor did the state explicitly mandate some or all of them for He-M 521 Medicaid Certified family homes. Any one of the recommended measures, e.g. evacuation plan and practice drills, could

managing [CJ’s] falling to the ground, and (5) “the extent to which communications between the program and the Home Provider occurred...”

²⁵ The Area Director was the person who requested the agency investigation and, as noted, three months after the death. She was also the spouse of the person the report recommended with whom she review her role and responsibilities - - the Executive Director of the Area Agency. At the very least, the appearance of a conflict of interest is raised by this fact. Coupled with other factors (see e.g. footnote 23) the recommendation may also raise questions about the objectivity and independence of the investigation and remedial efforts as well as whether there was the requisite accountability for this tragic death.

²⁶ The Vermont P & A investigation made findings not only about emergency protocols for non-fire related matters, but on violations of fire and life safety requirements under He-M 1001, which were applicable to the causes of the deaths in the Tilton fire and in the fire that took JH’s life.

have saved JH's life²⁷ and reduced the risk of injury or death to other individuals in like circumstances.

- In JH's case, there was no AA or BDS He-M 202 investigation of the death or conditions that existed before the death. There was a BEAS investigation of the alleged unsanitary conditions JH was experiencing. However, that investigation, the report and files were expunged six months after the investigation pursuant to policy. The reconstructed account showed that the investigation was significantly flawed in that the investigator failed to inspect the home, the investigator failed to evaluate health and safety risks of the client as required by regulation or evaluate the risk of the client's ability to evacuate promptly in case of fire. Because the allegations were deemed "unfounded," no corrective or preventative actions were required in JH's situation in regard to the unsanitary conditions or fire safety.
- In ST's case, there was no BEAS or He-M 202 investigation of his death. As noted, there was a review by the DHHS Sentinel Review Committee, but that has not been shared with DRC. Since that death, there have been additional disseminations about the need for increased vigilance about "medically frail" individuals but as described below in Section V(A)(3), it is unclear how effective those issuances have been.

h. Failure to Conduct Adequate Pre-placement or Subsequent Periodic Reviews to Address Deficiencies Early and Promptly and thereby Prevent or Reduce Risk of Death

- There was a failure on DHHS, AA and vendor level in all cases to conduct onsite and sufficiently comprehensive initial inspections of homes prior to individuals moving in or on a periodic basis to ensure that the homes met life safety needs of the client and were otherwise suitable.
- In all five situations, had effective inspections, on-sites, and monitoring occurred, they likely would have identified and remediated the causes or contributory factors that led to the deaths.
 - In all five cases, required monitoring by the service coordinator should have exposed almost all of the issues and deficiencies in each case and prompted or led to their resolutions, e.g. life and fire safety risk issues, lack of appropriate behavioral approaches, inadequate staff coverage, mistreatment by provider (in case of CJ), the need to address choking incidents (in case of ST and VH), falls or fractures (in case of ST, VH and CJ), and unsanitary conditions (in case of JH and CJ).

²⁷ Many of the relevant circumstances and conditions in the JH fire were the same as the Tilton fire. While one was an enhanced family care model and the other a family home, both required certification as Medicaid was the funding source and required the same level of responsibility in regard to life safety of DHHS, AAs, vendors, and providers to provide care for the clients residing with their families in He-M 521 homes. Each morning at about 5:00 a.m. the primary/certified caretaker left the home, leaving the spouse or companion in charge of the care of three residents in case of Tilton, and one, JH, in the other. Neither residential situation was up to current life safety codes and had not undergone the required inspections, and each had a client on the second floor incapable of self-evacuating. Nor as indicated at was there an evacuation plan in place or fire drills.

- Proper pre-placement and annual certification inspections of the provider homes in the cases of JH, ST, the Tilton residents, and CJ would have revealed a number of environmental hazards as well as fire safety issues and hazards which in the case of JH and the Tilton residents led to their deaths.
- Pre-placement certification visits for VH and CJ proposed residences or annual reviews in the case of ST should have led to denial or revocation of certification or resulted in conditions being placed on continued certification such as supplemental staff coverage, clinical support, etc.

In sum, the use and quality of the investigation process for purposes of accountability and prevention was inconsistent at best. While two good investigations were done, one by the State Fire Marshall's Office and the other by Region 9 Area Agency, for the most part, external investigations were either not initiated when warranted or completely inadequate. In none of the cases have they been effectively used to get at the scope of the problem. The latter finding reflects the systemic finding of the 2009 SB 138 Quality Improvement Committee that in the DHHS/AA system "there has been a lack of clear and consistent review and feedback mechanisms to assure that identified concerns are addressed and that quality is enhanced."²⁸

D. Related or Similar Findings and Deficiencies Cited in at Least Five Public Government Reports from 2001-2010

1. Introduction/Overview of Five Reports

Many, if not most, of the deficiencies cited in the investigation reports or their causes are systemic in nature. They have been repeatedly found and cited in one state government report after another authored by commissions convened by the Legislature and/or the Governor. The deaths reported on in this paper represent the most extreme and tragic consequences of the findings in the reports.

Four of the five reports were published prior to one or more of the deaths. While some of the recommendations from these reports have been fully or partially implemented, most have not. Substantial or full implementation of these recommendations had (and continues to have) the potential of preventing or reducing the risk of deaths and other incidents, including the ones which are the focus of this report. The reports²⁹ are:

- Renewing the Vision, 2001, prepared and published by BDS (hereinafter Renewing 2001).

²⁸ Id. at p.4.

²⁹ These reports can be accessed through www.drcnh.org/deaths.html.

- The Governor’s Commission on Area Agencies, 2005, pursuant to the Governor’s Executive Order, made up of 12 persons, including the DHHS Commissioner and designees, family members and other stakeholders, and individuals from the public and business community (hereinafter Governor’s Commission on AA 2005).
- SB 138 Workforce Development Committee Report (2007) mandated by the Legislature in SB 138 (2007) made up of 15 government officials and stakeholders (hereinafter SB 138 Workforce Report 2007).
- The SB 138 Quality Improvement Committee Report (2008) under the same authority and mandate as the above referenced Workforce Report, also made up of 15 members (hereinafter SB138 Quality Report 2008).
- DHHS/BDS High Cost Review Committee Report, April 2010, made up of DHHS, BDS AA officials and one vendor representative (hereinafter DHHS High Cost Report 2010).³⁰

The focus of and the reason for the DHHS High Cost Report 2010 was to address the system’s so called “high cost clients.” Most of the persons who fell into this category had significant behavioral/psychiatric and/or physical medical issues. 433³¹ of the approximately 4,000 persons on the Medicaid DD Waiver were so identified in this report. Most of the findings and recommendations in the report were the same or similar to previous reports and this paper.

While there has been some progress in addressing the findings in the DHHS High Cost Report 2010, like the previous reports, most of the major findings and recommendations remain unaddressed.

The following are the major findings from the five reports (updated as appropriate) which are related to the issues in the deaths.

- **The ability to hire and retain qualified direct support staff has been severely compromised due primarily to wage scales remaining at or near poverty levels.** As noted by the SB 138 Workforce Report 2007, the turnover rate of direct support staff runs between 50 and 74%. (Id. at 6). As most recently found by the DHHS High Cost Report 2010:
 - In 32% of the cases surveyed, staff turnover had significantly impacted the care of the individual.
 - In 36% of the cases the needed staff resources were not readily available.

³⁰ Each report was developed with substantial input and/or in collaboration with personnel of the DHHS/AA system, providers, individuals with disabilities, families, advocates, members of the public and experts. The DHHS High Cost Report 2010, was prepared exclusively by a committee made up of personnel from DHHS/BDS staff or contractors, AA’s and vendors, and was based substantially on a self-assessment by Area Agency staff and the analysis and experience of the committee, composed of senior/executive staff from the respective agencies. It was issued in April 2010 after the last death reviewed in this paper and nearly 10 years after the first death.

³¹ 433 persons in this category represented a 64% increase from 264 persons in FY 2004. DHHS High Cost Report 2101, p. 1.

- **Pre-service and in-service training is insufficient, as is support and supervision of direct support staff.**
- **The ability to hire qualified EFC providers is severely hampered due primarily to low rates of reimbursement. There has been one small rate increases for EFC providers in 16 years.** The DHHS High Cost Report 2010, in fact, found that in only “57% of the cases [studied], the individual had enjoyed a stable living arrangement for the past five years.”
- **The system has experienced a severe erosion of the clinical, programmatic, and oversight infrastructure and capacity over the past 15 or more years as evidenced by:**
 - The reduction of full time dedicated staff trainers statewide in the DHHS/AA system from 15 to 1. SB 138 Quality Report 2008, p. 7.
 - A substantial decrease in staff, over time, at the State and Area Agency level dedicated to quality assurance improvement. For example, at BDS there was once a Quality Assurance Team with five full time staff, who visited program sites and issued reports once every 18 months. *2008 Report, p.7.* That dedicated staff no longer exists.
- **The clinical capacity of the system has eroded. This has had the most harmful effect on individuals with significant medical, behavioral and/or psychiatric issues as evidenced by the Area Agencies own self-assessments reported in the DHHS High Cost Report 2010:**
 - In 50% of the cases the individual's behavioral needs were not being appropriately met.
 - In 39% of the cases the individual's clinical/therapy needs were not being appropriately met.
 - In 25% of the cases the individual's safety needs were not being appropriately met.
 - In 45% of the cases ongoing crises and the responses to these crises had produced a negative effect on the care and supports for the individual.
 - 55% of the 433 individuals **had medical issues**, yet the Committee’s reviews found that the management of medical needs **presented significant challenges**.

And as the SB138 Quality Report 2008 earlier found:

[E]xpertise in specific clinical and professional areas has diminished, as clinical services were reduced in favor of more individualized community supports and funds were redeployed **to offset lack of rate increases**. This has left a gap in the service delivery system in regards to specialty services, such as behavioral supports, communication, assistive technology, employment, and services to individuals with significant medical, multiple disabilities or aging concerns.³²

³² Id. at 7 The Committee recommended that in addition to enhancing its training activities regarding core service-provision skills, the service system needs to provide more in-depth training to its staff and providers at all levels regarding these specialty areas, as well as autism, brain injury, **and dual diagnoses (such as developmental disability and mental illness)**. (Emphasis added.)

- **There is a need for increased housing options beyond enhanced family care especially for individuals with more significant multiple needs involving aging, medical and/or behavioral issues, in addition to intellectual disability.**³³
- **Employment opportunities as well as meaningful avocational activities for individuals served by the system are inadequate, predating the recession and economic slowdown.**

The self-assessment in the DHHS High Cost Report 2010 indicated that in:

- 46% of the cases the individual was not offered appropriate employment opportunities.
- 45% of the cases meaningful activities were not part of the individual's daily schedule.

And as the DHHS High Cost Committee found:

Social isolation and lack of meaningful engagement is especially acute for individuals with behavioral, psychiatric, or medical challenges. In fact, the absence of meaningful activities in a person's daily life **can be the cause of challenging behaviors and can exacerbate underlying psychiatric problems. In contrast, having the support to participate in meaningful activities can improve physical and mental health and reduce challenging behaviors.** (Emphasis added.)

- **There is a diminished and/or lack of standardized method of oversight, monitoring and quality assurance activities at the State and AA level** in accordance with each entities' legal responsibilities in this area. This applies both to the proactive, periodic reviews as well as post hoc reviews such as external investigations and internal incident reviews and remediation. Lack of attention to corrective action after deficiencies are found has been a particular concern, as found by the SB 138 Committee.

Although [BDS, AA, and vendor quality assurance and improvement] endeavors have enhanced the system's capacity and led to increased focus on achieving improved outcomes, **they have been pursued in a rather fragmented manner, resulting in uneven statewide performance. In addition, while there have been significant efforts to collect good information on system quality, there has been a**

³³ This as found in Renewing 2001 reiterated by the Governor's Commission on AA 2005 (p.18).

The majority of parents...expect their children to remain in their home community, but move out of the family's house once they were grown. Families agreed **that no one model of residential services would work for everyone. *** They asked that there be an increased effort to develop a variety of residential options, including supervised apartments, group homes, family care, and individual homes.** They also talked about the importance of including individuals and their families as active partners with the Area Agency in planning services. **In particular, families of children with specialized needs were concerned about the availability of accessible housing or residential services for those who have intensive medical problems or behavioral issues.** (Emphasis added.) 2001 Renewing the Vision, III(G)

And as the DHHS High Cost Report 2010 found: "[W]hen serving people who have significant medical, behavioral, or psychiatric issues or who pose a risk to community safety, individual service arrangements may not be the most effective option either from a clinical or financial perspective."

lack of clear and consistent review and feedback mechanisms to assure that identified concerns are addressed and that quality is enhanced. Id. at p. 3-4

- **The system has endured funding stagnation for the past 16 years, which has and continues to account for many of the deficiencies** described above.
 - Per person expenditures to clients on the DD Waiver **has dropped** from \$75,400 annually³⁴ in 1994 to \$43,468 currently, **or 42%**, and after adjusting for inflation,³⁵ the effective reduction is \$29,800, **or 60%**.
 - NH's level of fiscal effort--funding for developmental services vs. NH's wealth--dropped from 10th to 32nd since 1995.³⁶
- **There has been a growing lack of individualized, person centered and driven services**, a previous hallmark of the system (post Laconia State School) or at least a stated core principle and explicit legal requirement. The lack of focus on the needs of each person were among the chief factors in the deaths reported on in this paper. This finding has been reflected in the findings of the various commissions and committees on a systemic level.³⁷ As most recently found by the DHHS High Cost Committee's self assessment, in 40% of the cases sampled, the person's budget did not appear to be based on the person's needs.³⁸
- As funding, services, programmatic supports and work force training have been significantly curtailed and perhaps some of the zeal of earlier years of the AA system has waned, **expectations on the level and quality of services and the obligations of the AA system and providers has arguably been lowered.**³⁹ It could be said that a vicious cycle has developed where stagnant funding has led to lowered services, which has led to lower expectations by all persons in the system, including individuals and families. Indeed the DHHS High Cost Report 2010 identified as a critical factor for improving services, the need to "[c]reat[e] expectations about the individual having a meaningful and productive life." p. 13. This factor is not an intangible but has a real effect on services. Individuals and families

³⁴ www.cu.edu/ColemanInstitute/stateofthestates, p.218. (2011) The \$43,468 expenditure is the lowest in New England; Maine is the highest at \$79,425. Id at 25. The cost of institutionalization for this population nationally is \$191,116 and much higher for New England. Id at 19.

³⁵ Based on the CPI Inflation Calculator of the US Bureau of Labor Statistics.

³⁶ www.cu.edu/ColemanInstitute/stateofthestates, p. 60 .

³⁷ See SB 138 Quality Report 2008, p.1

³⁸ See also SB 138 Quality Report 2008, p.1. As the DHHS High Cost Committee went on to find for this population (as with others), for achievement of good outcomes, it is critical that:

- The individual, family, and/or guardian should be included in all aspects of service planning and delivery, and have a **primary voice in decisions regarding where, when, and how services are provided.** (Emphasis added.)
- There be effective communication, collaboration, and trust within the individual's circle of support.
- True customization of supports and services to meet the needs of the individual and family.

³⁹ See Cohen, R. "The Erosion of Developmental Services, RAP Sheet, Winter 2007 available at <http://www.drcnh.org/Rapquality107.pdf>.

often “settle” for less than what is needed because they feel they have no choice or are not informed about options and choices.

E. Observation and Comment on Responsibility For Funding Stagnation and Consequences to Existing and Prospective Clients

The Legislature and Governor ultimately decide on the budget and therefore bear the responsibility for budgetary decisions which have resulted in the economic stagnation and consequences to the DD system and its clients over the past 16 years. They do not bear the consequences alone, however. DHHS and Area Agencies share in the responsibility. They have been inconsistent at best in requesting funding amounts needed to maintain and improve services to existing or prospective clients. Even when proposals include all or most of what is needed, the information to support the request has generally not been adequate.⁴⁰ DHHS/BDS does not possess or present adequate performance or evaluative data to the Legislature or Governor to enable them to evaluate the request and support maintenance or increased budgets. Caseload information about existing clients is provided as is prognostications about future consequences to “Waitlist clients,” however information about how the funding/service erosion has been affecting and will likely continue to affect existing client needs is generally not provided.⁴¹ For example, the deaths reported on in this report (with the exception of the two publically reported on fires) are not well known, nor are the findings and results. BDS/OCS system of collecting and analyzing abuse and neglect data was better ten or more years ago, and what data exists now is not disseminated as part of budget or related presentations. The Sentinel Reviews of deaths and other critical incidents (or redacted versions or summaries) are not published and are not conducted with any transparency. Unlike nursing homes, home health care agencies or hospitals in the United States, including New Hampshire⁴² or developmental disability systems in some other states⁴³ little if any hard data about how AA’s are doing is posted or presented.

⁴⁰ For the 2010-2011 biennial budget DHHS/BDS did indicate what was needed to maintain existing services and fully fund the waitlist, as well as quite commendably include sums to implement key SB 138 Workforce and Quality Improvement Committee recommendations, e.g. bringing direct support staff wages at parity with NH Hospital mental health workers, funding rate increases for EFH providers, and funding to greatly improve staff development for direct support workers. However, funding for these SB 138 Committee recommendations was then not included in the Governor’s Budget.

⁴¹ At least a partial exception to this dynamic occurred in the 2011 session of the legislature for the 2112-2113 budget. DHHS/BDS, in response to steep cuts proposed by the House to the developmental services budget, indicated that there would be severe human and financial costs to individuals and families though again prior data indicating the effects of funding stagnation was not being provided.

⁴² See <http://www.medicare.gov/default.aspx>

⁴³ See e.g.

http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Government&L2=Newsroom&L3=Department+of+Developmental+Services+News%2c+Updates%2c+and+Reports&L4=Quality+Assurance+and+Improvement+Activities+Reports&sid=Eeohhs2&b=terminalcontent&f=dmr_g_news_mortalityreports&csid=Eeohhs2

While it cannot be stated with any certainty whether DHHS/BDS proposed budgets over the years would have fared better if more information was available, the Legislature and the Governor would at least have had more information and may have better understood the consequences of continued underfunding.

If policy makers are not presented with robust performance data and the consequences resulting from funding stagnation or reductions, and are sometimes even given a misleading picture,⁴⁴ it is far more difficult to stem the tide. Of course, policy makers also have the responsibility to demand salient information. In any case, the result is that the system has gradually eroded and the consequences go undiscerned or undetected. It is akin to an old metaphor describing a frog slowly being boiled alive. If a frog is placed in boiling water, it will jump out, but if it is placed in cold water that is slowly heated, it will not perceive the danger and will be cooked to death.

⁴⁴ Broad brush pictures have been painted by some DHHS Administrations to the effect that Area Agencies are performing at optimal levels, and that individuals and families are satisfied. While there are many examples of good practices, the findings of the reports cited in this paper belie these broad-brush representations that are sometimes made. This is why salient and accurate performance data is so important so that policy and budget decisions are based on accurate and valid information, not on sweeping and misleading positive or negative generalizations.

V. Recommendations

A. Previous Actions Taken Related to Findings in the Investigation Report and this Paper

1. Introduction

Some statewide corrective/preventative actions have been taken as a result of two or three of the deaths. They largely fall into two areas—fire safety and actions to address “frail clients,” and are summarized in (2) and (3), respectively, below. Several other actions have been taken though not directly as a result of the deaths, but potentially should have a preventative or corrective effect on some of the deficiencies and systemic factors identified throughout this paper and in the investigation reports. These are discussed in subsection (4) below.

2. Fire Safety

As a result of the Tilton fire, a number of actions related to fire and life safety were taken based on a joint effort and June 2006 Report from the State Fire Marshall’s Office and DHHS, as Appendix C. The Legislature appropriated additional funds for several of the recommendations. The actions include:

- Sending lists to local emergency responders of community residences or facilities in their towns in the disability, elderly and child care systems so that they were aware of them in the event of an emergency.
- Requiring all new community residences (EFCs and staffed models) to have hardwired or wireless interconnected smoke alarms with battery back up on every level and in every bedroom and requiring all existing residences to work towards installing interconnected smoke alarms.
- Making sure that all individuals placed in certified community residences of up to three persons should be reasonably capable of recognizing the danger of fire and are able to evacuate. If an individual is determined as being slow to evacuate, s/he shall have a ground floor bedroom unless it is a facility with automatic fire sprinklers.
- Requiring all AA Providers and the State to develop safety plans to protect individual residents. Regular fire drills, including during sleep-time hours, are to take place.
- Requiring ongoing fire safety training for AA’s, vendors, providers and clients with local fire departments participating in conducting the training.
- Developing and using a Fire Safety Checklist by all licensing surveyors and for AA’s and vendors as a self-assessment tool to proactively address potential life safety issues.
- Requiring installation of wider windows in client bedrooms in which only one means of egress exists.

This effort to upgrade the life safety features of certified homes⁴⁵ and enhance fire safety and assessment and risk prevention measures was done with great urgency, commitment and obvious know how. DRC has not done a formal follow up to determine whether all measures have been carried out, though we do know that many have. The Departments, Area Agencies, vendors, providers and the Legislature and Governor are to be commended on both the urgency and thoroughness with which they developed and implemented these measures. People in certified community residences⁴⁶ should be safer for it.

3. DHHS's Policy and Other Changes.

Based on information that DRC was given access to,⁴⁷ several actions were taken in the aftermaths of VH's and ST's deaths. A description of the actions and analysis of their efficacy are contained in Appendix C. Briefly they entailed:

- **Establishment of a Sentinel Review Policy and Protocol in 2005** in which sentinel events (e.g. deaths) are reviewed (but not investigated) by senior DHHS officials in order to draw and apply lessons from the event. **When this process was instituted, OCLS/BDS death investigations were stopped**, along with the critical investigative fact-finding of such investigations, including determination of culpability and responsibility. The result and the documentation of these Sentinel reviews are kept confidential. Because these reviews are kept confidential, external authority, including DRC, cannot evaluate their thoroughness or effectiveness.⁴⁸
- **New language was added to several sets of regulations, including most notably He-M 506 on staff training, He-M 517 on Covered Medicaid waiver services, and He-M 1001 on Community Residences.** However an actual examination of the reported changes shows little or no material or significant change, and in one case an actual weakening of a provision. See Appendix F, p. 1-3.
- **Area Agencies were requested to collect information and conduct annual reviews on "medically frail" individuals pursuant to BDS guidance documents.** The information gathered from these reviews was then to be provided to the BDS staff nurse who in turn would conduct her own selected reviews. While DRC has not fully evaluated the effectiveness of this initiative, this seems like a positive development, but several weaknesses do appear, and improvements are needed. One concerns which clients are covered in the reviews. In one sense, the definition of "medically frail" seems over inclusive and in another

⁴⁵ In 2006, there were 970 certified community residences, serving over 1600 individuals. The vast majority of those residences were EFC homes as opposed to the shift/staff model residences.

⁴⁶ As discussed below, none of these measures were applied to Medical Consumer Directed Homes, such as the one in which JH resided.

⁴⁷ DRC reviewed all the investigation reports done at the Area Agency level for these deaths, but was denied access by DHHS to investigations or sentinel reviews they apparently did of CJ and VH's deaths. Thus DRC's findings about state level actions are based on all the data reviewed in each investigation and responses from DHHS on all the actions they took as a result of these investigations which was provided by Ken Nielsen, Esq. of the Office of Client and Legal Services.

⁴⁸ The cessation of actual death investigations at the state level was also very troubling. New regulations just going into effect should permit resumption of death investigations by OCLS.

sense the definition may exclude individuals who also need additional clinical attention - - persons with primarily behavioral issues. See Appendix F, p. 3.

- **Proposed changes to He-M 1200 on Administration of Medication** seek to expand the regulations beyond just medication management to include health care coordination of clients in the system and some additional measures for individuals considered “medically frail.” An early draft does indicate that the DHHS is moving in the right direction, though some of the same weaknesses in the policy disseminations described in 3 above exist. See Appendix F, p. 3.

In addition to these limitations, DHHS changes do not get at many of the other issues and underlying causes in the deaths described in this paper. Recommendations to address those as well as the other limitations are set forth in Subsection B below.

4. Other System Changes that Related to the Issues Described in the Investigation Reports and this Paper

At least three other pertinent changes in policy or practice have been instituted in the past year. They could have a remedial effect on some of the issues identified in the death investigations though they were not developed in response to the deaths. Two were recommended by the SB 138 Quality Improvement Committee in 2009.

The first enables the specification of staff training in a client’s service agreement, individualized to the needs of the client and beyond the minimum required by regulation. That requirement has been placed in the He-M 522 regulations covering individuals with acquired brain disorder. It has not been placed in the He-M 503 regulations covering the much larger group of individuals with developmental disabilities. The He-M 503’s are up for re-adoption and the expectation is that the same provision will be inserted in those regulations.

The second is the transfer of abuse and neglect investigations from the Area Agencies to OCLS to avoid the appearance of or actual conflict of interests. This change is now codified in the He-M 202 regulations. Other changes in those regulations should also permit better tracking and addressing of abuse and neglect trends.

Third, BDS and AAs initiated a nationally known program called START in collaboration with the Institute on Disability/UNH in which clients with significant behavioral and/or psychiatric needs are identified and clinical capacity is built up to support them. Originally started around a few

clients in some of the area agencies, it was recently rolled out statewide, and if properly supported and resourced, holds promise.⁴⁹ For more details, see *the DHHS High Cost Report 2010 p.6*.

B. Recommendations

1. Introduction

While the actions described above have had or may have impact, as indicated they are not sufficient to address most of the deficiencies and underlying systemic factors that caused the deaths and other issues cited in the reports. The specific recommendations below are designed to remedy those deficiencies and issues.

These recommendations are generally in addition to the recommendations in the JH and ST investigation reports and the cited government reports. Most of the recommendations in those reports remain valid and necessary.

Note : (1) In those cases, where the recommendation below is similar to a recommendation from the one of the government cited reports, there is a cross-reference to it, and (2) as applicable and unless specified otherwise, most of the recommendations should be incorporated into each of the following components of the DHHS/AA service delivery system:

- a. Assessment and evaluation processes (including personal safety, clinical and quality of life assessments).
- b. Service agreement planning, development and implementation and monitoring, including determinations of residential placements.
- c. Staff recruitment and training and administrative and clinical supervision and support to staff.
- d. Quality Assurance proactive and post-hoc activities at all levels including, but not limited to, licensing, certification, service coordination, monitoring, quality enhancement, root cause analysis, incident-specific and trend-systemic feedback/corrective mechanisms, as well as data and information disseminations.
- e. Appropriate regulations and contracts with Area Agencies, vendors, and providers.

2. Specific Recommendations

a. Personal Safety and Clinical Assessment Process and Implementation of Strategies and Services to Address Issues on Individual Client Level

⁴⁹ BDS is also considering a health screening instrument to help identify individuals with significant or complex health needs and to make sure those needs are addressed.

DHHS/BDS should improve policy and practices to ensure that the individual needs of persons are met by improving the processes for:

- (1) Assessing risk of harm to self or others due to the individual's disabilities, behaviors, life and fire safety issues, or other environmental or situational factors,⁵⁰
- (2) Effectively developing and implementing strategies to address the identified risks,
- (3) Conducting or utilizing quality clinical assessments, including as appropriate functional behavioral assessments or other behavioral evaluations, communication, medical, and psychiatric or medication evaluations to ensure proper identification of needs in these areas and strategies to address them.

b. Increased Residential Options and Exercise of Choice

- (1) Ensure that residential placement and residential model decisions as well as staff qualifications are objectively determined based on the needs of the individual (and not on the least expensive model available.)
- (2) In that regard, increase availability of housing options so that a wider diversity of options exist statewide, including individual homes, staffed/supervised or semi-supported apartments/homes as well as enhanced family care. The number of individuals in any given residence should continue to be small (e.g. 3 or less as a norm) so that individualization is not lost, and in fact promoted, and congregation and segregation do not re-emerge. *Similar recommendations in Renewing 2001, Section II(G), Gov. Commission 2005, p. 18 and DHHS High Cost 2010, p. 1.*

c. Improved Pre-Service, In-Service Training and Supervision

Ensure adequate and effective pre-service and in-service training and continuing professional development with corresponding certifications significantly beyond the minimal “orientation” and “training” required by He-M 506, in accordance with recommendations in the SB 138 Workforce Report (2007), SB 138 Quality Report (2008), and the DHHS High Cost Report (2010).⁵¹ The enhanced training should (1) ensure skill acquisition in addressing behavioral, medical and environmental issues, abuse and neglect and incident reporting obligations, emergency and care issues, and (2) promote values and rights concerning choice, self-determination and individualization. (See subsection (g) below for further recommendations on the latter.) In order to

⁵⁰ See e.g. in Rhode Island-- <http://www.bhddh.ri.gov/ddd/pdf/DDDRiskAssessment.pdf>.

⁵¹ Specifically in the above referenced 2007 Report, see recommendations # 4 and 5 on p. 8; in the 2008 Report, see recommendations 4 and 5 on p. 2 and recommendations on pp. 6-8; and in the 2010 Report, recommendation #4a on page 9 and #11b on p. 12.

compliment, reinforce and/or ensure training is carried out, staff should be supervised, supported and evaluated by appropriately qualified staff.

d. Abuse and Neglect Reporting, Incident Review and Remediation, and External Investigations

(1) Strategies should be developed and implemented to improve reporting of suspected incidents or conditions of abuse and neglect both internally within agencies and to external mandated agencies, such as OCLS and BEAS and for children, DCYF. This applies both to mandated reporters and individuals with disabilities and other non-mandated reporters. Strategies to look at include, but should not be limited to:

- (a) Improved pre-service and in-service training on reporting and its importance.
- (b) Holding mandated reporters accountable when it is discovered that they did not report a reportable case of abuse, neglect or exploitation or other rights violations.

(2) Standardize and improve incident and reporting and remediation process statewide to clarify what is subject to incident reporting, and to what level within the agency, and to ensure that corrective and preventative actions are taken so that the same or similar actions do not recur.

(3) Continue with the initiation of the independent investigations unit under OCLS and all the elements of the process spelled out in the revised He-M 202 process.

(4) Salient data should be taken from incident reports of particularly serious incidents and external OCLS investigations (and BEAS investigations as well) and analyzed; and as appropriate, acted upon on a state, regional, and provider basis as part of the quality assurance system.

(5) DHHS/BEAS should develop clear rules and/or protocols specifying:

- (a) the process and criteria when a BEAS or other DHHS investigator may or should enter and/or inspect a home (with or without permission) as part of their investigative or protective service responsibilities, and
- (b) what to inspect or observe. The latter should include a checklist or guidelines on standard items to look for such as fire or life safety issues, the existence of an evacuation plan for a vulnerable adult, etc.

(6) DHHS should modify its retention policy with regard to unfounded BEAS investigation files to require that all documents in these cases be retained for five years, as with “founded cases.”

e. Measures to Ensure He-M 521 Certified Family Homes are Safe

DHHS/BDS should apply “as is” or with appropriate modification, pertinent provisions of He-M 1001 and the Joint 2006 Fire Marshall and DHHS report’s recommendations to He-M 521 Medicaid certified family homes in the area of fire or life safety.

f. Quality Assurance and Enhancement Activities

(1) DHHS/BDS should report on the post 2005 reviews of persons deemed “medically fragile” and describe the steps taken to ensure that any life safety, medical, or behavioral issues have been addressed. To the extent that the reviews have not been sufficient to make or act upon those determinations, additional or supplemental reviews should be undertaken. At a minimum, it is recommended that the report be submitted to the Governor, the Joint Health and Human Services Oversight Committee for the Legislature, the Developmental Services Quality Council, and the Medical Care Advisory Committee. This should be done within six months provided that any pre-existing reports summarizing results be made available as soon as possible.

(2) A report should be compiled and presented regarding the implementation of all the recommendations of the 2006 Joint DHHS-State Fire Marshall Report.

(3) The Developmental Services Quality Council should continue to play its role in developing and then recommending to DHHS/BDS quality and performance standards, methods of evaluations, feedback and accountability mechanisms for adoption by DHHS/BDS.

(4) The DHHS/BDS/AA Quality Assurance system(s) should improve its quality assurance/enhancement systems so that both the individuals’ health, welfare and safety needs are being taken care of as well as other quality of life needs. Improvements or enhancements are recommended in:

(a) The residential certification or licensing process so that it assures that the home and provider(s) meets all necessary environmental, emergency and life and fire safety, health, training, and service standards prior to the individual being placed.

(b) The annual certification and licensing process to ensure that the home and provider continue to meet standards and updated requirements.

(c) The Quality Assurance Process which focuses on service quality and client outcomes and quality of life, to include:

(i) Root cause analyses when deficiencies are found e.g. lack of training, poor hiring practices; inadequate funding, supervision, services; and poor practices in addressing behaviors, etc.

(ii) Corrective and feedback mechanisms that ensure that identified deficiencies are corrected and when the deficiencies are determined systemic in nature, underlying issues are corrected system (or subsystem) wide.

(iii) A “red and pink flag” system to ensure immediate or urgent correction when emergencies or urgent issues have been identified in visits or reviews.

(iv) A system to disseminate⁵² all (1) certification, licensing, quality assurance reports and corrective activity, (2) trend data from these reports and, (3) incident reviews and investigations, and other data collection activities to:

(a) Individuals and families so that they make informed decisions about services or advocate for improvements.

(b) Legislative and executive branch policy makers and the public in general so that they know how appropriations are being spent and laws are being administered and can make fully informed decisions about policy changes and budget requests.

(c) Area Agencies, vendors, providers, other stakeholders.

The staffing complement at the DHHS/Bureau level should be increased so there are adequate numbers of qualified staff to carry out these and other required quality assurance and oversight functions.

See also Governor's Commission Report 2005, pp.27-28 on further recommendations regarding quality assurance.

g. Improved Salary Structure and Benefits for Direct Support Workforce

Per the *SB 138 Workforce Committee Report 2007, pp.3-7*, funding should be appropriated:

(1) To support a salary schedule for AA and vendor-employed direct support staff that is at parity with the NH Hospital annual salary schedule for Mental Health Worker I with recognition and incorporation of differentials for the completion of advanced training and education which results in increased competence.

(2) For annual rate increases/salary/stipends for all staff and providers indexed with the Consumer Price Index, to include recognition and incorporation of salary increase differentials for the completion of advanced training and education which results in increased competence.

(3) To reimburse EFC providers at 100% the cost of coverage for a single person health care plan (not to exceed the average cost of the three largest NH plans for a 45 year-old female).

Also, per the SB 138 Workforce Report, DHHS and/or the Legislature should study the need for health insurance coverage or improved health insurance coverage for all Area Agency and vendor staff and make recommendations accordingly.

h. Enhancement of Clinical Capacity

Substantially enhance the clinical capacity of the system particularly with regard to addressing the more challenging needs of persons with behavioral, medication, psychiatric, and/or

⁵² The Quality Council is very conscious of the need for more transparency and having information more accessible to individuals and families in order to better self-advocate and make informed choices.

aging issues by carrying out the applicable recommendations of the 2005 Governor's Commission Report, the 2010 DHHS High Cost Review Committee, and/or by taking other equally appropriate and effective actions and activities.

(1) The recommendations from the DHHS High Cost Review Committee 2010 are generally excellent and are designed to improving clinical capacity to serve these populations.

(2) Particularly relevant from the Governor's Commission Report are the following recommendations.

(a) The development of a human resources plan with input from key stakeholders to determine adequate numbers of qualified administrative, professional/programmatic, supervisory, paraprofessional/direct support personnel at all levels of the Service Delivery System in order to carry out the responsibilities of the service delivery system taking into account, among other salient factors, **the needs of persons with challenging behavioral and/or medical issues.** (Emphasis added) *Governor's Commission Report 2005, p.24.*

(b) Under the oversight of the Governor and/or DHHS, the establishment of a task force of leaders/experts in health, home health, aging, mental health, developmental disabilities, with input from key stakeholders, to develop initiatives promoting, at the state and/or local level, better coordination, integration and best practices in physical and mental health, acute and chronic health prevention and treatment **for individuals with developmental disabilities with challenging or complex needs...** (Emphasis added) *Governor's Commission Report 2005, p.25.*

(c) DHHS should ensure that individuals on the waiver [Medicaid] have access to the Medicaid State Plan for nursing oversight and coordination. *Governor's Commission Report 2005, p.25.*

(3) BDS should ensure that its system(s) to review and address the acute and chronic needs of individuals with challenging or complex behavioral, medical and/or psychiatric needs include not just persons who fall within the high cost categories but all individuals who have such needs.

i. Safeguarding and Promoting Culture of Individual Rights, Choice and Self Determination

(1) Address the culture or practice that is failing to adequately focus on and, in fact, discourages safeguarding and advocating for individual needs or rights. Adopting the recommendations in this paper are an essential part of achieving this change of culture and practice. Of particular relevance are:

(a) Improved staff training on skills and values, as well as administrative and clinical support thereafter to reinforce such training.

(b) Review of practices related to:

- (i) Determining when guardians are needed and then promptly obtaining one (who can then perform a protective and advocacy role),
- (ii) What to do when guardians may be in a conflict or not performing their role,
- (iii) Facilitating the use of other and lesser restrictive forms of protection and advocacy when warranted (whether or not the individual has a guardian) such as AAs actively referring individuals to the Disabilities Rights Center, the designated protection and advocacy agency for NH, or other appropriate advocacy or legal service organizations.
- (iv) Actively promoting or making referrals of individuals and their guardians to independent case management/service coordination, when the appearance of or actual conflict of interest exists. DHHS/BDS should make changes in policy and practice to promote use of independent case management and remove any impediments to families or Area Agencies in using them.
- (v) Finding and utilizing ways to provide sufficient information to individuals, families and guardians so that they may know their rights and choices and can exercise them, including, but not limited to, completing and disseminating the consumer guide booklet BDS is developing. *SB 138 Quality Report 2008, pp. 1-2 (including recommendation 7), 10-1*
- (vi) Promoting and reinforcing effective self and family advocacy.