State of Vermont

Vulnerable Adult Fatality Review Team

2020 Report

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2020 Annual Report

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Dedication

This year we would like to dedicate this report to the many Vermonters who lost their lives to COVID-19 in 2020, and the countless first responders and healthcare workers who worked diligently to serve Vermonters during this unprecedented pandemic.

Introduction

The Vermont General Assembly enacted legislation establishing the Vulnerable Adult Fatality Review Team (the "Team") in May 2016. Pursuant to 33 V.S.A. § 6961, the Team functions under the auspices of the Office of the Attorney General. The purpose of the Team is to examine select cases of abuse and neglect related fatalities and preventable deaths of vulnerable adults in Vermont to:

- Identify system gaps and risk factors associated with the deaths;
- Educate the public, service providers, and policy makers about abuse and neglect related fatalities and preventable deaths of vulnerable adults and strategies for interventions; and
- Recommend legislation, rules, policies, procedures, practices, training and coordination of services to promote interagency collaboration and prevent future abuse and neglect related fatalities.

The Team achieves this purpose by bringing together members from multiple disciplines, who work with vulnerable adults, to share their experience and expertise. Together, the team reviews cases. The Team's purpose is not to place blame on one agency or department, but to work together to identify deficiencies and make future recommendations.

Team Members

The multidisciplinary Team consists of members representing State and private entities and associations. The Team is comprised by the following members:

- Elizabeth Anderson, Office of the Attorney General (Co-chair)
- Virginia Merriam, Office of the Attorney General (Co-chair)
- Bard Hill, Department of Disabilities, Aging and Independent Living
- Joy Barrett, Department of Disabilities, Aging and Independent Living
- Scott Dunlap, Department of Public Safety
- Lauri McGivern, Office of the Chief Medical Examiner (Vice-chair)
- Shawna Mead, Department of Disabilities, Aging and Independent Living Adult Protective Services
- Tanya Wells, Vermont Department of Health
- Rhonda Williams, Vermont Department of Health
- Sean Londergan, Long-Term Care Ombudsman
- Nietra Panagoulis, Victim Advocate, Chittenden Co. States Attorney
- Rose Hill, MD, University of Vermont Medical Center
- Ed Paquin, Disability Rights Vermont

- AJ Ruben, Disability Rights Vermont
- Devon Green, Association of Hospitals and Health Systems
- Jill Olson, Visiting Nurses Association
- Cindy Bruzzese, Vermont Ethics Network
- Donna Benway, University of Vermont Medical Center
- Ursula Margazano, Gifford Health Care

2020 Activities

This is the fourth report for the Vulnerable Adult Fatality Review Team. During the year, the Team did an in-depth review of one case. Although the Team had originally planned on reviewing two cases, COVID-19 restrictions reduced this to one, in-depth case review. The Team met on January 14, 2020, in Burlington at the Department of Health to recap the prior year and to finalize our mission for the 2020 sessions. The Team met again on March 10, 2020, in Waterbury to hear presentations from Amy Roth, Assistant Director for DAIL, Developmental Services Division on the Vermont service model that provides care to Vermonters with Intellectual Disabilities (ID) and Developmental Disabilities (DD) and Karen Barber, General Counsel, for the Department of Mental Health (DMH) on the service delivery system for individuals who have a mental health diagnosis. The Team then met on June 30, 2020 via Microsoft Teams to give an update on the Team's plan to move forward with case reviews via Microsoft Teams. Finally, the Team met on September 29, 2020 and November 10, 2020, via Microsoft Teams, to complete our case review and develop our recommendations.

The Executive Committee continued to meet on a weekly basis (with some exceptions) throughout the year.

Recommendations

The Team would like to acknowledge the work of the many dedicated and compassionate Vermonters who support our vulnerable Vermonters. Vermont is proud of its belief in self-determination and has led the country in its philosophy of community-based services. While most individuals in Vermont are served successfully, our recent case review revealed that there is a small segment of individuals, who have very complex needs, for whom the current system has failed to adequately provide care within a least restrictive yet safe setting.

We recognize the need to increase the capacity to provide high quality community-based services, both in terms of training and retaining staff who are committed and qualified to carry out the work needed to help support people with all manners of disability-related behaviors, including those manifesting with the most intensity. The mission of the Team is to help identify any systemic issues that could use improvement so that no Vermonter is left underserved.

For our in-depth case review, the Team focused on the untimely death of a young adult who was being served within a developmental services program in Vermont. Resident 1 (R1) was a 22-year-old with a medical history of autism spectrum disorder, obesity, and anxiety, who was

found deceased in bed in 2017. R1 had self-injurious behaviors, aggression towards others, a limited ability to communicate and an extensive history of property damage. At the time of RI's death, R1 resided in a Shared Living Provider (SLP) home, overseen by Lamoille County Mental Health Services (LCMHS), with around-the-clock care which included a 2:1 staffing ratio.

R1's death was investigated by Vermont State Police (VSP), Adult Protective Services (APS), The Medicaid Fraud & Residential Abuse Unit (MFRAU), the Office of the Chief Medical Examiner (OCME), Disability Rights Vermont (DRVT) and the Department of Aging and Independent Living (DAIL) Developmental Disability Service Division's (DDSD) Quality Management Team.

R1's cause of death was listed as Bronchopneumonia complicating tracheobronchitis of probable viral etiology. The manner of death was ruled as natural. The records indicate that R1 had been exhibiting signs and symptoms of a cold and cough for 4 days prior to R1's death. No medical assessment or treatment had been sought.

According to the care plan, R1 had limited communication skills (echolalia) and required significant support communicating their wants and needs appropriately. R1 reportedly became very frustrated when trying to communicate, particularly if R1's caregivers were unable to understand them. Support included consistent verbal cueing, prompting, patience and encouragement. R1 also could use picture prompts but generally would point at what they wanted. When R1 was in school, they used a computer and worked with a communication device.

The Team learned R1 had lived at home, being cared for by their biological family, for much of their life. At some point, the care became too much for the family (additional younger siblings) and R1 moved into a SLP home with a long-time staff person who worked with R1 at school. This provider had been working with R1 for an extended period of time and was very familiar with R1's behaviors. This placement lasted for more than five years.

When this placement ended, R1 was moved to another SLP where a slow transition plan was put in place. This unfortunately, ended quickly due to the level of their needs and the significant physical damage they caused. R1 was placed at the only state crisis program, Vermont Crisis Intervention Network (VCIN), for approximately one month before being placed in a home with a SLP in Washington County. The housing model at the latter home included an attached living space and a 2:1 staffing ratio. The moves, new staff members, and disruption of R1's normal routine were a difficult adjustment for R1 and their clinical team at LCMHS saw an increase in the intensity of their behaviors as R1 became more de-regulated.

This de-regulation manifested in extreme violent outbursts which resulted in one staff person sustaining a concussion and R1 causing significant property damage including repeatedly pulling the toilet out from the floor. R1's clinical team at LCMHS made numerous attempts to work with R1 and the immediate team, even bringing in external clinical services from Amici Associates, who were located in close proximity to R1's home. (Given the level of care required to serve R1, finding a SLP placement was extremely difficult. While not ideal, the location of the

home in Washington County was more than 30 miles from the agency requiring additional travel time for staff).

The records indicated the SLP had a history of delinquent paperwork, including documentation of medications, and inconsistent cooperation with the clinical team. This included a lack of documenting and tracking progress of R1's monthly ISA goals, important data for the clinical team to review. R1, who had developed behaviors around the consumption of food as a self-soothing behavior as a child, in one month consumed more than 138 boxes of macaroni and cheese. R1's weight gain and water retention from the salty foods was so significant that their new shoes no longer fit. The LCMHS records noted concerns that the SLP was working too many hours, resulting in a lack of rest, and not accepting help. Additionally, the SLP reported spending an exorbitant amount of money, between $1,000-3,000 per month, on food in an attempt to mitigate R1's behaviors (although this was not supported by the clinical team).

The Team heard from staff at LCMHS who recognized that this placement was not ideal, however, there were no other options available for R1. The LCMHS team put together the most comprehensive plan they could while continuing to look for a different living arrangement.

The Team's mission is to review these tragic events and identify ways to improve the system of care for individuals with disabilities within our state. The VAFRT has identified resources and recommended actions, which, had they been available to LCMHS and R1, could have mitigated some of the concerns identified.

1) Creation of Plan to Improve Augmentative Communication Services: The Vermont Communication Task Force has been working to address the limited Augmentative Communication Services that are available in Vermont. At present, there are only two individuals within the State who provide facilitated communication services to the Vermonters who need these services. The Team believes that with more communication options, R1, may have been able to express their needs more effectively than they did. Given the likelihood of trauma caused by life changes, including loss of or changes to previous relationships (such as family and prior SLP), R1's inability to effectively communicate likely contributed to this dysregulation. Additionally, improved communication supports may have increased the likelihood that R1 could have expressed when, and if, they were feeling unwell in the days prior to their death (the LCMHS team reported R1 exhibited signs of illness for days leading up to R1's death).

We recommend DAIL, in collaboration with the Vermont Communication Task Force, propose a specific and measurable plan to expand the capacity to provide those who would benefit from it with more robust support from professional specialists, including both behavioral support specialists and communication specialists. This includes expanded capacity to provide and train staff in facilitated communication and other augmentative communication services to aide in understanding and addressing the support needs of people with complex behaviors and communication barriers. Whether implemented on a local, regional, or statewide basis, we believe this initiative will help local direct care staff to understand and address the needs of the people they serve more effectively, especially the population similar to R1 that are most at risk.

2) Utilization of Trauma Informed Services: Making sure that trauma-informed practices are a regular part of treatment for individuals who have developmental disabilities and who also have experienced trauma. The Vermont Clinical Training Consortium has been addressing this and does statewide training to Designated Agencies (DA's). We recommend that the State add more evidence-based training standards and requirements for DA and SSA staff to improve the use of trauma-informed practices. We also recommend that DAIL pursue a dedicated staff resource to support evidence-based training standards to ensure that DA's are following best practices.

3) Improved Crisis and Clinical Support Services and Service Delivery: R1 exhibited extremely challenging behaviors which generally required 2:1 staff support. When R1 left this long-term placement, R1 stayed a short time in a new SLP home and then was transitioned to VCIN. VCIN is the only emergency crisis bed in Vermont to support individuals with an ID/DD diagnosis. LCMHS team members reported R1 spent a month at VCIN, which is considered a long-term placement. During the uptick in R1's behaviors, while in the SLP placement, there was no place for R1 to go to reduce the stress level of the staff members and to give R1 a place to be safe and regulate.

DAIL has entered into a Request For Proposal (RFP) process to identify a provider who could offer a transitional residential care option. The model proposed by DAIL would serve 2 to 4 people, providing longer term clinical and crisis "transitional" residential services to individuals with an ID/DD diagnosis. This would be staffed 24 hours per day and have access to clinical support. The Team supports DAIL's proposed RFP. The Team believes this is crucial and needs to encompass a statewide network that is adequately prepared and resourced to provide the types and levels of professional and academic expertise to respond to people with ID/DD and co-occurring conditions experiencing crisis, mental health crisis, housing dislocation, and other disruption in services and community integration in all areas in Vermont.

R1's team also reported a lack of overall clinical services in Vermont specifically in the area of psychiatrists with expertise in Developmental Services. DVRT, who also reviewed this case, concluded of "greatest concern is the lack of capacity in Vermont to obtain and retain highly trained and professional home care staff to provide consistent and safe care to people with disabilities able to live in the community with appropriate supports and staffing." As a state we need to explore how to recruit and retain clinical professionals to work within the Vermont service delivery system. The Team recommends that DAIL should fund, or request additional funding from the legislature, to support a focused initiative for the recruitment of experienced clinicians who would become a statewide resource for the population identified.

The Team believes that quality monitoring and oversight are a core component in ensuring the quality of services and recommend that DAIL propose a plan to increase capacity for quality monitoring and oversight of the Home and Community Based Services (HCBS), including the development and review of encounter data, and the follow-up and trending of Critical Incident Reports.

4) Improvement in the Utilization of Respite Services: In addition to a transitional crisis bed, the Team also identified provider burnout and a lack of respite services as a contributing factor to the stress levels within R1's team. In most cases, respite services are considered the responsibility of the SLP. The SLP is required to hire, conduct the background checks, and oversee the respite budget. In cases, such as with R1, where the intensity of the care is so significant this may be too much for the SLP to handle. Additionally, due in part to R1's significant care issues, finding respite providers was a challenge. The Team believes the Designated Agency (DA) should have responsibility to ensure that respite is available and used such that SLP's receive needed breaks, and when the SLP is unable or unwilling to find, hire, train and supervise appropriate respite employees, the DA should intervene early and effectively. The Team recommends that Service Coordinators from designated agencies assess the status of respite and its usage as part of their monthly home visit documentation, and that complete respite service encounter data be collected and be made available to service coordinators, provider agencies, and DAIL quality management staff.

5) Support for the Commissioner Alert System and Team Coordination: The Team supports the development of DAIL's new "Commissioner Alert" system. The intent of the system is for the Office of Professional Guardian (OPG) to ensure that guardians describe their efforts to gain improvements in services in full detail. OPG will institute a new practice of sending a Commissioner's Alert to the Commissioner of DAIL, the Commissioner of Corrections, and the Commissioner of DMH when the guardian feels that the relevant service system is not providing a level of service which addresses health and safety risks in an adequate fashion or when they believe there is a clear risk of harm that is beyond their power to address.

The added alert system would contribute to a team approach in addressing concerns with higher risk individuals. We recommend that a MOU be developed to allow for the DS Quality Management Team, Office of Public Guardian (OPG), APS, and MFRAU (and any other relevant departments) to share information and to meet on a quarterly basis to discuss any cases in common or high-risk situations.

6) Enhanced Statewide Oversight: DAIL should create more rigorous statewide requirements for Shared Living Providers and other care givers that include CPR certification and training on how to respond to and document health conditions and behaviors of persons under their care, including when to contact a physician or arrange transport to an Emergency Department/initiate 911.

LCMHS reported that based on this case they made changes to the SLP contract which now includes language demanding and monitoring compliance with home provider documentation of services and critical events and imposing swift decisive sanctions for violations of these requirements. We support this change and recommend that DAIL require that it be implemented by all DA's and SSA's. (The Team recognizes that this requires the capacity to find alternative care providers/staff if the sanctions cause or require termination and that without expanded resources and coordination the DA's will face the same dilemma of not being able to fully sanction inadequate employees for lack of replacement staff).

Improved oversight and monitoring by the agencies that employ and/or contract for direct care would include requirements of unannounced visits to shared living providers by case managers/service coordinators/program managers. DAIL should enforce these requirements by creating more explicit standards and using quality review processes to enforce these requirements.

Conclusions and Future Activities

- The Team will continue to fulfill our legislative mandate by meeting quarterly for case review and trainings that will serve as a foundation for future recommendations that prevent deaths of Vulnerable Adults in Vermont.
- The Team will meet in the near future to discuss this year's focus.
- The Team will elect a new Chair and Vice-Chair in 2021, per bylaws.

Respectfully submitted,

Virginia Merriam, Co-Chair January 13, 2021

Elizabeth L. Anderson January 13, 2021
Elizabeth Anderson, Co-Chair