

EXAMINING PREVENTABLE DEATHS IN THE DEVELOPMENTAL SERVICES SYSTEM

A Call to Action—Keeping Vulnerable Citizens Safe from Harm

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.

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.

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

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:

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.

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.

- 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.
 - 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

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.

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.