COMMONWEALTH of VIRGINIA

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November 1, 2022

To: Governor Glenn A. Youngkin
The Honorable Robert D. Orrock, Chair, House Committee on Health, Welfare, and Institutions
The Honorable L. Louise Lucas, Chair, Senate Committee on Education and Health

Fr: Nelson Smith, Commissioner, Department of Behavioral Health and Developmental Services (DBHDS)

House Bill 659 (2022) or Chapter 568 of the 2022 Virginia Acts of Assembly directs the Department of Behavioral Health and Developmental Services (DBHDS) to report on recommendations regarding investigations into the deaths of individuals that occur while they are under the care of a DBHDS-licensed facility. The language reads:

> *The Department of Behavioral Health and Developmental Services (the Department) shall establish a work group, which shall include the Commissioner of Behavioral Health and Developmental Services, the Director of the Department of Criminal Justice Services, the Commissioner of Social Services, the State Registrar of Vital Records, and the Chief Medical Examiner, or their designees, and representatives of the disAbility Law Center of Virginia, the Virginia Hospital and Healthcare Association, the Virginia Association of Community Services Boards, providers of behavioral health services licensed by the Department, law-enforcement agencies, emergency medical services providers, community stakeholders such as social workers, community mental health providers, and case managers, and other appropriate agency staff and other stakeholders, to study and make recommendations regarding appropriate investigations, including recommendations regarding when autopsies may be appropriate, of the deaths of individuals with intellectual or developmental disabilities who are residents of the Commonwealth and who die while receiving services from a program licensed by the Department. The work group shall report its findings and recommendations to the Governor and the Chairmen of the House Committee on Health, Welfare and Institutions and the Senate Committee on Education and Health by November 1, 2022.*

In accordance with this item, please find the enclosed report. Staff are available should you wish to discuss this report.

CC: John Littel, Secretary of Health and Human Resources
Susan Massart, House Appropriations Committee Staff
Mike Tweedy, Senate Finance Committee Staff

Report of the Work Group on Mortality Investigations and Prevention

Chapter 568 of the 2022 Acts of Assembly

To the Governor and Chairs of the House Committee on Health, Welfare, & Institutions and the Senate Committee on Education & Health

November 1, 2022

DBHDS Vision: A Life of Possibilities for All Virginians

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Preface

Chapter 568 of the 2022 Virginia Acts of Assembly directs the Department of Behavioral Health and Developmental Services (DBHDS) to report on work group recommendations regarding the deaths of individuals with intellectual or developmental disabilities while under the care of a DBHDS-licensed provider. The language states:

> *The Department of Behavioral Health and Developmental Services (the Department) shall establish a work group, which shall include the Commissioner of Behavioral Health and Developmental Services, the Director of the Department of Criminal Justice Services, the Commissioner of Social Services, the State Registrar of Vital Records, and the Chief Medical Examiner, or their designees, and representatives of the disAbility Law Center of Virginia, the Virginia Hospital and Healthcare Association, the Virginia Association of Community Services Boards, providers of behavioral health services licensed by the Department, law-enforcement agencies, emergency medical services providers, community stakeholders such as social workers, community mental health providers, and case managers, and other appropriate agency staff and other stakeholders, to study and make recommendations regarding appropriate investigations, including recommendations regarding when autopsies may be appropriate, of the deaths of individuals with intellectual or developmental disabilities who are residents of the Commonwealth and who die while receiving services from a program licensed by the Department. The work group shall report its findings and recommendations to the Governor and the Chairmen of the House Committee on Health, Welfare and Institutions and the Senate Committee on Education and Health by November 1, 2022.*

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Executive Summary

The Department of Behavioral Health and Developmental Services (DBHDS) worked in partnership with the Virginia Department of Health (VDH) Office of the Chief Medical Examiner (OCME) to identify stakeholders in the mortality investigations process within the I/DD system and organize meetings of the House Bill 659 (Chapter 568) Workgroup on Mortality Investigations and Prevention. Work group members included representatives from DBHDS, OCME, the disAbility Law Center of Virginia (dLCV), the Department of Criminal Justice Services (DCJS), the Office of the State Inspector General (OSIG), and various advocacy organizations (see Appendix A).

The Developmental Disabilities Mortality Review Committee (MRC) was established in 2012 as part of Virginia's Settlement Agreement with the United States Department of Justice. The Settlement Agreement required DBHDS to move individuals previously in the state's training centers into integrated community settings. The MRC was established to examine these system changes and their impact on preventable mortality. Since that time, the Committee has engaged in system of care improvements through integration of clinical evidence, data-driven determinations, and evidenced based quality improvement recommendations. The scope of the committee reviews deaths of all individuals who were receiving a service licensed by DBHDS at the time of death and diagnosed with an intellectual disability and/or developmental disability (I/DD). Analysis of the mortality trends, patterns, and problems can identify opportunities for system improvements to reduce risks to all individuals with developmental disabilities receiving behavioral health and/or developmental services. DBHDS seeks to prevent instances of abuse, neglect, exploitation, and unexplained or unexpected death by identifying and addressing relevant factors during mortality reviews. Mortality review determinations are utilized to develop quality improvement initiatives in order to reduce mortality rates to the fullest extent practicable.

As individuals with developmental disabilities (DD) have transitioned to more integrated, community environments, a new system of care has been developed to meet their needs. Following the DOJ Settlement Agreement, one key change in this transition from residing and ultimately passing away while in the care of a state operated facility, was that involvement of the Office of the Chief Medical Examiner (OCME) was no longer mandated for each death of a DD individual in the community. The OCME provides invaluable information and investigation related to understanding the causes and manner by which people die, but it is not practical or necessary for every person who dies to receive this level of investigation. The workgroup aimed to explore the opportunities to enhance the work of the MRC and the OCME, to ensure that the Commonwealth continues to advocate and understand the complex circumstances under which individuals with developmental disabilities may live and die, and utilize that knowledge to improve the overall system of care.

Two meetings of the work group were held on June 30, 2022 and August 2, 2022, as posted to Commonwealth Calendar, with broad discussion centered on the following themes:

- Improved quality assurance to ensure that the individuals that fall under the current scope of the MRC are being appropriately identified and investigated.
- Increased need for initial and ongoing training related to identifying and reporting deaths to law enforcement and the OCME.

- Increasing access and resources for medical autopsies for families who wish to pursue additional investigation into a person's death.
- Expanding the scope of mortality review to other state operated institutional settings where individuals with DD reside.
- Ensuring appropriate financial resources are provided to support enhancements in technological infrastructure for data collection. There is a need for additional resources to support the current work of the MRC and OCME to meet established requirements for mortality review given the limited availability of forensic pathologists to meet the demand.

Developmental Disabilities Mortality Review Committee (MRC)

History and Current Practices

The Developmental Disabilities Mortality Review Committee (MRC) was formed in 2012 as part of Virginia's Settlement Agreement with the United States Department of Justice. The Settlement Agreement required DBHDS to move individuals previously in the state's training center into integrated community settings. The MRC was established to examine these system changes and their impact on preventable mortality.

During its inception, the MRC faced several challenges. There was initial difficulty identifying and validating diagnoses for the target population for investigation by the MRC. Data collection was not comprehensive and limited to information from DBHDS licensed providers. Certain medical records including those from primary visits or medical hospitalizations were inaccessible and access to death certificates was limited. Furthermore, many reviews were delayed due to lack of timely access to records. This led to significant structural and procedural changes to the DBHDS DD Quality Management System in January 2019 and an eventual re-establishment of the Mortality Review Committee charter, which included a revision of processes and increased collaboration with the OCME. Senate Bill 482 (Chapter 851; 2020) legislatively established the DBHDS DD MRC and provided them greater access to information and records regarding individuals whose deaths are being reviewed by the Committee.

DBHDS and the MRC contribute to system of care improvements through integration of clinical evidence, data driven determinations, and evidence-based quality improvement recommendations. Deaths of all individuals who were receiving a service licensed by DBHDS at the time of death and diagnosed with an intellectual disability and/or developmental disability (I/DD) are reviewed. Analysis of the mortality trends, patterns, and problems can identify opportunities for system improvements to reduce risks to all individuals with developmental disabilities receiving behavioral health and/or developmental services. DBHDS seeks to prevent instances of abuse, neglect, exploitation, and unexplained or unexpected death by identifying and addressing relevant factors during mortality reviews. Mortality review determinations are utilized to develop quality improvement initiatives in order to reduce mortality rates to the fullest extent practicable.

The MRC DBHDS Deputy Commissioner for Clinical and Quality Management serves as the committee chair, with membership consisting of a multidisciplinary group of individuals with a

range of clinical expertise including mortality review, licensing and human rights, quality management, data analysts, and experts related to the provision of community DD services and the transition from training centers. The Committee is required to review all deaths reported into the DBHDS incident management system within ninety days. The review includes information from medical records, the most recent individualized program plan and physical examination records, the death certificate and autopsy report, any evidence of maltreatment related to death for the individual, and an interview, as warranted, of anyone having information regarding the individual's care. At minimum, the MRC is required to meet on a monthly basis, however, to meet the requirement of reviewing deaths within ninety days, the MRC meets twice per month for three to four hours each meeting.

Deaths are categorized utilizing a tier system:

Tier 1 cases require a detailed, comprehensive review of multiple factors and areas of focus by the MRC. A case would be considered tier 1 if a cause of death is unknown or otherwise unable to clearly be determined, the cause of death is unexpected suicide or homicide, abuse and/or neglect is specifically documented, there is documented law enforcement involvement or investigation, or there are documented specific or well-defined risks to safety and well-being.

Tier 2 cases do not require additional review by the full committee. A case would be considered tier 2 if all of the following criteria are met: the cause of death must clearly be determined or established; the death must be either an expected death, with no abuse or neglect, involvement of law enforcement, or documented well-defined safety and well-being risks, or be an unexpected death that occurred as a result of an acute medical event, new medical condition or sudden and unexpected consequences of a known medical condition. A tier 2 case cannot have any documentation of abuse or neglect, specific or well-defined risks to safety and well-being, or law enforcement involvement.

The MRC utilizes a specific, state-determined, definition for a potentially preventable death. A potentially preventable death denotes deaths that might have been prevented with reasonable valid intervention (*e.g., medical, social, psychological, legal, and educational*). Deaths determined to be potentially preventable have identifiable actions or care measures that should have occurred or been utilized. For a death to be determined potentially preventable, the actions and events immediately surrounding the individual's death must be related to deficits in the timeliness or absence of, at least one of the following factors:

- Coordination and optimization of care
- Access to care, including delay in seeking treatment
- Execution of established protocols
- Assessment of, and response to, the individual's needs or change in status

Any actions recommended by the MRC are reviewed at each meeting to ensure resolution. Trends in mortality are reviewed by the Committee quarterly. Finally, the MRC must prepare and deliver a report of deliberations, findings, and recommendations, if any, to the DBHDS Commissioner. The Committee is further responsible for collecting and analyzing mortality data to identify trends, patterns, and problems at the individual service delivery and systemic levels and develop and implement quality improvement initiatives to reduce mortality rates to the

fullest extent practicable and publish an annual report[1] summarizing the activities of the committee and data for the relevant fiscal year.

It is important to note that statewide mortality review of individuals with developmental disorders varies from state to state. The purpose of the mortality review, waiver eligibility, definitions, and state government entities involved in the process vary. Trends across states are not often comparable, but rather serves a part of an overall system of oversight, quality, and continuous improvement for the care of individuals with developmental disorders.

Office of the Chief Medical Examiner (OCME)

Medicolegal Death Investigation

The Virginia Medical Examiner system was established in 1947 to provide autopsy services to local medical examiners. The Office of the Chief Medical Examiner (OCME) has evolved to a nationally accredited system to investigate unnatural deaths to medically certify the cause and manner of death. Deaths that may fall under the jurisdiction of the OCME are reported to medicolegal death investigators (MDI) who are available 24-hours a day and seven days a week in each district. "Medicolegal" is the term used to describe any unclear or vaguely suspicious death that must be investigated. The MDI in consultation with an Assistant Chief Medical Examiner (ACME), who is a forensic pathologist, determines the disposition of each case.

Disposition options include:

- Turn-Down - natural death that does not fall under the jurisdiction of the medical examiner
- External Examination - cause and manner of death can be determined through examination and toxicology specimen collection by a local medical examiner as directed by District Office to assure no trauma in addition to natural disease
- Autopsy - transport to District Office for autopsy or advanced examination techniques under the direction of an ACME (only about 40 percent of medical examiner cases require a full autopsy)

Under § 32.1-283 of the Code of Virginia, the OCME is required to investigate and medically certify deaths that are or may not be natural (accident, homicide, suicide), and independently investigate deaths of Virginians in exclusive custody of state and local government. This section also permits the state to seize custody of the decedent on a temporary basis from next-of-kin to investigate these deaths. It is important to note that state oversight is not considered state custody, and such as individuals on probation, parole, or home detention, or individuals living in an independent community care facility (such as those licensed by VDH, Department of Health Professions (DHP), DBHDS, or other state or Federal agency) do not fall under the OCME jurisdiction. The disposition of the deaths and the management of deaths in custody is dependent on the manner of death.

- Accident, Suicide, Homicide, Suspected Unnatural - Autopsy

[1] https://rga.lis.virginia.gov/Published/2022/RD91/PDF

- Natural Disease in state or local institution - Autopsy
- Natural Disease in facility not under exclusive state control (i.e., an individual who is admitted to a referral hospital or other medical facility) - External Examination

The Role of OCME for Deaths of Individuals with Developmental Disabilities

Deaths of individuals with developmental disorders in DBHDS state operated facilities are statutorily required to be reported to the OCME. However, as more individuals with developmental disabilities have transitioned to DBHDS licensed community-based settings, the jurisdiction related to the role of OCME thus changes. The OCME currently triages reported deaths in DBHDS licensed facilities to determine jurisdiction. The triage process considers circumstances of death, local law enforcement investigation, and other factors that are deemed "at risk" circumstances. The OCME only investigates cases meeting the requirements to be considered medical examiner cases that necessitate external examination or autopsy to certify cause and manner of death.

The OCME does not have the authority or resources to require autopsy examination for natural deaths. This is the proper role for a hospital autopsy with the authorization of next of kin.

Considerable Impacts of Potential Changes to the Current OCME Authority

The OCME does not have the resources to perform autopsies on current medical examiner cases such as drug and vehicular deaths. If the OCME were to investigate all DD deaths reported to DBHDS, this would add more than 400 autopsies per year, equivalent to nearly two additional forensic pathologists. Due to the national shortage of forensic pathologists and budgetary restrictions only have 12 of the currently authorized 20 forensic pathologist positions are filled by the OCME. Proposing expansion to the role and scope of the OCME with respect to deaths of individuals with developmental disorders, would set precedent for the government to seize control of decedents from next-of-kin to compel examinations in cases of natural death in other circumstances such as licensed health care facilities including hospitals as well as individuals on parole, probation, or house arrest. Such legal and operational impacts should be considered before legislative changes are made.

Summary and Recommendations

The workgroup focused on identifying opportunities exist to enhance the established processes to reduce preventable deaths in the developmental disabilities population. There were a number of opportunities noted related to improved training and knowledge across the system to ensure that DD deaths that fell under the jurisdiction of the OCME were being reported and investigated. Some deaths may warrant a referral to the medical examiner's office for consideration of a medicolegal review. Deaths appropriate for referral are those for which it is not readily evident if the cause was natural or suspected unnatural. An example of this would a death related to aspiration. Additionally, there are a number of medical conditions that co-occur amongst individuals with developmental disorders. Workgroup participants expressed concern that medical providers often readily attribute deaths to underlying conditions when further investigation may be appropriate. Such cases often occur when the death certificate attributes

cause of death to the developmental disorder. Workgroup members also noted that there is a need to identify individuals with developmental disabilities outside of settings licensed by DBHDS such as local jails and corrections. While beyond the scope of the current DBHDS DD Mortality Review Committee, it was acknowledged that it is important to also develop efforts to reduce preventable mortality in those settings as well.

As noted previously, the OCME emphasized that the forensic pathology workforce is limited and it is essential that they continue to maintain the capacity to meet currently established Code requirements. Workgroup participants also expressed the need to balance mandating death investigations with caregiver and personal choice to forego investigative processes including autopsies during a time of grief. Lastly, additional financial, technological, and training resources would be needed to implement system enhancements.

Recommendations

The work group came to an agreement to the following recommendations for enhancing the mortality investigation of individuals with developmental disorders.

1. Establish policies and procedures and identify resources and funding for hospital autopsies of selected individuals with developmental disabilities receiving a DBHDS licensed service, with authorization by next-of-kin.
2. DBHDS and OCME should prepare training on appropriate reporting of deaths to law enforcement and OCME regarding individuals receiving services from DBHDS at the time of death or immediately prior to admission to another hospital. This training can be required for DBHDS providers and will be shared with law enforcement agencies. There would also be a need for alignment in the DBHDS incident reporting system to track the number of deaths referred to law enforcement/OCME and the outcome of that referral.
3. Conduct a retrospective data review of the DD MRC to determine the number and types of deaths that could be medical examiner cases. This would review cause of death as a reason for referring to the medical examiner (i.e. aspiration, pneumonia).
4. Establish a structure and process for ensuring individuals with ID/DD in Virginia Department of Corrections (DOC) facilities are identified to determine mortality prevention strategies.

Appendix A – Work Group Membership

Alexis Aplasca, DBHDS

Dana Schrad, Virginia Association of Chiefs of Police

Erin Haw, dLCV

Maria Garnett, DCJS

Angelica Howard, DBHDS

J. Lynn Hamner, OSIG

Jennifer Fidura, Virginia Network of Private Providers

Jennifer Wicker, Virginia Healthcare and Hospital Association

Sharon Lindsay, DSS

Patricia Cafaro, DBHDS

Tara Davis-Ragland

William Gormley, OCME

Elizabeth Hobbs, Virginia Sheriffs Association

Joseph Hilbert, VDH

Keith Davies, OSIG

Keshia Singleton, VDH

Mindy Carlin, Virginia Association of Community Based Providers

Alisa Foley, DSS

Cassidy Taylor, Virginia Association of Community Based Providers

Dana Traynham, dLCV

Emily Reynolds. Office of the Children's Ombudsman

Jennifer Faison, VACSB

Karin Clark, DSS