COMMONWEALTH of VIRGINIA

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December 1, 2023

To: The Honorable Glenn A. Youngkin, Governor of Virginia
The Honorable Winsome Earle Sears. Lieutenant Governor
The Honorable L. Louise Lucas, Senate President Pro Tempore
The Honorable Todd Gilbert, Speaker of the House of Delegates

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

RE: §37.2-314.1, Code of Virginia

§37.2-314.1 Code of Virginia directs the Department of Behavioral Health and Developmental Services (DBHDS) to report annually to the Governor and the General Assembly on activity of the Mortality Review Committee. The language reads:

> *F. The Committee shall report its activities annually to the Governor and the General Assembly by December 1. Such report shall include statistical and other data on the deaths of persons with a developmental disability who were receiving services from a provider licensed by the Department or in a training center or other state facility at the time of their death and recommendations developed by the Committee to address the conditions that led to such deaths. Any statistical compilations prepared by the Committee shall be public record and shall not contain any personally identifying information.*

Please find enclosed the report in accordance with Code of Virginia §37.2-341.1. DBHDS Staff are available should you wish to discuss this request.

cc: Secretary John Littel

Annual Mortality Review Report

(§37.2-314.1, Code of Virginia)

December 1, 2023

A Life of Possibilities for All Virginians

Preface

§37.2-314.1 Code of Virginia directs the Department of Behavioral Health and Developmental Services (DBHDS) to report annually to the Governor and the General Assembly on activity of the Mortality Review Committee

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Executive Summary

This is the ninth Annual Mortality Report of the Virginia Department of Behavioral Health and Development Services (DBHDS). The information contained in this report is based on reviews of the deaths of individuals with a developmental disability that occurred during state fiscal year (SFY) 2023, as reported in the DBHDS incident reporting systems. SFY 2023 covers July 1, 2022 to June 30, 2023.

As of January 5, 2023[1], there were 16,295 individuals enrolled on a Virginia Developmental Disability (DD) Home and Community Based Services (HCBS) waiver[2]. DBHDS authorizes many specialized services to thousands of residents for the following waivers: Community Living, Family and Individual Supports, and Building Independence.

As a commitment to the Commonwealth of Virginia the DBHDS Intellectual and Developmental Disabilities (IDD) Mortality Review Committee (MRC or Committee) contribute to system of care improvements through integration of clinical evidence, data driven determinations, and evidenced-based quality improvement recommendations. Deaths of all individuals who were receiving a service licensed by DBHDS 90 days before the date of death and diagnosed with an intellectual and/or developmental disability (IDD) are reviewed.

Analysis of the mortality trends, patterns, and problems can identify opportunities for system improvements that reduce risks to all individuals with IDD receiving behavioral health and/or developmental services. On an ongoing basis, 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 then utilized to develop quality improvement initiatives in order to reduce mortality rates to the fullest extent practicable.

[1] January 5,2023 was selected as a point in time for the middle of the SFY.
[2] Virginia Waiver Management System. Accessed by DBHDS on December 7, 2023.

§37.2-314.1 Mortality Review Commission
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Key Findings

- The DBHDS IDD MRC reviewed 336 deaths that occurred during SFY 2023, a 19% decrease from the previous SFY 2022 (416 deaths were reviewed).
- The MRC utilizes a two-tier review process, which allows a targeted focus on unexpected or unexplained deaths. These deaths are categorized as Tier 1, or Tier 2 with deaths categorized as Tier 1 having specific clinical concerns identified in the case review. Full criteria are listed on Pages 7- 8. Of the 336 deaths reviewed in SFY 2023, 190 deaths (56.6%) were categorized as Tier 1, and 146 were categorized as Tier 2.
- The median age at time of death was 57 years old; the mean age at death was 54 years old. Both the median and mean are identical to those observed in SFY 2022.
- The leading cause of death in SFY 2023 was Failure to Thrive/Slow Decline, which was a top cause of death in previous years but has now surpassed COVID-19 as the leading cause.
- The number of deaths caused by COVID-19 dropped to 16 in SFY 2023 as compared to causing 46 deaths in SFY 2022 and 60 deaths in SFY 2021. While still a top cause, the decline of COVID-19 deaths in this SFY impacted the total number of deaths reviewed by the MRC, the number of deaths determined to be unexpected, and the number of deaths determined to be potentially preventable.
- The MRC determined more deaths were expected (233 deaths, 69%) than unexpected (103 deaths, 31%). The top category of expected deaths was Genetic malformations, deformations and chromosomal abnormalities and the top category of unexpected deaths was Respiratory Disease.
- Eleven deaths (3%) were determined to be potentially preventable (PP), a decrease from SFY 2022 when 22 deaths (5%) were determined to be PP.
    - Similar to previous years, the majority of deaths determined to be PP in SFY 2023 (8 of 11) involved a failure to execute established protocols.
    - As in the previous year, choking was the top cause of PP deaths in SFY 2023 (8 in SFY2022 to 4 in SFY2023).
- The overall Crude Mortality Rate (CMR) decreased to 17.49 from 23.6 in SFY 2022.
    - There was a decrease in CMR in every age group except for individuals 81+ years old, where there was an increase to 185.19 in SFY 2023 from 166.7 in SFY 2022.
    - Notably, there was large increases in the number of individuals on the waiver ages 0-40 years old, which likely contributed to the decline in CMR.

Recommendations

An important component of health and safety oversight within DBHDS remains the analysis and review of mortality data to identify important patterns and trends that may help to decrease risk factors. This analysis also provides information that guides system enhancements through process improvements and determines recommendation development in response to findings.

In order to ensure the provision of safe, effective, person-centered, timely, efficient, and equitable care to all individuals with IDD, the MRC documents recommendations for systemic quality improvement initiatives from patterns of individual reviews on an ongoing basis. From this analysis, including a review of the data presented in this report, the DBHDS IDD MRC also makes at least four recommendations annually for systemic quality improvement initiatives, and reports these recommendations to the DBHDS Developmental Disabilities Quality Improvement Committee and the DBHDS Commissioner. Recommendations in this report integrate new findings from the current year, while building on recommendations and data from previous years.

Recommendation 1: The MRC should increase the number of individuals with IDD receiving preventive screenings by educating providers and family on the importance of preventive screenings and risk factors for specific diseases that benefit from preventive screenings.

Recommendation 2: The MRC should determine if there are patterns of similar or correlating environmental and/or medical components (ie. Medical conditions, level of supervision, diet, behavior supports, etc.) that may be contributing factors or areas of targeted interventions for potentially preventable deaths in the IDD population.

Recommendation 3: The MRC should work with the respective offices at DBHDS to identifying reasons for failure to adhere to case specific established protocols to develop targeted interventions related to failure of execution of established protocols as a potentially preventable factor.

Recommendation 4: The MRC should monitor and distinguish various causes of Failure to Thrive/Slow Decline that may be applied to mortality prevention strategies in the IDD population.

Status of Recommendations from SFY 2022

Recommendation 1: The MRC should utilize and collect frailty data for IDD cases during the last two quarters of SFY 2022 and analyze it to determine if a frailty assessment is a more sensitive and objective way to capture a person's needs and/or change in status.

DBHDS conducted a review of the literature and outreach to other states for validated frailty tools used for this specific population and type of retrospective review. However, the frailty assessments freely available were deemed not suitable for this purpose. Development of a new frailty tool was not feasible this year due to available resources needed to ensure this would be valid and reliable.

Recommendation 2: DBHDS should work to increase the percentage of adherence to the execution of provider established protocols for medical emergencies to greater than 70 percent for individuals with IDD residing in DBHDS licensed provider residences.

The medical emergency toolkit is nearing completion for distribution out to providers. Collaboration with the Office of Integrated Health (OIH) resulted in posting of education, training and other materials in the state learning center and during community and provider meetings. This is intended to provide foundational knowledge to impact improvement in the adherence to execution of provider established protocols for medical emergencies.

Recommendation 3: DBHDS should work to achieve that 30 percent of DBHDS IDD licensed providers complete REVIVE! Training (naloxone administration to reverse the effects of an opioid overdose) in the next year.

OIH added audio to the REVIVE! Training and encouraged providers to have staff complete the training. To date, 67 staff have completed REVIVE! Training, and it remains available online. DBHDS will continue to promote and make REVIVE! Training accessible however at this time DBHDS does not have a means to track percentage of provider completion.

Recommendation 4: DBHDS should review the choking events reported through their incident management system to work collaboratively across the Risk Management Review Committee (RMRC) and MRC to identify potential systemic factors that can mitigate choking risks.

The Risk Management Review Committee (RMRC) added choking as a care concern, working collaboratively with OIH. OIH conducted a nursing conference on improving care for IDD individuals at risk for choking and developed a Choking and Airway Obstruction training module on the Commonwealth of Virginia Learning Center (COVLc), which remains available to all providers.

Recommendation 5: The MRC should review causes of death determinations to encompass more specific diagnoses, which would contribute further to targeted interventions and education about conditions affecting individuals with IDD.

The process for identifying cause of death was updated. Using the International Classification of Diseases, tenth revision (ICD-10), the MRC established a list of causes of death which includes specific diagnoses (e.g. chronic obstructive pulmonary disease) rather than use of a broad category (e.g. respiratory disease). This has resulted in identification of targeted interventions and education specific to the underlying condition and diagnosis.

Background

The purpose of the DBHDS IDD MRC is to focus on system-wide quality improvement by conducting mortality reviews of individuals with IDD who were receiving a service licensed by DBHDS within 90 days of their death, utilizing an information management system to track the referral and review of these individual deaths. DBHDS demonstrates on an on-going basis that it identifies, addresses, and seeks to prevent instances of abuse, neglect, exploitation, and unexpected deaths.

At each meeting the MRC:

- Performs comprehensive clinical mortality reviews utilizing a multidisciplinary approach that addresses relevant factors (e.g., medical, genetic, social, environmental, risk, susceptibility, and others as specific to the individual) and quality of service.
- Evaluates the quality of the decedent's licensed services related to disease, disability, health status, service use, and access to care, to ensure provision of a reliable, person-centered approach.
- Identifies risk factors and gaps in service and as appropriate, specifies whether these are systemic recommendations or recommendations to specific providers, to promote safety, freedom from harm, and physical, mental, and behavioral health and wellbeing.
- Reviews citations issued by Office of Licensing related to required recommendations, to determine whether further action is required and for inclusion in meeting minutes.
- Refers any required recommendations not included in the initial citation and Corrective Action Plan (CAP) to the Office of Licensing for further investigation, and/or other divisions represented by members, when appropriate.
- Assigns recommendations and/or actions to DBHDS IDD MRC member(s) as appropriate.
- Reviews and tracks the status of previously assigned recommended actions to ensure implementation and completion.

The MRC provides ongoing monitoring and data analysis of provided services in order to identify trends, patterns, and issues of concern at the individual and systems levels. Once identified, the MRC develops and implements quality improvement initiatives (QII) to promote the health, safety, and well-being of individuals with IDD and reduce mortality rates to the fullest extent practicable.

Process

As described in the charter (updated annually), the MRC convenes at least monthly, and as frequently as necessary, to ensure that deaths are reviewed within 90 days of the date of death. Attendance by specific subject matter experts is required at each meeting. During SFY 2023, the MRC met 22 times, and membership requirements were met at each meeting.

For all IDD decedents, and within 90 calendar days of a death, the Mortality Review Office (MRO) compiles a clinical sequence of events summary leading up to the death, based on specific and required documentation from the preceding three months prior to the date of death. For each mortality case review, the MRC seeks to identify and determine:

- The cause of death
- If the death was expected or unexpected
- Whether the death was potentially preventable
- Any relevant factors impacting the individual's death
- Any other findings that could affect the health, safety, and welfare of these individuals

- Whether there are other actions that may reduce these risks of mortality, to include provider training and communication regarding risks, alerts, and opportunities for education
- If additional actions or measures are needed based on the case review, the MRC will then make and document relevant recommendations and/or interventions

Mortality Review Process Enhancements in SFY 2023

The main process enhancements of this fiscal year were related to ongoing identification and improvement of the data validity and reliability of the MRC. This included:

- Updated the charter:
  - Added the Mortality Prevention Strategies
  - Update required membership
- Transitioned to a new electronic database for the electronic Mortality Review Form (eMRF)
- Developed a process in collaboration with Virginia Department of Health, DBHDS Incident Management Unit, Information Technology and DBHDS computerized data systems to automate the process of obtaining demographic data for individuals reviewed by the MRC. This process was established to improve upon data reliability and validity of the new electronic Mortality Review Form.
- Collaborated with DBHDS Office of Patient Continuum Services, for a comprehensive list of IDD individuals discharged from closed DBHDS Training Centers to ensure discharge date reliability and validity.

Key Definitions

- **Expected Death** denotes a death that occurred as a result of a known medical condition, anticipated by health care providers to occur as a result of that condition and for which there is no indication that the individual was not receiving appropriate care. Clear evidence that the individual received appropriate and timely care for the medical condition exists.
- **Unexpected Death** denotes a death that occurred as a result of a condition that was previously undiagnosed, occurred suddenly, or was not anticipated. Deaths are considered unexpected when they are not anticipated or related to a known terminal illness or medical condition; are related to injury, accidents, inadequate care; or are associated with suspicions of abuse or neglect. An acute medical event that was not anticipated in advance nor based on an individual's known medical condition(s) may also

be determined to be an unexpected death. An unexplained death is also an unexpected death.

- **Unknown** may be used in two distinct contexts - If there is insufficient information to classify a death as either expected or unexpected OR there is insufficient information to make a determination as to the cause of death.
- **Other (Cause of Death)** denotes a cause of death that is identified but not attributable to one of the major causes of death used by the MRC for data trending.
- **Potentially Preventable (PP) Deaths** denotes deaths in the opinion of the MRC that might have been prevented with reasonable valid intervention (e.g., medical, social, psychological, legal, educational). If the individual was provided with known effective medical treatment or public health intervention and died despite this provision of evidenced based care, the death is not considered PP. A death may be determined to be PP regardless of whether the death is actionable by DBHDS or within the control of DBHDS. Deaths that occur in settings that are not licensed by DBHDS may be PP deaths. Deaths that do not indicate a violation of a licensing standard may be PP. Deaths determined to be PP have identifiable actions or care measures that should have occurred or been utilized. When the MRC determines a death is PP, the MRC categorizes factors that might have prevented the death. For a death to be determined PP, 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 changes in status
- **Tier 1 case criteria** - A case is categorized as Tier 1 when *any* of the following criteria exists:
    - Cause of death cannot clearly be determined or established, or is unknown
    - Any unexpected death (such as suicide, homicide, or accident). This includes any death that was: not anticipated or related to a known terminal illness or medical condition, related to injury, accident, inadequate care nor associated with suspicions of abuse or neglect. A death due to an acute medical event that was not anticipated in advance nor based on an individual's known medical condition(s), may also be determined to be an unexpected death.
    - Abuse or neglect is specifically documented
    - Documentation of investigation by or involvement of law enforcement (including forensic) or similar agency
    - Specific or well-defined risks to safety and well-being are documented
- **Tier 2 case criteria** - A case is categorized as Tier 2 when *all* the first four criteria exists:
    - Cause of death can clearly be determined or established
    - No documentation of abuse or neglect

- No documentation of investigation by or involvement of law enforcement (including forensic) or similar agency
- No documentation of specific or well-defined risks to safety and well-being noted
- An expected death that occurred as a result of a known medical condition, anticipated by health care providers to occur as a result of that condition and for which there is no indication that the individual was not receiving appropriate care.
- An unexpected (unexplained) death that occurred as a result of a condition that was previously undiagnosed, occurred suddenly, or was not anticipated. This includes any death that was: not anticipated or related to a known terminal illness or medical condition, related to injury, accident, inadequate care or associated with suspicions of abuse or neglect. A death due to an acute medical event that was not anticipated in advance nor based on an individual's known medical condition(s) may also be determined to be an unexpected death.

For actions recommended by the MRC, the MRC shall consider if one of the following three mortality prevention strategies[3] may be utilized:

- Primary Prevention Strategies - Educational and changes to services designed to help prevent a condition or event from taking place, that have been found to contribute to morbidity or mortality, such as education on reducing falls.
- Secondary Prevention Strategies – Focus on early detection and timely treatment of conditions or injuries to minimize harmful effects and prevent further morbidity or mortality, such as interventions that support and promote cancer screening.
- Tertiary Prevention Strategies – Optimization of the treatment and management of conditions or injuries, such as ensuring access to evidence-based treatment.

Virginia Deaths

The MRC determined a cause of death in 335 out of 336 (99.7%) of cases, with only one death classified as having an unknown cause. This is consistent with the previous two years, when the number of deaths classified as unknown was two (SFY 2021) or one (SFY 2022).

Legislation passed by the General Assembly in 2020 (SB482) grants the MRC greater access to information and records, for all IDD deaths reviewed by the MRC. This includes access to Virginia state death certificates through the Virginia Department of Health.

[3] Staugaitis, S., Lauer, E. (2015). *Risk Management Mortality Review & Reporting in Developmental Disabilities*. Univ of Mass Press, (69).

This year, current and historical causes of death were coded into categories so that trend data can be tracked more easily. Due to more specificity related to diseases and diagnoses identified by the MRC, the two tables in this section of the report align with the International Classification of Diseases, Tenth Revision (ICD-10) coding system. The ICD-10 provides a list of cause of death titles for mortality reporting (Table 2) as well as category groupings that consolidate several medical conditions (Table 3).

Table 1: Number of Deaths Classified as Unknown

Year	Unknown
SFY 2017	31
SFY 2018	34
SFY 2019	42
SFY 2020	16
SFY 2021	2
SFY 2022	1
SFY 2023	1

The decrease in the number of deaths classified as Unknown (as shown in Table 1), are related to identifying specific diagnoses resulting in death versus the broader category of deaths utilized in previous years as well as direct access to death certificates through the Office of Vital Statistics.

The total number of deaths by cause are displayed in Table 2. The most common cause of death for SFY 2023 was Failure to Thrive/Slow Decline. Failure to Thrive is described by the National Institute of Aging as a syndrome of weight loss, decreased appetite and poor nutrition, and inactivity, often accompanied by dehydration, depressive symptoms, impaired immune function, and low cholesterol. Failure to Thrive/Slow Decline, as described in this report includes individuals with protein malnutrition those with symptoms of global decline by no causative illness despite an appropriate clinical workup. While Failure to Thrive/Slow Decline was attributed to 28 deaths in SFY 2023, there were 29 deaths due to Failure to Thrive in SFY 2022. This cause of death will continue to be monitored to determine if there is a trend.

COVID-19 was the top cause of death in the previous two years (causing 46 deaths in SFY 2022 and 60 deaths in SFY 2021), but the number of deaths caused by COVID-19 dropped to 16 in SFY 2023. This decline mirrors the impact of COVID-19 in the broader population. The federal public health emergency for COVID-19 ended on May 11, 2023, marking a significant turning point of the pandemic. While individuals with disabilities remain in a vulnerable risk category for severe disease or death from COVID-19, widespread access to vaccines, therapeutics, and other mitigation efforts have been put in place to remain attentive to the health and safety impacts of COVID-19. DBHDS has received federal grant support allocated to an infection prevention team that provides free training on universal infection precautions, donning and doffing personal protective equipment including N-95 respirators and face masks, testing for COVID-19, and providing infection prevention supplies in collaboration with the Virginia Department of Health. With respect to the findings of the MRC, the decline of COVID-19 deaths in this SFY impacted the total number of deaths reviewed by the MRC, the number of deaths determined to be unexpected, and the number of deaths determined to be potentially preventable.

Table 2: Number of Deaths by Cause, SFY 2023

Cause of Death	SFY 2023
Failure to Thrive/Slow Decline	28
Sepsis	25
Cancer w/metastasis	21
Cerebral Palsy	20
Pneumonia	18
Congestive Heart Failure (CHF)	17
COVID-19	15
Sudden Cardiac Death	14
Aspiration Pneumonia	11
Down Syndrome	11
Seizure	9
Choking	8
Intestinal Obstruction	7
Cancer w/o metastasis	7
Myocardial Infarction (MI)	7
Acute Respiratory Failure	5
Aspiration	5
Lennox Gastaut Syndrome	5
Coronary Artery Disease (CAD)	4
Gastrointestinal Bleed (GIB)	4
Accident	4
Muscular Dystrophy	3
Dementia	3
Neurodegenerative Disease	3
Cerebral Vascular Accident (CVA)	3
Anoxic brain injury	3
Other (2 or fewer in SFY 2023)	74
Total	**336**

The "Other" category includes causes with one or two deaths.
Causes with one death include: *Achalasia; Agenesis of corpus callosum, complications of; Alcohol Poisoning/OD; Alpers-Huttenlocher Syndrome; Alzheimer's disease; Arthrogryposis Multiplex Congenita; Bowel Obstruction; Cancer; Cardiac Disease; Cardiomyopathy; Cardiovascular Disease ; Cerebral hemorrhage; Charcot-Marie-Tooth disease ; Congestive heart failure;; Chromosomal Disorder 10P15.3P14; Chromosome 15Q and duplication syndrome; Chronic Obstructive Pulmonary Disease ; Colitis; Congenital (in utero) Disorder Complication: Congenital brain stem AV malformation; Congenital Hydrocephalus; Cystic Fibrosis; Dandy Walker Syndrome; Drug Toxicity/Overdose; Dubowitz Syndrome; Duchenne Muscular Dystrophy; Epilepsy; Gastrointestinal Disease; Heart Disease; Homicide; Influenza; Intraoperative Complications; Lennox Gastaut Syndrome; Leukodystrophy; Lissencephaly; MEPC2 Duplication Syndrome; Metabolic Encephalopathy; Methylmalonic acidemia; Necrotizing Fasciitis; Obesity hypoventilation syndrome; Ogilvie syndrome; Paraesophageal Hernia; Parkinson's disease; Perforated bowel; Periventricular Leukomalacia; Pierre Robin sequence; Moebius Syndrome; Post Procedure Complications; Potocki-Shaffer Syndrome; Progressive Supranuclear Palsy; Pulmonary Embolism; Pulmonary HTN;*

RSV; Sarcoidosis; Shock, complications of; Spina Bifida; Transposition of Great Arteries; Trauma; Turner's syndrome; Unknown; and Williams Syndrome.
Causes with two deaths include: *Type 1 Diabetes; Intracranial Hemorrhage; Post Operative Complications; Prader-Willi Syndrome; Renal Disease; Renal Failure; Rett Syndrome; & Stroke.*

Table 3 displays trend data, sorted in descending order based on the number of deaths in SFY 2023. These categories will be used throughout the report. The most common category observed in SFY 2023 was respiratory disease.

Table 3: Number of Deaths by Category, SFY 2018 – SFY 2023 (All Deaths)

Category	SFY18	SFY19	SFY20	SFY21	SFY22	SFY23
Respiratory Disease	43	72	79	132	120	65
Cardiovascular Disease	41	39	71	67	53	48
Endocrine, Nutritional, & Metabolic Disease	31	15	27	17	35	37
Genetic malformations, deformations, and chromosomal abnormalities	11	9	16	18	29	35
Congenital malformations, deformations, and chromosomal abnormalities	2	13	5	18	28	30
Cancer	23	30	34	33	33	29
Infectious Disease	17	19	41	23	26	26
Neurological Disorder	9	19	24	36	41	25
Gastrointestinal (GI) Disease	11	10	12	13	15	16
Neurodegenerative Disorder	5	18	7	21	10	8
Renal Disease	9	11	6	8	7	4
Traumatic Disorder	1	1	2	2	8	4
Post-Operative Complications	6	3	3	3	3	3
Accident	2	1	2	3	4	2
Birth injury central nervous system disease						1
Drug Toxicity/Overdose	1		1	7		1
Mental, Behavioral and Neurodevelopmental Disorder						1
Unknown	34	42	16	2	1	1
Multiple Medical Problems	10	8	discontinued in SFY 2020			
Harm to self/Suicide				1		
Hematological Disease	3	1		2	1	
Musculoskeletal and Connective Tissue Disease	2	1	8	2	2	
Grand Total	**261**	**312**	**354**	**408**	**416**	**336**

In previous years, causes of death with less than 3 deaths were grouped into 'Other' category. Given the reduction in number of causes with implemented categories, all categories are now listed in the main table.

While the majority of individuals reviewed by the MRC are both on a waiver and receive a DBHDS licensed service, the MRC reviews all deaths of individuals with IDD receiving a licensed DBHDS service, which may include other behavioral health services, regardless of waiver status. The number of deaths by category for individuals who were not on a waiver are

reported in Table 4 (subset of the total reported above in Table 3). Respiratory Disease was also the top category for this group.

Table 4: Cause of Death Category for Non-Waiver Individuals, SFY 2023

Cause of Death Category	SFY 2023 Deaths
Respiratory Disease	14
Cardiovascular Disease	11
Genetic malformations, deformations, and chromosomal abnormalities	9
Infectious Disease	6
Endocrine, nutritional & metabolic disease	3
Congenital malformations, deformations, and chromosomal abnormalities	2
Neurological Disorder	2
Post-operative Complications	1
Cancer	1
Drug Toxicity/Overdose	1
Gastrointestinal Disease	1

End of Life Care

The American Association for Individuals with Intellectual and Developmental Disabilities (AAIDD) updated their end-of-life position statement in January 2020[4], on caring for individuals with IDD. The MRC acknowledged that choice related to the type of end-of-life care can be reflective of interventions and actions related to contributing mortality factors and began capturing this data for reporting purposes in SFY 2021. The MRC makes recommendations not only to impact mortality rates, but also to increase quality of care and quality of life regardless of health status.

It is important to note having a Do Not Resuscitate (DNR) order or active hospice care, does not automatically equate to a determination of expected or not potentially preventable by the MRC.

Do Not Resuscitate Status (DNR)

The number and percentage of individuals who had a DNR in place is displayed in Table 5. The percentage has increased over time to 75% of individuals reviewed by the MRC in SFY 2023.

Table 5: Number and percent of deaths with DNR by SFY

[4] https://www.aaidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life (accessed Dec 12, 2023)

State Fiscal Year	DNR	No DNR	Percent with DNR
SFY 2020	148	206	42%
SFY 2021	224	184	55%
SFY 2022	251	165	60%
SFY 2023	222	114	75%

DNR status by residential setting is displayed in Table 6. Individuals who lived in a group home, nursing facility/skilled nursing facility/assisted nursing facility (NF/SNF/ALF), or state facility were most likely to have a DNR in place. Those receiving inpatient care, living in a sponsored placement, or intermediate care facility for individuals with intellectual disability (ICF/ID), or in a private residence, less often had a DNR in place.

Table 6: Do Not Resuscitate by Residential Setting, SFY 2023

Residence	DNR	Total	Percent
Group Home	109	147	74%
Private Residence w/ Family	39	74	53%
Sponsored Placement	23	34	68%
ICF/ID	16	26	62%
NF/SNF/ALF	19	26	73%
Private Residence Other	8	17	47%
State Facility	6	8	75%
Inpatient Care	2	3	67%
*Other		1	0%

**Other denotes one individual with IDD who was unhoused during the 90 days prior to death. This individual declined assistance and other efforts by DBHDS and other entities to obtain housing and was also incarcerated at times during this period.*

Hospice

Of the 336 individuals who died in SFY 2023, 131 were receiving hospice services (39%). This represents a slight increase from previous years. Hospice services were also more common among individuals whose deaths were expected. For expected deaths, 120 out of 233 (51 percent) received hospice services, compared to 11 out of 103 (11 percent) of those with unexpected deaths. This may contribute to the increase in the number of deaths determined to be expected as hospice records demonstrated additional support in addressing needs at end of life.

Table 7: Hospice Services by SFY

SFY	Receiving Hospice
SFY 2020	35%
SFY 2021	34%
SFY 2022	34%
SFY 2023	39%

Hospice services by residential setting are displayed in Table 8. Individuals who lived in a group home, sponsored placement, or NF/SNF/ALF were most likely to be receiving hospice services.

Table 8: Hospice Services by Residential Setting, SFY 2023

Residence	Hospice	Total	Percentage
Group Home	69	147	47%
Private Residence w/ Family	22	74	30%
Sponsored Placement	15	34	44%
ICF/ID	8	26	31%
NF/SNF/ALF	11	26	42%
Private Residence Other	4	17	24%
State Facility	2	8	25%
Inpatient Care		3	0%
Other		1	0%

The number and percentage of individuals receiving hospice services by age group is shown in Table 9. Hospice services were most common among individuals in the 81+ category, a finding consistent with the previous year.

Table 9: Hospice Services by Age Group, SFY 2023

Age Group	Hospital	Total	Percentage
0-17	2	10	20%
18-30	6	33	18%
31-40	11	39	28%
41-50	20	49	41%
51-60	21	64	33%
61-70	42	77	55%
71-80	18	48	38%
81+	11	16	69%

Expected and Unexpected Deaths

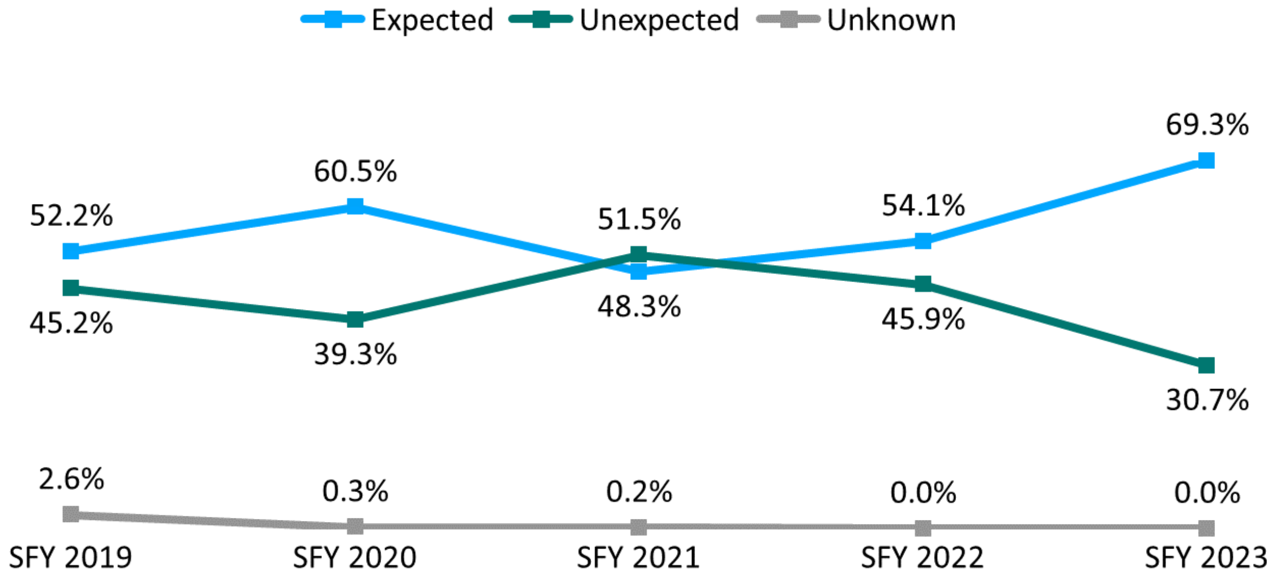
The number of expected and unexpected deaths by year is shown in Table 10. In SFY 2023, 233 out of 336 deaths (69%) were determined to be expected. This represents a 15 percentage point increase from the previous year.

The decrease in unexpected deaths (31% in SFY 2023 vs. 46% in SFY 2022) appears to reflect, in part, the decrease in deaths caused by COVID-19. There were 43 unexpected deaths caused by COVID-19 in SFY 2022 and 48 in SFY 2021. However, in SFY 2023, there were 13 unexpected deaths caused by COVID-19, a 70 percent decrease from the previous year.

Table 10: Expected and Unexpected Deaths, SFY 2019 – 2023

Determination	SFY 2019		SFY 2020		SFY 2021		SFY 2022		SFY 2023	
	Deaths	%	Deaths	%	Deaths	%	Deaths	%	Deaths	%
Expected	163	52%	214	61%	197	48%	225	54%	233	69%
Unexpected	141	45%	139	39%	210	52%	191	46%	103	31%
Unknown	8	3%	1	0%	1	0%	0	0%	0	0%

Figure 1: Expected and Unexpected Deaths, SFY 2019 to SFY 2023



The top categories for cause of death for expected and unexpected deaths are shown in Table 11. The top category for expected deaths was Genetic malformations, deformations, and chromosomal abnormalities, while the top category for unexpected deaths was respiratory disease.

Table 11. Top causes of Expected and Unexpected deaths, SFY 2023

Expected	
Category	**Deaths**
Genetic malformations, deformations, and chromosomal abnormalities	35
Endocrine, nutritional & metabolic disease	33
Respiratory Disease	28
Cancer	27
Congenital malformations, deformations, and chromosomal abnormalities	25

Unexpected	
Category	**Deaths**
Respiratory Disease	37
Cardiovascular Disease	24
Neurological Disorder	10
GI Disease	8
Congenital malformations, deformations, and chromosomal abnormalities	5

Potentially Preventable Deaths

In SFY 2023, the MRC determined 325 out of 336 (97%) of deaths were not potentially preventable based on established criteria. The MRC has made efforts to increase the identification of potentially preventable deaths to ensure that both individual service level and systemic improvements can be identified. However, due to the relatively small number of deaths (as compared to the DD population in Virginia) reviewed annually, some fluctuation in the numbers should be expected. There have been significant efforts through DBHDS to identify and enhance supports to individuals with complex medical and behavioral conditions. For example, DBHDS has made efforts to help providers identify a change in health status and request a re-

evaluation of the individual's SIS level to determine if the person qualifies or a higher level of support. This is one factor that may contribute to the decreased number of potentially preventable deaths, as more individuals are being appropriately reassessed to determine if needs change, however overall, the reasons are likely multifactorial.

Table 12: Potentially Preventable Deaths, SFY 2019 – 2023

Determination	SFY 2019		SFY 2020		SFY 2021		SFY 2022		SFY 2023	
Not potentially preventable	258	83%	328	93%	365	89%	392	94%	325	97%
Potentially preventable	11	4%	17	5%	39	10%	22	5%	11	3%
Unknown	43	14%	9	3%	4	1%	2	0%	0	0%

The top causes of PP deaths are listed in Table 13. As in the previous year, choking was the top cause of PP deaths in SFY 2023 (8 in SFY2022 to 4 in SFY2023). Individuals with IDD are at an increased risk for dysphagia due to the severity of their intellectual disability co-morbid health conditions (ie. Cerebral Palsy, Down Syndrome, Multiple Sclerosis, and other Neurological illnesses), age, and medication side effects. Dysphagia in these individuals is usually chronic and requires strategies, treatments, and modifications to help maintain safe swallowing function and decrease risk for complications while improving healthy outcomes. Per the Journal of Intellectual Disability (2021) and National Library of Medicine, 4.68% of all ID individuals during the years 2005-2017 died from choking (aspiration, ingestion, or inhalation of gastric contents, food or other objects compared to 0.18% of non-ID individuals who died from choking during the same time. Those with mild/moderate ID were 21.6 times more likely to die from choking and severe/profound ID were 30.7 times more likely to die from choking[5].

DBHDS RMRC also identified choking as a care concern which includes any choking incident that requires physical aid by another person, such as abdominal thrusts (Heimlich maneuver), back blows, clearing of airway, or CPR, and is working with the MRC and OIH to implement education and interventions for providers and will continue to monitor choking risk for IDD individuals.

[5] 2005-2017 US Multiple Cause-of-Death Mortality files as noted in Cause of death in adults with intellectual disability in the United States in the Journal Intellectual Disability Research Jan 2021; 65(1): 47–59; and on the National Library of Medicine website: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7710575/.

Table 13: Top Causes of Potentially Preventable Deaths, SFY 2023

Cause of Death Category	Cause of Death	Number
Respiratory Disease	Choking	4
Cardiovascular Disease	Myocardial Infarction	2
Cardiovascular Disease	Congestive Heart Failure	1
Endocrine, nutritional, & metabolic disease	Failure to Thrive/Slow Decline	1
Endocrine, nutritional, & metabolic disease	Aspiration	1
Traumatic Disorder	Trauma	1
GI Disease	Perforated bowel	1

Out of the 11 deaths determined to be PP, eight involved a failure to execute established protocols. The frequency of the four factors for deaths determined to be PP are displayed in Table 14.

Table 14: Factors in Potentially Preventable Deaths, SFY 2023

Factor	Number
Access to care	5
Assessment of and response to, the individual's needs or changes in status	5
Coordination and optimization of care	7
Execution of established protocols	8

Mortality Prevention Strategies

As noted in last year's Annual Report, DBHDS previously consulted with the Center for Developmental Disabilities Evaluation and Research (CDDER) at the Eunice Kennedy Shriver Center at the University of Massachusetts to incorporate the standardized use of mortality prevention strategies within the actions taken by the MRC. These are different from the definition of primary, secondary, and tertiary prevention as defined by the Centers for Disease Control and Prevention (CDC) which focus on specific activities, taken at an individual or practice level, aimed at reducing health risks. It is important to note that mortality prevention strategies aim to systematically identify and group the type(s) of actions recommended or taken by the MRC. This type of categorization aids in the development of more system wide interventions. When a death is determined to be potentially preventable, the MRC assigns that case one or more of these three mortality prevention strategies. Each case may have more than one mortality prevention strategy.

- Primary Prevention Strategies - Educational and changes to services designed to help prevent a condition or event from taking place, that have been found to contribute to morbidity or mortality, such as education on reducing falls.
- Secondary Prevention Strategies – Focus on early detection and timely treatment of conditions or injuries to minimize harmful effects and prevent further morbidity or mortality, such as interventions that support and promote cancer screening.

- Tertiary Prevention Strategies – Optimization of the treatment and management of conditions or injuries, such as ensuring access to evidence-based treatment.

Results indicate that both Primary and Secondary Mortality Prevention Strategies were the most frequently assigned by the MRC in order to strengthen prevention strategies, decrease risk of future incidents, and maintain a safe environment. The majority of the quality improvement initiatives and targeted interventions focused on education to the provider community, individual and family or caregivers, as well as efforts to increase focus on early detection and timely interventions. The MRC will continue to monitor these strategies for trend data as this was the first year of implementation.

Table 15: Mortality Prevention Strategies Identified for PP Deaths

Level	Number
Primary	7
Secondary	7
Tertiary	4

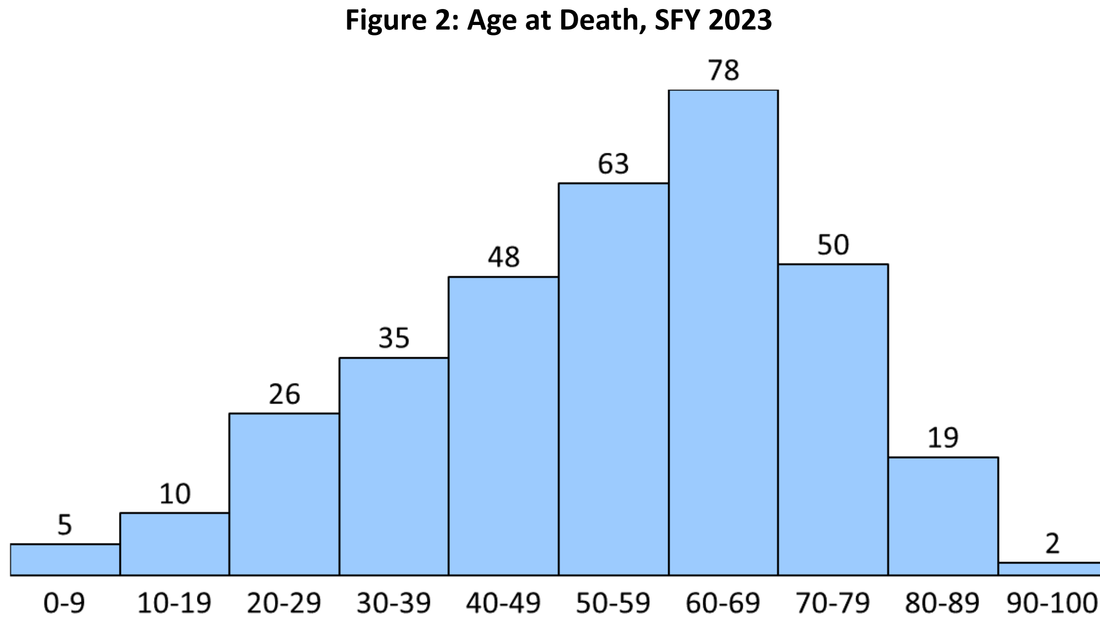
Population Demographics

This section includes demographic trends for individuals reviewed by the DBHDS IDD MRC. A separate comparison shows mortality rates for individuals authorized to receive DD waiver services. The crude mortality rate is the total number of deaths within a specific timeframe divided by the mid-interval population, adjusted per 1,000. Crude mortality rate here is reported for the DD waiver population as the denominator can be validated and compared from year to year.

The overall crude mortality rate for SFY 2023 was 17.49 deaths per 1,000, a decrease compared to the rate of 23.6 in SFY 2021. There was a decrease in CMR in every age group except for individuals 81+ years old, where there was an increase to 185.19 in SFY 2023 from 166.7 in SFY 2022. Notably, there was large increases in the number of individuals on the waiver ages 0-40 years old, which likely contributed to the decline in CMR. There are a number of factors that impact crude mortality rate, such as age, gender, and race, which are further shown within this section. Additional factors are conducted for the individual's service program. In Virginia, the Supports Intensity Scale (SIS) is used as an assessment to develop a service program that reflects the array of services and supports that an individual may receive to meet their needs.

Age

Number of deaths by age group for all deaths reviewed by the MRC is shown in Figure 2 below.



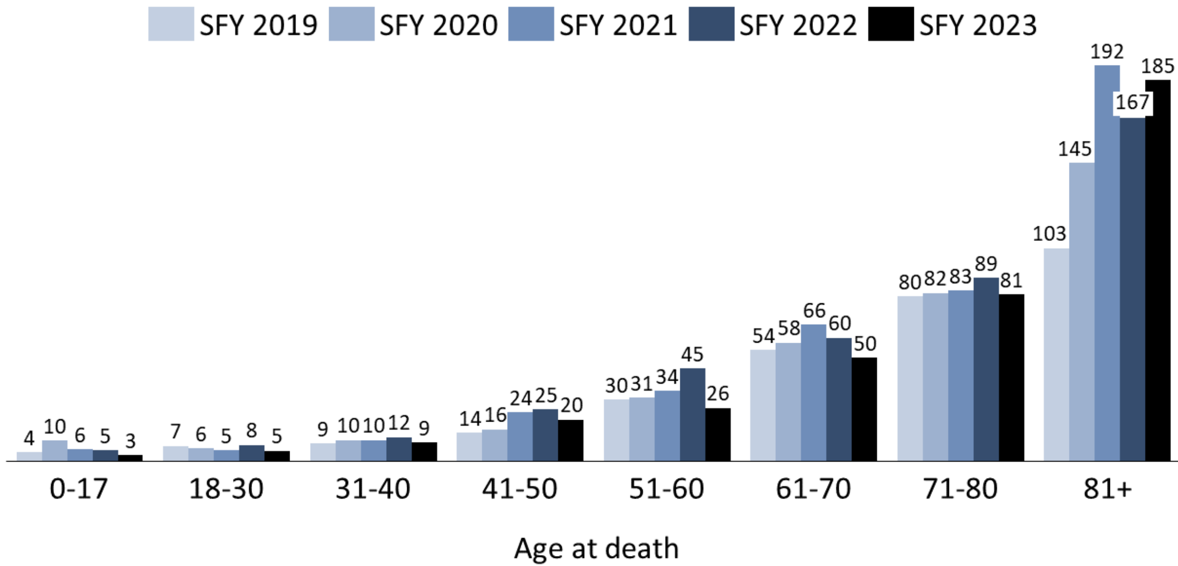
The Crude Mortality Rate by age for individuals receiving waiver services is displayed in Table 15. As in previous years, the rates were higher among older age groups.

Table 16: Crude Mortality Rates by Age per 1,000 population, SFY 2023

Age Group	Waiver Deaths	Waiver Population	Crude Mortality Rate
0-17	3	1020	2.94
18-30	28	5645	4.96
31-40	32	3486	9.18
41-50	43	2122	20.26
51-60	52	2018	25.77
61-70	71	1416	50.14
71-80	41	507	80.87
81+	15	81	185.19

Figure 3 below compares the CMR by age group for SFY 2019 – SFY 2023. The rates for SFY 2023 are similar to those observed in previous years.

Figure 3: CMR by Age Group, SFY 2019 – SFY 2023



Gender

The CMR by gender for waiver recipients is displayed in Table 17. Out of the 285 deaths of individuals receiving waiver services in SFY 2023, 61% were male, which is consistent with the distribution of the waiver population.

Compared with the previous year, the CMR declined about equally for both male and female individuals, from 23.9 to 17.7 for female individuals and from 23.4 to 17.4 for male individuals.

Table 17: Crude Mortality Rates by Gender per 1,000 population, SFY 2023

	Waiver Deaths	Waiver Population	Crude Mortality Rate
Female	110	6230	17.66
Male	175	10063	17.39
Unknown		2	
Total		**16295**	**17.49**

The Top Cause of Death Category by gender is shown in Table 18, and respiratory disease was the top category, followed by cardiovascular disease for both male and female individuals.

Table 18. Top Cause of Death Categories by Gender, SFY 2023

Female	
Category	**Deaths**
Respiratory Disease	25
Cardiovascular Disease (CVD)	17
Endocrine, nutritional & metabolic disease	14
Congenital malformations, deformations and chromosomal abnormalities	13
Cancer	11

Male	
Category	**Deaths**
Respiratory Disease	40
Cardiovascular Disease (CVD)	31
Genetic malformations, deformations and chromosomal abnormalities	24
Endocrine, nutritional & metabolic disease	23
Infectious Disease	21

Race

All deaths by race for individuals reviewed by the MRC in SFY 2023 is shown in Table 19. The average age at death for all Caucasian individuals was 55.6 years old, while the average age for Black/African American individuals was 50.9 years old.

Table 19: All Deaths by Race, SFY 2023

Race	Number	Percentage
Caucasian	237	70.5%
Black/African American	87	25.9%
Other	3	0.9%
Unknown	3	0.9%
Other Multi-Race	2	0.6%
Asian	2	0.6%
American Indian or Alaska Native and Black or African American	1	0.3%
Native Hawaiian or Other Pacific Islander	1	0.3%
Total	**336**	

Table 20: Waiver Deaths by Race, SFY 2023

Race	Waiver Deaths	Waiver Population	CMR
Caucasian	203	9923	20.46
Black/African American	75	4763	15.75
Other	6	1551	3.87
Unknown	1	58	17.24
Total	**285**	**16295**	**17.49**

Table 20 displays the CMR by race for SFY 2023. As in the previous year, the CMR for Caucasian individuals is slightly higher than the CMR for Black/African American individuals.

The top cause of death categories by race for Caucasian and Black/African American individuals is shown in Table 21. Respiratory Disease was the top category for both groups, followed by cardiovascular disease.

Table 21: Top Cause of Death Categories by Race, SFY 2023

Caucasian		Black/African American	
Cause	**Deaths**	**Cause**	**Deaths**
Respiratory Disease	43	Respiratory Disease	18
Cardiovascular Disease	30	Cardiovascular Disease	15
Genetic malformations, deformations, and chromosomal abnormalities	28	Endocrine, nutritional, & metabolic disease	11
Endocrine, nutritional, & metabolic disease	25	Infectious Disease	8
Congenital malformations, deformations, and chromosomal abnormalities	22	Cancer	7
Cancer	21	Congenital malformations, deformations, and chromosomal abnormalities	7

Services and Supports

CMR for individuals receiving waiver services by Supports Intensity Scale (SIS) level is shown in Table 22. Consistent with previous years, the CMR for individuals with SIS Levels 1-3 was low compared with individuals with higher levels.

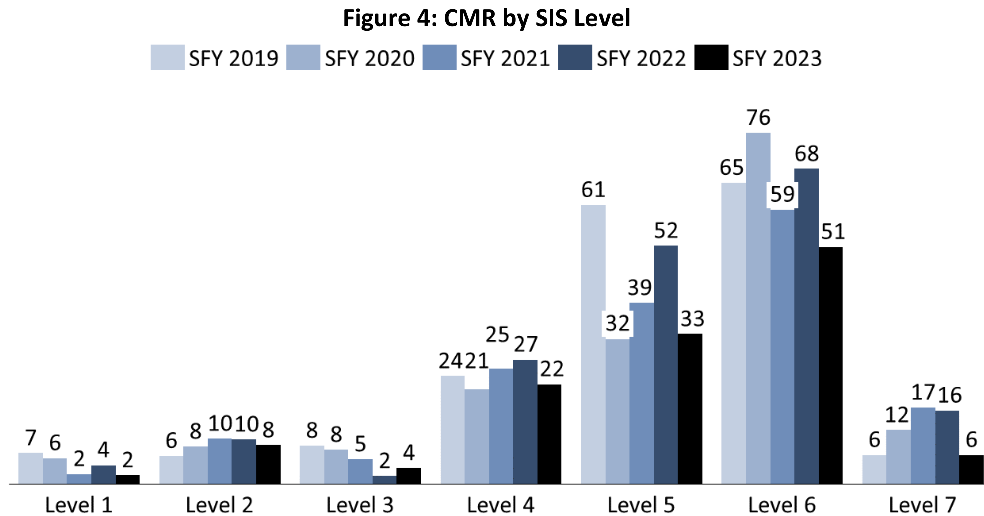
As in the previous year, the CMR was highest for individuals with a SIS level of 6, which reflects individuals with high levels of medical supports. The rate for individuals with SIS Level 6 decreased from 68.4 in SFY 2022 to 51.5 in SFY 2023. The top cause of death categories for these individuals were respiratory disease (12), Congenital malformations, deformations and chromosomal abnormalities (12), Genetic malformations, deformations and chromosomal abnormalities (9), Endocrine, nutritional & metabolic disease (8), Infectious Disease (7). The median age was 55, and the average age was 52. Two of the deaths in this group were determined to be Potentially Preventable in SFY 2023.

The CMR for individuals with SIS Level 7 decreased from 16.0 in SFY 2022 to 6.4 in SFY 2023.- However, only 6.7% of the individuals receiving waiver services fall into this category, so some random fluctuation is expected based on the relatively small size of this group.

Table 22: Deaths and CMR by SIS level, SFY 2023

SIS Level	Waiver Deaths	DD Waiver Population	CMR
1	2	1008	**1.98**
2	46	5421	**8.49**
3	2	563	**3.55**
4	134	6166	**21.73**
5	21	644	**32.61**
6	72	1399	**51.47**
7	7	1094	**6.40**
Total	**285**	**16295**	**17.49**

CMR by SIS level for the past five years is shown in the Figure 4. Individuals with SIS Level 6 have consistently had a higher CMR than individuals at other SIS levels, although the rate dropped significantly from last year.



Residential Setting

In previous reports, types of residential settings were grouped into one of five categories: independent living, congregate living, community institutional living, state facility, and unknown. To better identify service specific settings and potential opportunities for targeted interventions, the MRC listed specific residential locations as captured through the case reviews. Deaths by residential setting is indicated here in Table 23.

Table 23: Deaths by Residential Setting, SFY 2023

Residence	Deaths	Percent
Group Home	147	43.8%
Private Residence w/ Family	74	22.0%
Sponsored Placement	34	10.1%
ICF/IID	26	7.7%
NF/SNF/ALF	26	7.7%
Private Residence Other	17	5.1%
State Facility	8	2.4%
Inpatient Care	3	0.9%
*Other	1	0.3%

**Other denotes one individual with IDD who was unhoused during the 90 days prior to death. This individual declined assistance and other efforts by DBHDS and other entities to obtain housing and was also incarcerated at times during this period.*

CMR for individuals receiving waiver services in a congregate or institution setting, versus those living independently (including with family) is shown in Table 24. As in the previous year, the CMR for individuals in congregate or institutional settings was higher.

Table 24: CMR by Living Situation for DD Waiver Recipients, SFY 2023

Residential Living Situation	Deaths	DD Waiver Population	Crude Mortality Rate
Congregate or institution	174	4300	40.47
Independent	110	11995	9.17

Conclusion

In conclusion, this mortality review report sheds light on some of the distinct health challenges faced by individuals with intellectual and developmental disabilities. This year, Failure to Thrive was noted to be a top cause of mortality, which will drive future activities toward increased monitoring and the development of focused interventions.

It is evident that individuals with disabilities in Virginia and nationwide encounter variations in health characteristics and management compared to their non-disabled counterparts. Early recognition and intervention by licensed providers by the Department of Behavioral Health and Developmental Services (DBHDS) are important in addressing existing and potential health risk factors for all I/DD individuals. At the same time, there are ongoing efforts to remove barriers to healthcare and improve access to regular preventive services. This report is an important part of these efforts.

As the landscape of community living evolves for individuals with IDD, the Commonwealth remains dedicated to fostering the highest quality of life through accessible services and supports. With the improvements in the quality management process, the system more readily identifies opportunities to improve critical functions, including health and safety, person-

centered service planning, access to services, human rights, freedom from abuse and neglect, and outcome management.

The application of mortality prevention strategies will continue to be refined to tailor these approaches and achieve meaningful outcomes. This shift in focus involves the identification of risk factors predisposing individuals with IDD to negative outcomes, emphasizing the role these factors play in implementing interventions. The committee will continue to review, revise and update its processes, incorporating evidence-based practices and data-driven initiatives to further enhance its contribution to the welfare of individuals with developmental disabilities.