DISABILITIES RIGHTS CENTER, Inc.

Review of the Circumstances Surrounding the Death of VH, Former Client of NH's Health and Human Services/Area Agency System

Prepared by the Disabilities Rights Center

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The DRC is the designated federal protection and advocacy system for New Hampshire and is a member of the National Disabilities Rights Network.

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I. Introduction

The Disabilities Rights Center, Inc. ("DRC") is the organization designated by the Governor of the State of New Hampshire pursuant to federal statutes to protect the legal rights of people with disabilities. It is an independent, non-profit agency. The DRC's mandate, in accordance with federal statutes, includes the authority to investigate and/or review violations of these rights. The federal statutory scheme confers upon the DRC broad powers to seek records, conduct interviews, and gather all necessary information in the course of an investigation and/or review of the death of an individual.

VH was a seventy year-old woman diagnosed with mild mental retardation, schizophrenia, drug induced Parkinsonism, hypothyroidism, and bladder control issues. She died on December 18, 2004 and was found on the floor in her bedroom. It was determined by New Hampshire's Deputy Chief Medical Examiner, Jennie Duval, MD, that Ms. H died of "complications of schizophrenia" 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."

Such a death raises concerns of neglect and abuse. The DRC determined that it should review the matter to determine whether the care provided met with acceptable practices at all levels of the system of care delivery model. The DRC further determined that, as the death occurred in December 2004, it would be valuable to analyze what changes, if any, were made to the provider system to prevent a similar event occurring in the future.

At the time of her death, Ms. H received services through New Hampshire's Department of Health and Human Services/Area Agency system, which was developed to safely integrate individuals with developmental disabilities into New Hampshire communities. DHHS principally through the Bureau of Developmental Services oversees and supervises ten regional Area Agencies. The area agency in Region 8--Community Developmental Services, currently known as One Sky Community Services ("One Sky") was responsible for providing services to Ms. H. The direct support was provided by an enhanced family care provider, Rebecca Aylward, who had contracted with Options in Community Living, Inc ("OCL") which had, in turn, contracted with One Sky. OCL is no longer a direct service provider. An enhanced family provider model is similar to foster care but for adults, and is the primary out of home residential model in the area agency system.

To review the issues involved in Ms. H's death and to review what actions have been taken by New Hampshire since Ms. H's death, the DRC requested information from the State of New Hampshire, Division of Developmental Services; One Sky; and the State of New Hampshire, Office of the Chief Medical Examiner. The DRC also requested an analysis from independent consultant Carol Walsh. [1] The following is the DRC's report based on the information it

[1] Ms. Walsh is a nurse practitioner with 30 years of experience. She has provided consultations to the Massachusetts Department of Justice and to the Massachusetts Department of Mental Retardation Investigations Office. She has provided

obtained.

II. Summary

VH, was a seventy year-old woman diagnosed with mild mental retardation, schizophrenia, drug induced Parkinsonism, hypothyroidism, and bladder control issues. She died while in the care of an untrained, inexperienced 20-year old single mother, after a more than 24-hour period when it should have been clear that Ms. H was in acute distress.

One Sky was responsible for Ms. H's care at the time of her death and in the months leading up to her death. One Sky in turn contracted her care to OCL. OCL in turn contracted with individuals in the community to provide Ms. H's direct care. OCL is no longer in business.

As of March 2004, Ms. H was living with Marie Janvrin, an enhanced family care provider, who had the contract with OCL. At that time, Ms. H began deteriorating significantly, experiencing hallucinations, forgetfulness, confusion, and increased difficulty or inability in feeding, clothing, and cleaning up after herself, and problems with mobility, which led to falls and fractures. Twice, in August and September 2004, the ER at Exeter Hospital recommended that Ms. H receive VNA services, occupational therapy, a social worker assigned to her, and physical therapy, a recommendation also made by Ms. H's primary care physician in October 2004. OCL rejected all of these discharge orders, except for the physical therapy.

In late September/early October 2004, Ms. Janvrin terminated her contract with OCL due to her inability to meet Ms. H's increased need for care. Stating that there were insufficient funds to provide Ms. H with the care she needed, OCL placed her in respite care and then placed her permanently with Rebecca Aylward in late October 2004.

Rebecca Aylward was a 20-year old single mother raising two children, ages 1 and 2. She was the sister of Sara Durant, who was OCL coordinator and responsible at the vendor level for Ms H's care. Ms. Aylward was inexperienced and untrained in providing in-home one-on-one care. Though disputed by Ms. Durant, Ms. Aylward claims to have received no orientation as to Ms. H's needs. And there was in fact no documentation that orientation occurred.

In the 24-hour period before Ms. H's death, Ms. H failed to eat or drink, was leaning over as she sat, and was having extreme difficulty with mobility. Rather than obtaining emergency care for Ms. H, Ms. Aylward, after consultation with Nurse Pare, did nothing but take Ms. H with her as she ran her errands. Nurse Pare did not advise Ms. Aylward to obtain emergency care, nor did Nurse Pare assess Ms. H in person. Rather, Nurse Pare simply advised Ms. Aylward to have Ms. H drink fluids. Despite her inability to get Ms. H to eat or drink during

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primary care and clinical consultation and developed clinical and educational programs for persons with cognitive disabilities, their families, and support staff.

the day or to get into her bed that night, Ms. Aylward put her to sleep on the floor and spent the evening drinking wine coolers with her boyfriend whom she met on the internet. The next morning Ms. H was deceased.

A. Findings and Conclusions

1. There was a failure to identify a person at high risk for adverse events. There was an utter lack of health care oversight by properly trained professional and direct support staff.

2. There was a failure to provide Ms. H with a written plan for comprehensive health supports.

3. There was a failure to provide a process to ensure continuous clinical support to Ms. H by the Nurse Trainer during vacations, etc.

4. Nurse Pare failed to provide adequate running and dated progress notes.

5. Nurse Pare failed to adhere to He-M guidelines for administration of PRN medications as required by He-M 1201.05 (e)(1).

6. Nurse Pare lacked clinical sophistication and documentation skills.

7. Nurse Pare assumed clinical activities incongruous with her role, such as her dismissal of VNA skilled nursing services and ruling out the summoning of emergency response personnel the day before Ms. H died.

8. One Sky and OCL failed to provide continuous care management and on-site assessment. The contract with Ms. Aylward was a conflict of interest given that her sister was OCL Coordinator Sara Durant.

9. There was at best, a silo mentality between each responsible entity, a lack of coordination and no oversight. They were not considering the system as a whole to ensure that Ms. H was receiving the care she needed. The Bureau only contracted with One Sky for Ms. H's care and took no further responsibility. One Sky only contracted with OCL for Ms. H's care and took no further responsibility. OCL, in turn, contracted with Ms. Aylward, an unskilled and untrained young woman with significant childcare responsibilities, and provided little support or oversight. The hospital staff, physicians and nurses also took a limited view of their role. As a result, there was a breakdown in overall care for Ms. H.

10. One Sky recommendations for itself and requirements for OCL only provide narrow solutions, such as requiring that Ms. Aylward not continue as a provider, ensuring that answering service messages are received, ensuring that Nurse

Trainers adhere to He-M 1201, and providing policies and expectations. These changes, while useful, are not systemic. They fail to address the lack of responsibilities taken by the area agency and its contractors, the failure to provide consistent nursing care (in either a home or a through VNA) to Ms. H as recommended by her physicians, the placement of Ms. H with an utterly unqualified care provider, and the failure of the system to monitor Ms. H during her placement.

B. Recommended Corrective Action.

1. DHHS/BDS and One Sky should review and revise as necessary their current system(s) of service coordination and clinical monitoring and oversight to ensure that individuals in the DHHS and Area Agency system are receiving the appropriate level of care consistent with best practices. This should include, in particular, a review of whether the systems include adequate provision of comprehensive health plans for individuals who have significant or complex medical and health issues.

2. DHHS/BDS and One sky should review, and revise as necessary, their policies and practices relative to housing, placement or transfer of individuals particularly with significant and/or complex health and/or behavioral needs to ensure that the proposed environment is designed to meet the individual's needs and the personnel are trained, supervised and supported to provide service and care in accordance with the individual's health as well as other needs.

2A It is recommended that DHHS/BDS utilize an outside consultant, not connected with the system to conduct the reviews specified in 1 and 2.

3. DHHS/BDS should strongly consider adopting an objective assessment instrument, such as the Supports Intensity Scale (SIS), to determine level of need and services for individuals in the DHHS/AA systems. This has been under consideration by BDS and was the subject of deliberation by the SB 138 committee. Although it was not voted on by the committee, the proposal was well received.

3A DHHS/BDS incorporate as part of their quality assurance and contract monitoring of Area Agencies whether the policies and practices subject to 1,2, and 3 above are being carried out effectively on an ongoing basis.

4. Reiterating recommendations from Renewing the Vision (Section III (G)) (2001) and the Governor's Commission on Area Agencies (2005) (pp 18-19), DHHS/BDS should promote, and as appropriate, require that there be a

variety of community housing options and supports available, to include options for persons with more complex medical and behavioral needs.

Note: Increased options create more choice, allow for needs of all individuals to be met, and prevent resort to more restrictive settings, such as nursing homes. Despite the recommendations, from Renewing the Vision and the Governor's Commission, there have not been explicit top down strategic efforts to increase options. While the enhanced family care model may be appropriate for many individuals, for those whom other options are needed like Ms. H., financial considerations continue to discourage development of other models.

5. There must be a system of identifying which clients are in need of a guardian or an independent advocate to ensure that they receive a guardian and/or advocate in a timely manner. Many of the failures that resulted in Ms. H's death might well have been avoided if a competent guardian or advocate were in place to advocate her interests.

6. Physicians should consider the long term effects of psychiatric drugs prescribed to elderly individuals who are at a heightened risk of adverse side effects and drug interactions. Physicians should explain to individuals the benefits and risks of such quantities of medications in combination.

6A. DHHS/BDS should consider performing a study of the use of psychiatric drugs on clients served by the DHHS/BDS system.

7. The systems of hiring, supervising and evaluating staff (both direct support and professional staff) at the provider and area agency levels must be improved so that qualified and competent people are hired and retained and unqualified people are not. Reiterating recommendations from Renewing the Vision (Section III (G)) (2001), the Governor's Commission on Area Agencies (2005), and the SB 138 Committee Reports (Work force report generally and Quality Improvement Report, this should include education and training and improved salary and benefit levels.

8. DHHS/BDS should reinstate its investigation capacity so that there is a state level investigation of deaths that arise from suspicious or unusual circumstances, to include investigations when there is reason to believe that abuse or neglect contributed to the death. The SB 138 Committee already recommended effective July 2010, that abuse and neglect investigations conducted at the area agency level be transferred to DHHS/BDS. With a more robust investigative capacity at the DHHS/BDS level, sound practice would warrant that full death investigations be conducted at that level. Sentinel

reviews could still take place, but would have the benefit of full investigations.

9. DHHS should adopt more transparent policies in regard to release of state investigations and sentinel reviews, access to which have been blocked in this matter. These reviews by their nature are not internal quality assurance products and therefore should be available, redacted as needed. They are reviews of external agencies. Principles of transparency and good management (to help ensure corrective action) warrant more transparency.

III. Circumstances Surrounding the Death of VH

A. Background

The findings of consultant Carol Walsh, with which DRC concurs, are attached as Appendix A. In summary form they are as follows:

On December 18, 2004, Ms. H died unattended in the home of Ms. Aylward who was a contract provider who had contracted with OCL to provide home care to Ms. H. OCL had in turn contracted with One Sky, i.e. Region 8 in New Hampshire's area agency system, to provide care for Ms. H.

Ms. H was a seventy (70) year-old woman with a history of mental illness and mild cognitive impairment. Her diagnoses included mild mental retardation, schizophrenia, drug induced Parkinsonism, hypothyroidism, and bladder control issues. Ms. H had successfully lived for years with another contract home healthcare provider, Marie Janvrin. Ms. Janvrin ceased providing care to Ms. H in late September 2004 due to a decline in Ms. H's condition and Ms. H's increased need for care.

In March 2004, when Ms. H was still living with Ms. Janvrin, she was relatively healthy but beginning a process of significant deterioration. Ms. H's March 2004 profile, prepared by Service Coordinator Michelle Chavez of One Sky, indicated that she participated in a lot of cooking and household activities and exercised as much as possible. She was viewed as being actively involved in the community and enjoyed visiting friends, shopping, going out to eat, bowling, attending band concerts, picnicking and holiday parties. That said, in March 2004, Ms. H needed more and more help making choices as to food, clothing (appropriate clothing for the climate), and general purchases. She did not always understand what each of her medicines were for or why Dr. Timothy Breitholtz was prescribing or changing her medications.

The March 2004 Annual Update, prepared by OCL, indicates that Ms. H continued to experience hallucinations and had issues with forgetfulness and confusion. She required reminders or partial assistance to complete her daily hygiene routine. She required quite a bit of prompting to be self sufficient. She also suffered from incontinence and needed reminders to use facilities and to clean up after accidents.

Dr. Breitholtz noted on April 26, 2004 and on at least one other occasion that Ms. H was a good candidate for a nursing home, stating that Ms. H would meet the criteria for PASSAR for a nursing home and that her condition would only worsen over time. During this same period, OCL informed One Sky that Ms. H had significantly declined and, as such, her funding was far too low to cover her needs.

In August 2004, Ms. Janvrin further detailed Ms. H's declining health. Ms. Janvrin was concerned that Ms. H was frequently choking. Ms. Janvrin stressed that providing for Ms. H had become increasingly difficult due to her decreased mobility. Ms. H's decreased mobility made it difficult to transfer her from one spot to another and resulted in her falling more frequently. Ms. H broke her foot and her ribs due to falls. During this period, Ms. H's nurse trainer, Valerie Pare, RN, noted issues with her skin integrity, swelling, and redness of the lower extremities.

When Ms. H broke her foot, she was taken to the ER at Exeter Hospital. The case manager at Exeter Hospital ordered "skilled nursing, physical therapy, occupational therapy and social worker visits upon discharge." OCL overrode that discharge order for VNA services. OCL declined to implement much of the balance of the case manager's order. OCL chose not to provide occupational therapy or social worker visits. Instead, OCL only provided some PT.

In September 2004, Nurse Pare took Ms. H to the ER at Exeter Hospital for a lower extremity edema. The Exeter Hospital case manager's discharge orders again called for skilled nursing, physical therapy, occupational therapy and social worker visits. Nurse Pare informed VNA that there was no need for skilled nursing as she was in Ms. H's home daily. According to Nurse Pare, Ms. H would only need therapies. However, Sarah Durant, OCL coordinator, cancelled OT therapy because Ms. H was in premorbid level care. Ms. Durant also determined that social worker services were not necessary as the services were provided by OCL. Again, Ms. H received only PT, as well as erratic follow up on her skin care issues.

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

Ms. Janvrin terminated her role as in-home care provider in late September 2004. Ms. H was placed in respite care with Victoria Kear in September 2004 while OCL sought permanent placement.

In October 2004, Nurse Pare was feeding Ms. H such things as frankfurters on a roll and fried clams. She was doing this despite the fact that as far back as December 2003, there was a

physician's order, as a result of Ms. H's problems with choking, that Ms. H be provided with ground meats only to prevent choking. Nurse Pare did not adhere to the physician's order.

In the face of Ms. H's decline, OCL chose to place Ms. H with Ms. Aylward in late October 2004. Ms. Aylward was the sister of Ms. H's OCL case manager, Sara Durant[2]. Ms. Aylward was a 20-year-old single mother with a 1 ½ year old child and a 2 ½ year old child. She had never provided in-home one-on-one care in her life. Ms. Aylward had no training. She stated she received no orientation as to Ms. H's care, and was unaware when she began caring for Ms. H of some of her medical issues, such as her incontinence. Ms. Aylward stated that she learned about Ms. H's needs by working with her. Ms. Aylward was unaware of OCL's policies and procedures. Although her contract provided instructions for emergency procedures, she did not receive the contract until around the time of Ms. H's death, after Ms. H had been living with her for weeks. Although OCL claims that it did provide Ms. Aylward an orientation, it has no documentation to corroborate that an orientation took place. At the time of Ms. H's placement with Ms. Aylward, OCL was requesting additional funding due to the significant decline in Ms. H's condition.

On October 31, 2004, Dr. Braese, Ms. H's primary care physician, certified that Ms. H was in need of skilled nursing care, physical therapy and/or speech therapy or occupational therapy. OCL did not follow up on this order. Rather, Ms. H remained in the care of Ms. Aylward.

Nurse Pare was on vacation from November 4, 2004 to December 1, 2004. Nurse Terri Lyons covered for Pare during this period but had no contact with Ms. H. When not on vacation, Nurse Pare had poor insight into Ms. H's overall health. Nurse Pare never visited Ms. H at Ms. Aylward's residence.

Although Nurse Pare noted that OCL Coordinator Carlos Chavez was also responsible for coordinating Ms. H's care, he appears to have had no contact with Ms. Aylward and Ms. H until December 9, 2004, approximately ten days prior to Ms. H's death.

B. VH's Death

According to Ms. Aylward's statement to the Milton Police Department, the twenty-four hour timeline of events leading up to Ms. H's death is as follows:

> 7AM: Ms. H woke up on December 17, 2004 at her normal time, between 7 a.m. and 7:30 a. m. Ms. Aylward observed that Ms. H was "out of it." Ms. Aylward called Nurse Valerie Pare because Ms. H was having a hard time drinking and

[2] Ms. Durant continued working on Ms. H's case into November 2004, a patent conflict of interest considering her sister's involvement. She was ultimately replaced in November by Mike Chavez.

talking. Ms. H was limp and forgetting everything. Nurse Pare told Ms. Aylward to get Ms. H to drink fluids[3]. Ms. Aylward claims to have tried to get Ms. H to swallow water but she was not able to swallow the water and was spitting it up. Ms. Aylward helped Ms. H out to the couch. Ms. H declined breakfast but took one sip of water.

9:30AM: Ms. Aylward paged Nurse Pare. Nurse Pare returned the call at approximately ten a.m.

10AM: Ms. Aylward could not get Ms. H to walk so she put her in a wheelchair and pushed her to the front door. She then stood Ms. H up, got her to hold an outside railing and was able to get Ms. H down to Ms. Aylward's vehicle. Ms. Aylward then drove Ms. H to McDonald's as Ms. H had stated that she wanted something to eat. More specifically, Ms. H wanted chicken nuggets, French fries and a Coke. Ms. Aylward placed the order at the drive thru. Ms. H was only able to suck the Coke halfway up the straw. Ms. Aylward tried to assist Ms. H in eating the fries by placing them in her mouth. Ms. H did not attempt to eat them.

12:45PM: Ms. Aylward stopped at OCL in Hampton to get the check she received for caring for Ms. H. On the way to OCL, Ms. H was leaning to one side / not sitting up straight. Upon arriving at OCL, Ms. H chatted with some OCL employees in the parking lot.

2:30PM: Ms. Aylward and Ms. H arrived at Fleet Bank in Newmarket to cash the check. Ms. Aylward cashed the check and used the bank bathroom.

3:45PM: Ms. Aylward went to a stained glass store in Rochester to buy a gift. She went to Wendy's with Ms. H. Ms. Aylward ate but Ms. H did not have anything to eat.

4:45PM: Ms. Aylward and Ms. H went to Rochester to pick up Ms. Aylward's children (aged 1 ½ and 2 ½) from day care.

5:20PM: Ms. Aylward, Ms. H and the children went to Berwick, Maine to make a car loan payment and to talk with a friend.

6:30PM: Ms. Aylward, Ms. H and the children stopped at Cumberland Farms.

[3] Though not in the Milton Police Report, the day prior on December 16, 2004 and in response to a similar issue raised by Ms. Aylward, Nurse Pare ordered a PRN for an extra 10 mg of Abilify.

7PM: Ms. Aylward returned home. She had difficulty getting Ms. H up the front stairs to the residence as Ms. H was not grabbing the railing to help ascend the stairs. Ms. Aylward was able to get Ms. H into the house and to a chair in Ms. H's room. She left Ms. H in her room listening to the radio. Ms. Aylward then prepared her children's dinner. Ms. Aylward checked on Ms. H once between 7 and 8 to see if she wanted anything and Ms. H indicated that she did not want anything. Ms. Aylward also asked Ms. H what color Ms. Aylward's eyes are and Ms. H did not know even though she had routinely answered this exact question for Ms. Aylward in the past. This made Ms. Aylward believe that Ms. H was not doing well. Ms. Aylward asked Ms. H if she wanted to go to the doctors and Ms. H said that she did not. Ms. H responded to Ms. Aylward that she was okay. Ms. H was leaning-over in her seat when making this comment.

8:00PM: Ms. Aylward went to Ms. H's room to help her to bed. She gave Ms. H her medication and checked her mouth and thought that she had swallowed her medications. In response to Ms. Aylward, Ms. H indicated that she tried to walk to the bed but her legs gave out on her and she went to the floor. Ms. Aylward joked about whether Ms. H wanted to sleep on the floor. Ms. H indicated yes. Ms. Aylward put a pillow under Ms. H's head. Ms. H did not want a blanket. Ms. Aylward then shut the door to Ms. H's room.

830PM: Ms. Aylward's boyfriend arrived and spent the night. Ms. Aylward went to bed at 11:30pm.

1:30 to 2AM: Ms. Aylward checked on Ms. H during the night but was not sure what time as the power had gone out. Her estimate was that it occurred between 1:30 and 2 a.m. Ms. Aylward stated that she could see that Ms. H was breathing.

7:30Am: Ms. Aylward went into Ms. H's room to wake her up. She noted that Ms. H was not breathing and was not responding to Ms. Aylward. Ms. Aylward then called OCL to have Nurse Pare paged. After Nurse Pare did not return her call, Ms. Aylward called and had her paged again. Nurse Pare returned the second call between 8 a.m. and 8:30 a. m. Nurse Pare then told Ms. Aylward to call the police.

On December 21, 2004, the Milton Police interviewed Nurse Pare. Nurse Pare stated that Ms. H had first paged her at 8:44 and then again at 8:57 a. m. on the morning that Ms. H was discovered not breathing. Nurse Pare called Ms. Aylward at 9 a. m. When the officer inquired why Nurse Pare thought that the pages from Ms. Aylward came so late, Nurse Pare stated that Ms. Aylward had mentioned that the electricity had gone out and, as such, Ms. Aylward may have overslept.

Ms. Aylward later clarified and provided more details about the night in question. The clarifications and further details were as follows:

- Ms. Aylward also asked Ms. H if she wanted something to eat upon returning home on December 17, 2004.
- Ms. Aylward did not page Nurse Pare on December 17, 2004. Rather, she called and talked to Nurse Pare about bringing Ms. H into the community on Friday considering her condition.
- Ms. Aylward administered medications in the community. She administered Oxibutynin as prescribed. Ms. H received 5 mg four times a day. Ms. Aylward brought Oxibutynin with her when she was out with Ms. H.
- Ms. Aylward cut the straw at McDonalds and Ms. H was able to sip the Coke through the straw.
- Ms. Aylward only spoke to one employee in the parking lot at Options, Jane Pichette.
- Ms. Aylward did not use the bathroom at Fleet Bank. Rather, she went from Fleet Bank to a group residence were she had formerly worked and used their bathroom.
- Ms. Aylward further clarified that she never lost sight of Ms. H while making multiple stops. Ms. H remained in the vehicle but Ms. Alyward claimed to have always kept her in sight.
- Ms. Aylward claimed later that she in fact returned home at 4:30 p.m., rather than 7:00 p.m. She thought the Milton police officer misunderstood.
- Ms. Aylward stated that she thought Ms. H's extreme weakness was from medication and lack of food.

Ms. Aylward (who, at age 20, was underage for drinking alcohol) also later clarified that she had consumed six Bacardi wine coolers on the night of December 17, 2004. Her boyfriend was drinking beer. The investigator questioned whether it was good judgment to drink six wine coolers while caring for two small children and Ms. H. Ms. Aylward indicated that she was not as drunk as the investigator thought. She said that she didn't mention the drinking because she was underage and did not want to get in trouble.

The autopsy (discussed in greater detail below) revealed that Ms. H suffered from bleeding within the gastrointestinal tract. This is likely the physical malady that exacerbated her psychiatric disorder.

IV. Prior Investigations or Reviews of VH's Death

A. Autopsy Report: State of New Hampshire, Office of the Chief Medical Examiner

The April 7, 2005 autopsy findings were as follows.

1. **Chronic schizophrenia**
   a. Long history of paranoid schizophrenia;
      b. History of drug-induced Parkinsonism
   b. Recent exacerbation prompting increased dosage of psychotherapeutics;
      i. High therapeutic levels of aripirazole (Abilify) detected in postmortem blood.
   c. History of wheelchair dependence;
      i. Contusions on knees
   d. History of recent refusal of food and water;
      i. Postmortem vitreous chemistry consistent with dehydration;
      ii. Gastrointestinal hemorrhage.
2. **Probable hypertensive cardiovascular disease.**
   a. Nephrosclerosis
3. **Pulmonary granulomas of uncertain etiology (incidental).**
4. **Multinodular goiter with history of hypothyroidism.**
5. **History of mild mental retardation.**
6. **Cholelithiasis.**
7. **No evidence of significant trauma.**
8. **History of being discovered on the floor (beside her bed) where she insisted upon sleeping.**

Based upon these findings, Dr. Jennie V. Duval, Deputy Chief Medical Examiner for the State of New Hampshire concluded that Ms. H "died as a result of complications of chronic schizophrenia. The mechanism of death is likely a cardiac arrhythmia due to electrolyte imbalance due to dehydration due to refusal of food and water during acute exacerbation of chronic schizophrenia."

The autopsy report also indicates that Ms. H suffered from bleeding within the gastrointestinal tract. This is likely the physical malady that exacerbated her psychiatric disorder.

B. Police Report

The Milton Police Department determined that Ms. H's death was untimely as defined in the New Hampshire statutes. There were no charges resulting from the death. The report indicates that Corporal Lori N. White responded to the Ms. Aylward's residence based upon a report from Carroll County Dispatch. The officer found Ms. H dead at the scene. The officer observed that Ms. Aylward had reported finding Ms. H dead at 8:30. However, she did not call

the police in what the officer viewed as a timely manner. Ms. Aylward did not call 911 until 9:07 a.m. Ms. Aylward indicated that she did not know what to do. Instead of calling 911 immediately, she paged OCL nurse trainer, Nurse Pare. She claimed that Nurse Pare took a while to call back. Nurse Pare informed Ms. Aylward to call 911.

In addition to the facts contained in Section III, Ms. Aylward informed Corporal White that she administered Ms. Aylward's medications. She stated that she last provided medication to Ms. H at 8 p.m. the prior day. She stated that she did not keep med sheets as she would fill them in at the end of the month. The medications present at the Aylward residence at the time of Ms. H's death and that were Ms. H's are as follows: (1) Ferrous Sulfate, 325 mg; (2) Trazodone 50 mg; (3) Levothyroxine .1mg; (4) Abilify 20mg; (5) Evista 60 mg; (6) Actonel 35mg; (7) Zinc Sulfate 220mg; (8) Ocybutin 5mg; and (9) Actonel, 35mg. Ms. Aylward further indicated that the Abilify had recently been increased by Nurse Pare (as needed) for an additional 10 mg. She stated that the order had been added a few days prior when Ms. H started not doing well. On December 16, 2004, voices in Ms. H's head were telling her not to eat.

C. <u>One Sky Community Services: Complaint Investigation Report</u>

The factual findings of One Sky's investigator were generally consistent with the police report. Some of the clarifications that were noted by One Sky in its report are detailed in Section III. After going through the facts of the matter, One Sky's investigator made the following findings.

1. Ms. Aylward violated Ms. H's rights to be free from neglect per He-M 310.05 and to receive medical treatment in a timely manner per He-M 310.06. Ms. Aylward violated medication administration procedures per He-M 1201 (as required per He-M 1001.06(g) Health/Safety).

2. OCL violated Ms. H's rights in failing to comply with Health/Safety guidelines per He-M 1001.06 (b), failing to ensure the residence had written policies that specified the procedures to be followed in medical emergencies. Nurse Pare, RN with Options was found to have violated He-M 1201.05 (e)(1) Training and Authorization of Providers – Reauthorization requires that Nurse Trainer directly observe provider/staff administering medication. Nurse Pare had not observed Ms. Aylward passing medications.

The findings were considered violations per He-M 310.06(a)(2)- Treatment Right that provides that all consumers have the right to quality treatment with all rules adopted by the department in He-M 200 through He-M 1300.

The investigator made the following determinations as to corrective action that should be implemented by both OCL and One Sky:

Required Corrective Action re: Options

Options is required to submit corrective action regarding each of the following issues in writing and submit their corrective action to my attention at CDS within 30-days of receipt. All issues were verbally reviewed as proposed recommendations re: corrective action with Virginia Scully prior to completion of the report.

1) At this time, we do not feel that Rebecca has the judgment to have responsibility for the well-being of a person receiving services. If Options intends to employ or contract with Rebecca in the future, she should be required to repeat all training and that she only be utilized in situations where a supervisor is readily available and she will not be solely responsible for making decisions, until such time she demonstrates her ability to use sound judgment.

2) Options needs to ensure that all staff and providers have current policies and procedures on hand by 1-21-05, as agreed by Virginia Scully on 1-1 3-05. Also, Virginia stated that from now on, all new providers will have received the policies and procedures prior to providing services when they have Orientation, and Orientation and policy/procedure distribution will be documented for the record. Options is expected to provide CDS with a copy of the Orientation form to be utilized and the practice/policy that Resource Coordinators will reference in complying with the documentation expectation.

3) Virginia Scully reported that she will follow up with the Answering Service agency regarding the messages that Rebecca requested be forwarded to the nurse on 12-18-04. The message log states that the messages were received and forwarded. Options needs to address the issue and determine what happened if possible, and propose corrective action that will eliminate the same mistake occurring again.

4) In this situation, the provider who was under contract admittedly consumed alcohol to the point of intoxication. Options needs to advise CDS how they communicate their expectations regarding the consumption of alcohol and use of illegal substances to their providers and any other support personnel under contract.

5) Options needs to ensure that their Nurse Trainer trains staff and providers in accordance with He-M 1201; that the Nurse observes providers/staff administering medication as part of their initial authorization and any re-authorization to administer medication.

Recommendation re: CDS

It is recommended that CDS consider developing a policy/practice for provider agencies to reference regarding steps to take and issues to consider in the event of the death of a consumer. The practice may be to utilize a form that would address the following issues:

Specifically who contacts whom; Who takes responsibility for determining whether there will be someone appointed over estate, especially if there is a public guardian; Who would have authority to authorize/approve cremation or burial; Who will pack up personal belongings and when and where they will be stored until the question of the estate is resolved; How cash on hand and bank accounts should be handled; Who is allowed to access/remove any medications and client records, specifically addressing for providers/staff whether they can turn medications and/or records over to public officials i.e. police/fire/medical examiner; Utilizing a form for the provider/staff to have public officials sign if they remove confidential information or personal belongings; and Advising providers/staff to request that community officials provide identification, and asking the staff/provider to document the information or obtain a business card for follow up purposes of the provider agency or CDS.

D. Bureau of Developmental Services Investigation conducted by a multidisciplinary team consisting of legal counsel from the Office of Client and Legal Services, a registered nurse, and area agency liaison from the Bureau of Developmental Services.

The Bureau of Developmental Services conducted an investigation and issued a report. However, the DHHS erroneously takes the position that its Bureau's report is privileged from disclosure even when requested pursuant to the DRC's federal protection and advocacy powers. This position is in violation of federal law.[4]

The Bureau provided the secondary information that went into its report. And it also provided a disclosure of what acts the Bureau took in response to the Ms. H matter to reduce the likelihood of similar deaths. The Bureau also provided citations to regulations that were changed since the Ms. H matter, changes that were designed to improve the level of care (though not in direct response to Ms. H's death). This latter disclosure is discussed in section VII below.

E. Consultant Carol Walsh's Expert Report

The DRC retained Consultant Carol Walsh to review whether Ms. H's providers adhered to accepted standards, whether their failings, if any, contributed to Ms. H's death, whether there were any safeguards that could have prevented Ms. H's death, and the possible role of medications in Ms. H's death. The report is attachment A.

[4] 45 C.F.R. § 1386.22

Ms. Walsh reviewed the records the DRC had obtained regarding Ms. H's condition leading up to her death. A detailed recitation of the facts and the One Sky investigation are provided in Ms. Walsh's report. Ms. Walsh stated the following regarding the concerns raised by Ms. H's death and the follow up investigation by One Sky.

> The bulk of the investigation report describes the events most immediate to VH's death and persons responsible for rights violations. The immediate concern appears to have been Ms Aylward's activities just prior to and after the death of VH. While her activities were not laudable, the downward decline of VH, documented for well over one year, placed Ms Aylward in a situation far beyond her abilities. Moreover, physician evaluations in the past identified VH's needs as more consistent with nursing facility care than a home situation with a young single mother with two young children. The constant emphasis on VH's mental illness as the etiology of her complex presentation precluded identification of multiple clinical signs and symptoms that warranted further medical, not psychiatric, evaluation. For example, VH was diagnosed with "drug-induced Parkinsonism". There was no medication prescribed for this. VH presented with several episodes of "freezing" and apparent movement problems described by Ms Pare as "CP". This consultant makes note that there is no condition of intermittent cerebral palsy. This information does not appear to have been transmitted to any of VH's medical care providers. Moreover, emergency room care of a combative and psychiatrically impaired woman would not provide the comprehensive evaluation this woman needed. It appears that VH was never referred to a neurologist for evaluation. It is apparent that VH was treated for osteoporosis, with attendant increase for fracture risk, as she was prescribed Evista and Actonel, medications used to treat osteoporosis. The prescription of such medications was neither identified by diagnosis nor in any notes provided to this consultant.
>
> VH was prescribed multiple medications and, due to her age, was at increased risk for drug side effects or drug-drug interactions. As noted in the "BDS Medication Administration Curriculum II", "…side effects to antipsychotic medications can include…symptoms that mimic Parkinson's disease and are caused by damage to the brain". In the "BDS Medication Administration Curriculum VI", it is written "report all signs of extrapyramidal reactions…to the health care provider immediately…these can include rigid limb movements, shuffling with walking, …and other symptoms".

This consultant identifies the following:

1. The lack of any process to identify persons at high risk for adverse events, i.e., risk management process and identification of possible sentinel events: fall with fracture, hospitalization for lower extremity cellulites, and ER visit for "CP";
2. The lack of a written comprehensive health supports plan;
3. The lack of a process to ensure continuous clinical support by the Nurse Trainer during vacations, etc.;
4. The lack of provision of running and dated progress notes on the part of Ms Pare, RN. The handwritten notes provided were dated 02/01/2005 and source documents not provided;
5. The lack of adherence by Ms Pare, RN, to guidelines for administration of PRN medications outlined in He-M 1021;
6. The lack of clinical sophistication, poor documentation skills, and the assumption of clinical activities incongruent to her role on the part of Ms Pare, RN. Illustrative of the latter are 1) Ms Pare's dismissal of VNA skilled nursing services, a service she was not hired to perform and 2) Ms Pare's activities on 12/16/2004 when she, through phone call only, essentially "ruled out" any process that would summon an emergency response team and took it upon herself to contact the psychiatrist who, through Ms Pare's phone evaluation only, chose to increase the antipsychotic medication. Ms Pare should have advised that VH be immediately taken to the hospital. Ms Pare's activity, bereft of an "eyes on" assessment, was beyond the scope of nursing assessment as outlined in the New Hampshire Nurse Practice Act: "…uses sound nursing judgment based on preparation, knowledge, skills, understanding, and past nursing experience".
7. The lack of continuous case management and on-site assessment on the parts of OICL and the Region and the apparent conflict of interest of Sara Durant's continued involvement in the case.

V. Bureau of Developmental Services Response to Breakdown in H's Care[5].

A. Bureau Policy Changes re: Frail Clients in Response to H.

According to the Bureau, "[i]n response to this death the Bureau has requested area agencies to conduct annual reviews of their frail clientele and identifying those individuals to the Bureau. The Bureau's registered nurse conducts sight-reviews of selective number of individuals identified as having frail health issues to help insure that all issues are adequately addressed."

[5] In response to the DRC's request for all actions taken in response to the Death of Ms. H, the Bureau also indicated that it has implemented other statewide action to generally improve the quality of care provided to individuals. The Bureau provided some citations. These types of general developments is beyond the scope of this report.

B. **Sentinel Event Policy and Protocol**

The Bureau further stated that since Ms. H's death, "the Division of Community Based Care Services [of DHHS] has initiated a Sentinel Event Policy and Protocol to be informed of untimely deaths and other significant events. The protocol has been evolving since 2005 to refine the information collected and the Division has developed a framework for a Root Cause Analysis and Action Plan in response to a Sentinel Event." The Bureau provided a copy of the Sentinel Event Protocol.

According to Ken Nielson, Esq. of the Office of Client and Legal Services, the Sentinel Review Policy and Practice was created in response to the investigation he conducted into VH's death with others at the Bureau of Development Services. As noted above, DHHS has refused to turn over the investigation report to DRC. One Sky's Executive Director, Bob James, has also stated that the Sentinel Review system was created in response to Ms. H's death.

While DRC has not seen the investigation headed up by Attorney Nielson, these administrative and policy changes will (and have) discouraged, if not precluded investigations at the Bureau/DHHS level. Reviews serve somewhat different purposes and are by their nature quite different and less thorough and rigorous. While sentinel reviews of serious incidents and deaths have value, they are not substitutes for Department/Bureau level investigations. DHHS has also taken the position that the sentinel reviews are not open to the public, and as noted will not provide the Nielson investigation. These factors, coupled with the manner in which the sentinel review policy was developed raises concerns. It is not clear whether there has been an improvement in oversight and accountability in this regard as a result of Ms. H's death. It should also be noted that the Bureau of Elderly and Adult Services, the other unit within the DHHS that conducts abuse and neglect investigations does not conduct investigations when the victim dies as a result of abuse and neglect.

DRC will therefore conduct a follow up review to determine the value and effectiveness of the Sentinel Review policy and practice.

VI. <u>One Sky's Response to Breakdown in H's Care.</u>

One Sky's changes in its operations after Ms. H's death followed the Bureau's directives. The Bureau required One Sky to: (1) review all OCL individuals in frail health, to list all nurses and obtain documentation from them regarding the medical status of all frail individuals served by One Sky; (2) identify by vendor all individuals in frail health served by One sky; (3) review the Individual Service Plans (ISPs) of all individuals in frail health served by One Sky to identify unresolved treatment issues (document results); (4) assess health and safety of all individuals served by OCL; (5) document all monthly visits to OCL by One Sky service coordinators and OCL residential coordinators; (6) provide documentation that all nurses who conduct training of unlicensed staff have been trained as "nurse trainers", (7) provide the Bureau with copies of newly developed ISP process, progress note forms, and service coordinator checklists.

One Sky has also indicated that it took the following major steps: (1) One Sky staff visited all OCL homes to assess the health and safety of consumers; (2) One Sky (along with all area agencies) evaluated the condition of every frail individual; (3) One Sky added a nurse to its staff; (4) One Sky developed numerous new procedures, policies and reports; (5) One Sky imposed actions plans and reviews upon OCL; and (6) One Sky repaid $35,000 in Medicaid and $2,500 in fees.

One Sky diligently and aggressively followed up on the complaint investigations requirements as to OCL. One Sky further conducted a complete review of OCL's operation. A March 8, 2005 letter by One Sky addresses the following issues: (1) improving the working relationship with OCL ; (2) improving responsiveness; (3) transparency: (4) recruitment and training of new home providers; (5) thorough orientation and training of new staff (both general and client specific information); (6) improved monitoring and support for home providers; (7) greater vigilance on behalf of people with complex health/support issues, including systematic follow up of physician orders beyond medications. It is unclear the extent to which OCL met these requirements. One Sky followed up on these issues with a management review of OCL. After noting improvement and detailing factual findings, the review provides a section of continuing areas of concerns. Ultimately, on October 31, 2005, One Sky informed OCL that it would not renew its contract upon expiration. The OCL clients were transferred to an organization known as "LISS."

VII. Findings, Conclusions and Recommendations

A. Findings and Conclusions

1. There was a failure to identify a person at high risk for adverse events. There was an utter lack of health care oversight by properly trained professional and direct-support staff.

2. There was a failure to provide Ms. H with a written plan for comprehensive health supports.

3. There was a failure to provide a process to ensure continuous clinical support to Ms. H by the Nurse Trainer during vacations, etc.

4. Nurse Pare failed to provide adequate running and dated progress notes.

5. Nurse Pare failed to adhere to He-M guidelines for administration of PR medications as required by He-M 1201.05 (e)(1).

6. Nurse Pare lacked clinical sophistication and documentation skills.

7. Nurse Pare assumed clinical activities incongruous with her role, such as her

dismissal of VNA skilled nursing services and ruling out the summoning of emergency response personnel the day before Ms. H died.

8. One Sky and OCL failed to provide continuous care management and on-site assessment. The contract with Ms. Aylward was a conflict of interest given that her sister was OCL Coordinator Sara Durant.

9. There was at best, a silo mentality between each responsible entity, a lack of coordination and no oversight. They were not considering the system as a whole to ensure that Ms. H was receiving the care she needed. The Bureau only contracted with One Sky for Ms. H's care and took no further responsibility. One Sky only contracted with OCL for Ms. H's care and took no further responsibility. OCL in turn contracted with Ms. Aylward, an unskilled and untrained young woman with significant childcare responsibilities, and provided little support or oversight. The hospital staff, physicians and nurses also took a limited view of their role. As a result, there was a breakdown in overall care for Ms. H.

10. One Sky recommendations for itself and requirements for OCL only provide narrow solutions, such as requiring that Ms. Aylward not continue as a provider, ensuring that answering service messages are received, ensuring that Nurse Trainers adhere to He-M 1201, and providing policies and expectations. These changes, while useful, are not systemic. They fail to address the lack of responsibilities taken by the area agency and its contractors, the failure to provide consistent nursing care (in either a home or a through VNA) to Ms. H as recommended by her physicians, the placement of Ms. H with an utterly unqualified care provider, and the failure of the system to monitor Ms. H during her placement.

B. Recommended Corrective Action.

1. DHHS/BDS and One Sky should review and revise as necessary their current system(s) of service coordination and clinical monitoring and oversight to ensure that individuals in the DHHS and Area Agency system are receiving the appropriate level of care consistent with best practices. This should include in particular a review of whether the systems include adequate provision of comprehensive health plans for individuals who have significant or complex medical and health issues.

2. DHHS/BDS and One sky should review, and revise as necessary, their policies and practices relative to housing placement or transfer of individuals particularly with significant and/or complex health and/or behavioral needs to ensure that the proposed environment is designed to meet the individual's needs and the

personnel are trained, supervised and supported to provide service and care in accordance with the individual's health as well as other needs.

2A. It is recommended that DHHS/BDS utilize an outside consultant, not connected with the system to conduct the reviews specified in 1 and 2.

3. DHHS/BDS should strongly consider adopting an objective assessment instrument, such as the Supports Intensity Scale (SIS), to determine level of need and services for individuals in the DHHS/AA systems. This has been under consideration by BDS and was the subject of deliberation by the SB 138 committee. Although it was not voted on by the committee, the proposal was well received.

3A .DHHS/BDS incorporate as part of their quality assurance and contract monitoring of Area Agencies whether the policies and practices subject to 1,2, and 3 above are being carried out effectively on an ongoing basis.

4. Reiterating recommendations from Renewing the Vision (Section III (G)) (2001) and the Governor's Commission on Area Agencies (2005), DHHS/BDS should promote and as appropriate require that there be a variety of community housing options and supports available, to include options for persons with more complex medical and behavioral needs.

Note: Increased options create more choice, allow for needs of all individuals to be met, and prevent resorting to more restrictive settings, such as nursing homes. Despite the recommendations, from Renewing the Vision and the Governor's Commission, there have not been explicit top down strategic efforts to increase options. While the enhanced family care model may be appropriate for many individuals, for those whom other options are needed like Ms. H., financial considerations continue to discourage development of other models.

5. There must be a system of identifying which clients are in need of a guardian or an independent advocate to ensure that they receive a guardian and/or advocate in a timely manner. Many of the failures that resulted in Ms. H's death might well have been avoided if a competent guardian or advocate were in place to advocate her interests.

6. Physicians should consider the long term effects of psychiatric drugs prescribed to elderly individuals who are at a heightened risk of adverse side effects and drug interactions. Physicians should explain to individuals the benefits and risks of such quantities of medications in combination.

6A.DHHS/BDS should consider performing a study of the use of psychiatric drugs on

clients served by the DHHS/BDS system.

7. The systems of hiring, supervising and evaluating staff (both direct support and professional staff) at the provider and area agency levels must be improved so that qualified and competent people are hired and retained and unqualified people are not. Reiterating recommendations from Renewing the Vision (Section III (G)) (2001), the Governor's Commission on Area Agencies (2005), and the SB 138 Committee Reports (Work force report generally and Quality Improvement Report), this should include education and training and improved salary and benefit levels.

8 DHHS/BDS should reinstate its investigation capacity so that there is a state level investigation of deaths that arise from suspicious or unusual circumstances, to include investigations when there is reason to believe that abuse or neglect contributed to the death. The SB 138 Committee already recommended effective July 2010, that abuse and neglect investigations conducted at the area agency level be transferred to the DHHS/BDS. With a more robust investigative capacity at the DHHS/BDS level, sound practice would warrant that full death investigations be conducted at that level. Sentinel reviews could still take place, but would have the benefit of full investigations.

9. DHHS should adopt more transparent policies in regard to release of state Investigation and sentinel reviews, access to which has been blocked in this matter. These reviews by their nature are not internal quality assurance products and therefore should be available, redacted as needed. They are reviews of external agencies. Principles of transparency and good management (to help ensure corrective action) warrant more transparency.

Appendix A

CONSULTANT'S REPORT

NAME VH

DOB 09/20/1934 **DOD** 12/18/2004

REASON FOR CONSULTANT'S REVIEW

Ms Hutchison (VH) was a 70 year old woman with major mental illness and mild cognitive impairment who expired unattended in the home of Rebecca Alyward, a 20 year old mother of 2 young children. Ms Aylward was contracted through Options for Independent Community Living (OICL) to provide residential supports to VH. The death occurred less than two months after VH's move to Ms Aylward's home. This case was brought to the attention of attorneys at the Disability Rights Center, Inc., who contacted this consultant for case review.

CONSULTANT'S QUALIFICATIONS

This consultant is a nurse practitioner with 30 years of experience in the field of cognitive and other developmental disabilities. This consultant has provided consultation to the United States Department of Justice and the Massachusetts Department of Mental Retardation Investigations Office regarding the provision of quality medical care to persons with cognitive and other developmental disabilities. This consultant has provided primary care and clinical consultation and developed clinical and educational programs for persons with disabilities, their families, professional, and support staff

QUESTIONS POSED BY JAMES FOX, STAFF ATTORNEY, INCLUDE:

1. Whether and, if so, to what extent any of Ms. H's care providers (at all levels) failed to adhere to accepted standards of care;
2. Did the failings cause or contribute to Ms H's death;
3. Related to the first question if there were failings, what were causes or contributing factors? For example, were there problems with the residential model, staff qualifications, supervision or training or deployment, etc.?
4. Whether there are any safeguards that could have been utilized to help protect the situation that resulted in Ms H's death.
5. The possible role medication(s) may have played in the death?

6. Possible issues of recruitment and hiring of qualified persons, especially for those individuals with complex health needs.

SOURCES OF INFORMATION

Internal and external investigative reports; copies of email communications between relevant parties involved in or investigating the event; a chronological summary of medical\health events prepared by Valerie Pare, OICL Nurse Trainer; copy of guardianship request; OICL's "Organization and Policy Guide" and "Emergency Procedures and Medical Emergency Plan"; rules regarding ADMINISTRATION OF MEDICATIONS He-M 1201 and Medication Administration Pursuant to He-M 1201; copies of relevant ISP's; copy of Milton, New Hampshire police report, website of the Board of Nursing, State of New Hampshire.

SIGNIFICANT PARTIES RELEVANT TO THE EVENT

Rebecca Aylward (or Staples), home provider; Valerie Pare, RN, OICL Nurse Trainer; Sara Durant, case manager, OICL.

BACKGROUND INFORMATION

Full details of past history were not available. From information available to this consultant, VH had previously been hospitalized at Danvers State Hospital and had a history significant for major mental illness. Prior to her move to Ms Alyward's home, she had resided for 10 plus years with another home care provider. That living situation was reportedly terminated due to health issues of the home care provider and VH's declining health and ambulation issues that are described later in this document.

Diagnoses included chronic schizophrenia, mild mental retardation, drug induced Parkinsonism, hypothyroidism, and bladder control issues. Medications listed at time of death included ferrous sulfate 325 mgm by mouth; Trazodone 50 mgm by mouth; levothyroxine 0.1 mgm by mouth; Abilify 20 mgm by mouth (with additional PRN order to be discussed later in this document); Evista 60 mgm by mouth; Actonel 35 mgm by mouth; zinc sulfate 220 mgm by mouth; oxybutynin 5 mgm by mouth.

Of significant concern to this consultant are the repeated notations regarding the decline in VH's medical and psychiatric status and functional abilities prior to her move to Ms Alyward's home on 10/24/2004:

- In an email communication from Joyce Butterworth dated 02/14/2005 it was noted that Dr Brieholtz (psychiatrist) had on two occasions "mentioned…that VH was a good candidate for a nursing home", most recently on 04/26/2004 when "he wrote that VH would meet criteria for PASSAR for a nursing home, her condition would only worsen over time".

- In the “Annual Update” of the ISP of March 30, 2004, it was noted that”… Marie [home care provider at the time] has…defiantly notice [sic] over the past year a decline in Ginny’s memory and being able to complete ADL’s. On December 13, 2003, Ginny went to Exeter Hospital Emergency Room because she had a piece of meat that would not dislodge. She had an upper endoscopy to remove to remove the piece of meat”. Diet was changed to ground or puree to prevent choking.

- According to the document prepared by Valerie Pare, RN, VH fell on 8/18/2004 and was taken to the ER where diagnosis of fracture of the calcaneous (foot) was made; a boot was applied the next day. In-home VNA services were requested.

- Rockingham VNA documentation of 09/2004 include PT note of 09/21/2004 “…advised Marie that VH needed wheelchair van transportation for medical appointments...difficulty with transfers…non-weight-bearing and at wheelchair level of function”. Ms Pare noted issues with skin integrity, swelling, and redness of the “LE”. On 09/21/2004 Ms Pare wrote: “I took pt to vascular surgeon and started on Augmentin for cellulitis” and on 09/24/2004 wrote “Provider tells me LE edema redness increasing….I took to ER…was admitted until 09/28”.

- According to VNA notes, case manager at Exeter Hospital ordered “…resume skilled nursing, physical therapy, occupational therapy, and social worker visits” upon discharge. In another 09/28/2004 VNA case communication note, Tracy Colburn, RN, called to schedule a skilled nursing visit and spoke with “Valerie at OICL”. [Please note: notes transcribed in bold are as found in VNA communication notes.] It was written: “**Valerie stated she was in VH’s home and that there was no need for skilled nursing,** just therapies because Valerie is going to see VH every day”. Note of 10/1/2004 stated: “…OT called twice to caregiver Blair to…request visit on Sunday to resume therapies….so far there has not been any return call”. On 10/04/2004 note written as follows: “…OT called OICL to schedule a visit…**Sarah stated that VH is currently at her premorbid level of care and does not require further OT services”.** A 10/02/2004 noted that “…**Sarah at OICL stated she wanted to hold PT visits…”** and that “**Sarah stated that she felt that a social worker was not needed as these services are being addressed through OICL**”.

- By 10/12/2004 it was noted that visits were being refused by caregiver and the “MD was notified”. On 10/13/2004 the PT “…spoke with Valerie at OICL during the visit. Valerie was able to inform PT of findings of orthopedic visit on 10-7-04”. On 10/19/2004 note stated: “**RVNA skilled nursing visit added per Dr Braese** to assess skin integrity- open wound to left leg**.** Valerie from OICL arrived during

visit and stated it looked improved from when she saw it **last week.** RVNA planned for another visit to assess and treat VH's wound". Further visits and evaluations were not completed and VNA later learned that VH had moved out of the service area. [On 10/31/2004 there was a signed order from Dr Braese (PCP) certifying that VH was in need of skilled nursing care, physical therapy and/or speech therapy or continues to need occupational therapy. Diet ordered for ground meat". There was no documentation as to any follow-up regarding these orders post move].

- A respite stay with a possible new home care provider was attempted post discharge but ultimately VH's needs were felt to be too great.

- In notes provided by Ms Pare, it appeared that Ms Pare would "…pick up [VH] each am at respite + brought with me during the day" from 10/01/2004 through 10/21/2004. Evidently Ms Pare was not aware of the choking risk and orders for "ground meat" as she provided, at VH's requests, "frankfurter on roll…or fried clams".

- Ms Pare accompanied VH to a psychiatrist visit where Ms Pare described apparent paranoia and delusions; Abilify was increased from 10 mgm/day to 20 mgm/day. On 10/22/2004 Ms Pare wrote that "Blair call [sic] me in early am that client is having CP…and told respite to call 911. I met them in ER and when I got there pt claimed her CP was gone". According to Ms Pare's notes, VH was swearing and refused examination. After being given a piece of cake, VH allowed some examination and was returned to the respite home.

- In an email communication from V Scully, OICL, dated 10/25/2004 it was noted that VH would be moving on 10/25/2004 to the home of "Rebecca Staples" who had "met Ginny on a number of occasions and has three years in the field". From information available, there had been issues regarding the need for increased funding due VH's "irreversible medical conditions".

- VH did not receive day program services, although the need was mentioned.

From the information outlined above, it is clear that VH had experienced multiple and significant changes in the nine weeks prior to her move:

- 08/18/2004: fracture of right foot;

- 9/21/2004: hospital admission for right lower leg cellulitis;

- 10/2008: increase of Abilify from 10 mgm to 20 mgm by mouth every day due to change in psychiatric presentation;

- 10/22/2004: trip to ER for apparent movement disorder; described by Ms Pare as "CP".

On 10/29/2004 Ms Pare "asked Sara how they were doing". Ms Pare was told, according to her notes, that "…she was walking much better, more articulate" and that "LE…were [sic] dry and intact". According to information included in the Complaint Investigation Report dated 01/19/2005 and prepared by Sharon Richey, QI/Rights Investigator, Sara Durant had informed Ms Aylward of VH's mental illness and incontinence issues. As Ms Durant was the sister of Ms Aylward, the case management was transferred "to avoid any conflict of interest". Ms Durant reported that she had further contact with VH but "only on a personal basis when visiting". She "observed VH to be happy and doing very well". Ms Pare noted that she was out of the country on vacation from 11/4/2004 to 12/01/2004. There is no documentation as to presence or oversight of any other nurse trainer during Ms Pare's absence. According to the "Complaint Investigation Report" "…Terry Lyons was covering her caseload and had not been contacted about V" and evidently was not aware of any need to visit the home.

From the notes provided by Ms Pare, it appears that she had little, if any, on-site or physical contact with VH after 10/23/2004. This consultant was not provided with any written documentation of identified health supports and needs and will assume such was not provided to Ms Aylward to assist her in VH's care.

In a document prepared by Carlos Chavez, OICL coordinator, dated 01/28/2005, he noted no contact with VH and the home care provider until 12/09/2004. He mentioned that after conversations with Sara Durant who "had stopped by a few times in November" and with Ms Aylward that "I could do my first home visit…at our 30 day meeting scheduled for December 9th". He stated that he contacted Ms Aylward to "let her know about some of Ginny's upcoming doctor's appointments: November 5th with Dr Ameglio, Orthopedic; November 9th with Dr Smyd, Entomologist [endocrinologist]; November 11th with Dr Troxil, Urologist. Rebecca was able to accompany Ginny to all of these appointments without my assistance…I went to Ginny's hearing on December 11th ….where Ginny was approved for public guardianship".

From the information outlined above, it is clear that VH had experienced multiple and significant changes in her medical and psychiatric status prior to her move on 10/25/2004. It is also clear that staff of OCIL refused the on-site services of the VNA despite medical orders and did not provide the VNA relevant information regarding VH's move to a new home provider.

CHRONICLE OF EVENTS PRIOR TO DEATH

On 12/10/2004 Ms Pare wrote that she was contacted by Mike (apparently OICL Program Coordinator) to inform her that "Bekka was having increased problems with incontinence" (it is apparent she was referring to VH). Ms Pare wrote that she had discussed incontinence issues with Ms Aylward, despite the latter's insistence "she wasn't told". The toileting program, ordered as "every two hours" by the urologist, was described by Ms Pare as "when 1st wake up, after breakfast, before and after lunch, before and after dinner, and before bed". On 12/13/2004, Ms Pare "called Rebecca and she stated that Ginny was doing better and was waiting for an appointment for H&P".

On 12/16/2004 Ms Pare wrote that she was contacted by Ms Aylward who told her "Ginny had a gone out of this world look and that she was weak". Ms Pare further wrote that she asked Ms Aylward "if there was any unilateral weakness, facial dropping, c/o CP or headache, slurred speech, or increased drooling". Ms Pare also spoke with VH and asked if she was "okay". VH replied in the negative. Ms Pare described whispering on the part of VH and her concerns about being "followed to New Hampshire" and the statement "They told me if I don't eat or drink they won't take me out of New Hampshire". Ms Pare then wrote that she called "Brieholtz who was not in however he was the Doc on call" but who later contacted Ms Pare at her home. Ms Pare wrote that "he stated that it was probably the time of year she becomes more physiotic [sic] and she needs an increase in Abilify from 20 mgm to 30 mgm, even though that was a high dose". Ms Pare further wrote that she "suggested he make it PRN in case there was oversedation *we would be able to use our discretion*" (italics inserted by this consultant). Ms Pare then contacted Ms Aylward and wrote "*I told Bekka she needed to focus on the problem as if it were and acute medical issue; that she needed antipsychotics and fluids. I told her not to bother with food just fluids…as frequently as possible and if there was a decrease in urinary output or urine strong smelling it was a sign of dehydration".* Ms Pare wrote that later that evening "I called Bekka and she stated Ginny was doing a little better after the med." Ms Aylward asked if she could take VH for a ride in the car. Ms Pare wrote that "I told her anything you can do she can do. As long as you have enough fluids". There is no document available to this consultant for the PRN administration of an antipsychotic, its rationale, and parameters for identification of efficacy.

On 12/17/2004 Ms Pare wrote that she "tried to call Bekka during break to no avail. Jane (?) had told me Ginny came to office (Sat in car) that she looked weak, slouched and distent [sic]. I tried to call Bekka after work-no answer". Also on 12/17/2004, according to the "Complaint Investigation Report", Karen McLaughlin, who was covering for the Service Coordinator Michelle Chavez, was contacted by Mike Chavez, OCIL, regarding increase in psychiatric presentation, difficulties with ambulation, "seeming to freeze unless reminded to walk", and reports of voices telling VH not to eat or drink.

There was discussion regarding the need for a “new/improved wheelchair”. Ms McLaughlin also noted that she received a call from Ms Pare regarding ambulation concerns and need for a new wheelchair. “Valerie advised Karen that V was taking fluids and appeared to be doing somewhat better…. Karen advised Valerie that V be evaluated at the Portsmouth Pavilion if she declined or her symptoms worsened.”

According to reports, VH was weak “and slouching” throughout the day of 12/17/2004. Ms Aylward drove VH in her car to pick up her children from day care and noted “it was extremely difficult to get V into the house”. VH was “stumbling” and Ms Aylward allegedly assisted VH to the floor of her bedroom. VH allegedly stated that she wanted to “sleep on the floor”. VH was allegedly not able to give responses to usual questions; Ms Aylward attributed this to “the medications and symptoms she was experiencing due to her schizophrenia”. According to Ms Richey in her report, Ms Aylward had not been given a copy of the OICL “Emergency Procedures and Medical Emergency Plan”.

Ms Aylward allegedly checked on VH at 2 am and noted that “she was breathing, as evidenced by her stomach moving”. There was a power outage and electricity was lost. During this time, Ms Aylward was also reported to be hostess to a gentleman she had met over the Internet and with whom she was consuming alcohol. Sometime around 8:30 AM on 12/18/2004 Ms Aylward found VH still on the floor and not breathing. She reportedly contacted Ms Pare who advised, after some period of time for response, that she call 911. Officers of the Milton Police Department subsequently arrived at the home and called EMT’s. According to the police report, VH had been unable to take fluids and that she was having difficulty swallowing chicken nuggets and French fries purchased at McDonald’s earlier in the day. This consultant is not in possession of the final autopsy report; there was mention in documents of possible “dehydration”.

COMPLAINT INVESTIGATION REPORT FINDINGS

The following violations were found to have occurred:

1. Ms Aylward was found to have violated VH’s rights to be free from neglect; to receive medical treatment in a timely manner; and for violating medication procedures.
2. OICL was found to have violated VH’s rights in failing to comply with health and safety guidelines and ensuring the residence has a written copy of the medical emergency procedures.
3. Valerie Pare, RN, was found to have violated policy requiring Nurse Trainer to directly observe Ms Aylward passing medications.

DISCUSSION

The bulk of the investigation report describes the events most immediate to VH's death and persons responsible for rights violations. The complaints investigator's violations findings focused primarily on Ms Alyward's activities just prior to and after VH's death. This consultant finds that Ms Alyward's actions or inactions on the day before and of VH's death were below acceptable standards of care. However, the role that OCIL's staff played in the totality of this case cannot be underestimated. 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.

Moreover:

- The physician evaluations in the past identified VH's needs as more consistent with nursing facility care.
- The constant emphasis on VH's mental illness as the etiology of her complex presentation precluded identification of multiple clinical signs and symptoms that warranted further medical, not psychiatric, evaluation. For example, VH was diagnosed with "drug-induced Parkinsonism". There was no medication prescribed for this. VH presented with several episodes of "freezing" and apparent movement problems described by Ms Pare as "CP". This consultant makes note that there is no condition of intermittent cerebral palsy. This information does not appear to have been transmitted to any of VH's medical care providers. Moreover, emergency room care of a combative and psychiatrically impaired woman would not provide the comprehensive evaluation this woman needed.
- It appears that VH was never referred to a neurologist for evaluation.
- It is apparent that VH was treated for osteoporosis, with attendant increase for fracture risk, as she was prescribed Evista and Actonel, medications used to treat osteoporosis. The prescription of such medications was neither identified by diagnosis nor in any notes provided to this consultant.
- VH was prescribed multiple medications and, due to her age, was at increased risk for drug side effects or drug-drug interactions. As noted in the "BDS Medication Administration Curriculum II", "…side effects to antipsychotic medications can include…symptoms that mimic Parkinson's disease and are caused by damage to the brain". In the "BDS Medication Administration Curriculum VI", it is written "report all signs of extrapyramidal reactions…to the health care provider immediately…these can include rigid limb movements,

shuffling with walking, …and other symptoms". It appears that neither Ms Aylward nor Ms Pare communicated such to the relevant medical or psychiatric care provider.

This consultant identifies the following:

9. The lack of any process to identify persons at high risk for adverse events, i.e., risk management process and identification of possible sentinel events: fall with fracture, hospitalization for lower extremity cellulitis, and ER visit for "CP";
10. The lack of a written comprehensive health supports plan;
11. The lack of a process to insure continuous clinical support by the Nurse Trainer during his/her absence;
12. The lack of provision of running and dated progress notes on the part of Ms Pare, RN. The handwritten notes provided were dated 02/01/2005 and source documents not provided;
13. The lack of adherence by Ms Pare, RN, to guidelines for administration of PRN medications outlined in He-M 1021;
14. The lack of clinical sophistication, poor documentation skills, and the assumption of clinical activities incongruent to her role on the part of Ms Pare, RN. Illustrative of the latter are 1) Ms Pare's dismissal of VNA skilled nursing services, a service she was not hired to perform and 2) Ms Pare's activities on 12/16/2004 when she, through phone call only, essentially "ruled out" any process that would summon an emergency response team and took it upon herself to contact the psychiatrist who, through Ms Pare's phone evaluation only, chose to increase the antipsychotic medication. Ms Pare should have advised that VH be immediately taken to the hospital. Ms Pare's activity, bereft of an "eyes on" assessment, was beyond the scope of nursing assessment as outlined in the New Hampshire Nurse Practice Act: "…uses sound nursing judgment based on preparation, knowledge, skills, understanding, and past nursing experience".
15. The lack of continuous case management and on-site assessment on the parts of OICL and the Regional Area Agency and the apparent conflict of interest of Sara Durant's continued involvement in the case.

QUESTIONS

Whether and, if so, to what extent any of Ms. H's care providers (at all levels) failed to adhere to accepted standards of care.

Accepted standards for community-based care include the obligation to promote the health and safety of the individual. As described above, all OICL and Regional Area

Agency personnel involved in this case failed to adhere to this standard. Despite repeated evaluations and communications describing VH's decline and "irreversible" medical conditions and need for nursing home level of care, even with concerns regarding safety identified on the day prior to her death, VH was placed and remained in a home care situation that could in no way promote or provide for her health and safety. Moreover, especially problematic to this consultant, was OICL staff's refusal of and lack of identification for in-home VNA safety assessment and ongoing clinician monitoring. Identification of such is not solely within the purview of the nurse. It is likely that had such supports be pursued that VH's issues would have been identified far earlier.

Did the failings cause or contribute to Ms H's death.

Yes. Ms Pare wrote on 12/16/2004 "…I told Bekka she needed to focus on the problem as if it were an acute medical issue". *This consultant stresses that acute medical issues are not cared for in the home*. Moreover, it is clear that Ms Aylward had not been provided with the appropriate information regarding the identification of safety issues, presentation outside of the norm, and the seeking of emergency care. It is unclear to this consultant, who at OICL or the Regional Area Agency was ever identified to Ms Alyward as the person to turn to for questions, support, etc.

While this consultant is constantly referring to deficiencies and concerns regarding the interventions provided by Ms Pare, RN, rather than other parties, it appears that she was the most pivotal person involved and had professional obligations attendant to her licensure that differ from other non-licensed staff.

Related to the first question if there were failings, what were causes or contributing factors? For example, were there problems with the residential model, staff qualifications, supervision or training or deployment, etc.?

As described above, VH's needs were described as multiple. 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. The possible safety net of a day program (where more monitoring and evaluation could be provided) was discussed but never pursued. Due to the various staff changes, transfers, and vacation, it appears that there was no identifiable person in either OICL or the Region who was ultimately responsible to insure VH's safe transition to a new living situation, a transition that should have been identified as needing extensive support and oversight prior to the move. There appears to have been little in the way of

actual fact finding, but rather dependence upon phone calls and third parties for information regarding VH's status.

It is this consultant's expert opinion, that Ms Pare, RN, in her Nurse Trainer and professional nursing role, should have made OCIL aware that VH's needs were beyond those of the residential support model provided to VH as she was well aware of the sentinel events described in this document. In addition, it is unclear to this consultant as to the rationale and appropriateness of the Nurse Trainer, Ms Pare, providing some type of daytime "coverage" from 10/1/2004 through 10/21/2004 while VH was reportedly in a respite situation.

Whether there are any safeguards that could have been utilized to help protect the situation that resulted in Ms H's death.

Risk management strategies and a residential needs check list should have been employed. There was marked change in presentation, a fall resulting in fracture of foot, leg skin breakdown, and an acute care hospitalization prior to VH's move. Had a process for such review been in place, it is likely that VH's residential support needs would have been viewed far differently.

It is clear to this consultant from the documents provided that VH did not have the capacity to provide informed decisions regarding her residential and medical care. It is unclear if the sibling noted had any involvement. Guardianship was only put in place a few days before her death. One may speculate as to a different course of events had the need for a legal guardian and adjudication of such been identified far earlier. Based upon the information provided to this consultant, supportive documentation to seek legal guardianship was available for well over a year prior to VH's death.

The possible role medication(s) may have played in the death?

As mentioned above, elderly persons are at heightened risk for medication side effects and drug-drug interactions. VH had been treated throughout her life for major mental illness and was likely to have been exposed to medications that are very damaging to the nervous system and with long-term effects. It appears from the documents provided, that VH was not taking adequate fluids prior to her death. Lack of adequate hydration could enhance drug side effects and toxicity. Use of oxybutynin and Trazodone can also be problematic with the concomitant use of Abilify. However, also from the documents provided, it appears that VH was experiencing some sort of an acute condition, type unknown, prior to the addition of the PRN Abilify.

Possible issues of recruitment and hiring of qualified persons, especially for those individuals with complex health needs.

This consultant can only address recruitment issues for registered nurses. Recruitment is difficult as the pay is often poor, the population very unique, and previous exposure to such a population limited to non-existent. Job difficulties and burn-out often result due to friction and disagreement between the nurse and non-clinical staff and the type of work itself. Often the nurse is young and inexperienced and is faced with conflicts between good clinical practice and the imperative of community-based living. The nurse may be placed in situations in which he/she is expected to make decisions far beyond his/her expertise. In addition, the fragmentation of care among myriad medical and psychiatric providers, the lack of time spent with patients, and dependence upon unsophisticated care givers make communication and care planning very difficult. It is a sad fact that a population often so needy is most likely to be provided supports by very inexperienced nurses. In the case of VH, the problems were compounded by the presence of a major mental illness for which staff that usually deal with persons with cognitive disabilities are woefully ill-prepared. This consultant recommends that as a first step all registered nurses employed in such situations are given the financial and time expenditures necessary to become certified by the Developmental Disabilities Nurses Association. This association provides peer interaction and education necessary for expertise in care of a very vulnerable population.

I thank you for the opportunity to review this case. Please feel free to contact me with any questions. It is hoped that through analysis and follow-up of this case, significant changes can be promulgated to prevent such tragic situations in the future.

Respectfully submitted by,

Carol Walsh, APRN-BC, MPH

March 4, 2009

CONSULTANT'S REPORT

Addendum : May 10, 2009

As this consultant noted previously in this report, it seemed likely that VH was experiencing some sort of physical malady that exacerbated her psychiatric disorder. From the information available to this consultant, it was also apparent that it was highly unusual for VH to refuse to eat and drink.

Per request, the autopsy report dated February 21, 2005, was provided to this consultant. Of note was the finding of “black tarry stool throughout the colon”. Such a finding is consistent with bleeding within the gastrointestinal tract. This consultant contacted Thomas Andrew, M.D., Chief Medical Examiner for

the State of New Hampshire. Dr Andrew stated to this consultant that such bleeding could only occur prior to death.

Conclusion

Per the above, it is apparent that VH was experiencing a gastrointestinal bleeding event prior to her demise. It is apparent that VH should have been taken to an emergency room for evaluation and that Ms Pare was negligent in assuming that the cause of VH's distress was purely of a psychiatric origin.

Again, thank you for asking for my assistance in this very unfortunate case. Please feel free to contact me with any questions.

Sincerely,

Carol Walsh, APRN, BC, Nurse Practitioner