DBHDS

Virginia Department of Behavioral Health and Developmental Services

A Life of Possibilities for All Virginians

SFY 2024 Annual Mortality Report

December 2024

1220 Bank Street • P.O. Box 1797 • Richmond, Virginia 23218-1797
Phone: (804) 786-3921 • Fax: (804) 371-6638 • Web site: www.dbhds.virginia.gov

Contents

Executive Summary

This is the tenth 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) 2024, as reported in the DBHDS incident reporting systems. SFY 2024 covers July 1, 2023 to June 30, 2024.

As of January 5, 2024[1], there were 16,852 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 within 90 days of their death, and who were diagnosed with IDD are reviewed.

Analysis of the mortality trends, patterns, and problems can identify opportunities for system improvements that reduce risks to all IDD individuals 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 (QIIs) to reduce mortality rates to the fullest extent practicable.

Key Findings

- The DBHDS IDD MRC reviewed 370 deaths in SFY 2024, a 10% increase from SFY 2023 when 336 deaths were reviewed.
- The MRC utilizes a two-tier review process, which allows a more precise focus on Tier 1 unexpected (UXP) or unexplained deaths. These deaths are categorized as Tier 1, or Tier 2 per criteria listed below. Of the 370 deaths reviewed in SFY 2024, 203 deaths (54.9%) were categorized as Tier 1, and 167 deaths (45.1%) were categorized as Tier 2.
- The median age at time of death was 58 years old, an increase of one year from SFY 2023. The mean age at death was 54 years old in the previous three years.
- The leading cause of death in SFY 2024 was cancer with metastasis, as compared with SFY 2023 when the leading cause was failure to thrive/slow decline.

[1] January 5th was selected as a snapshot date for the middle of the SFY.
[2] Virginia Waiver Management System. Accessed by DBHDS in October 2024.

- The MRC determined more deaths were expected (XP) (288 deaths, 77.8%) than UXP (81 deaths, 21.9%) with one death ruled as unknown (unable to determine cause due to limited information received).
- Deaths were also group into disease categories based on the International Classification of Diseases-10 (ICD-10) to capture potential underlying diseases experienced by the population reviewed. The top category of expected deaths was Genetic malformations, deformations, and chromosomal abnormalities. The top category of UXP deaths was Cardiovascular Disease (CVD).
- Four deaths (1%) were determined to be potentially preventable (PP) in SFY 2024, a decrease from SFY 2023 when 11 deaths (3%) were determined to be PP. All four involved a failure to execute established protocols, and three involved failure to coordinate and optimize care.
- Failure to Thrive (FTT), a condition in which an individual loses weight or does not maintain weight that results in serious illness, and Protein Calorie Malnutrition (PCM) leading to muscle wasting, accounted for 21/370 (5.7%) deaths in SFY24.

Recommendations

Analysis and review of mortality data remain cornerstones of health and safety oversight within DBHDS. These efforts allow for identification of patterns and/or trends that may alleviate risk factors for the IDD individuals served by DBHDS. Furthermore, this analysis guides system enhancement through process improvement and informs recommendation development based on findings. The DBHDS IDD MRC provides recommendations for system-focused QIIs from trends identified during case review on an ongoing basis in order to ensure safe, effective, person-centered, timely, efficient, and equitable care for all individuals with IDD. Data analysis, which includes review of data presented in this report, the MRC makes at least four annual recommendations for systemic QIIs, and reports these to the DBHDS Commissioner and the Quality Improvement Committee (QIC). The recommendations below incorporate new findings from the current year and build upon data and recommendations identified in previous years.

Recommendation 1: The MRC should increase implementation of specific interventions for individuals with FTT/Slow Decline and PCM in an effort to impact mortality prevention strategies for the IDD population. FTT and PCM accounted for 21/370 deaths in SFY24.

Recommendation 2: The MRC should determine if there are patterns of similar or correlating environmental and/or medical components (i.e., medical conditions, residence type, supports, dietary protocols/restrictions, etc.) that may be contributing factors or areas of targeted interventions for individuals with a Supports Intensity Scale (SIS) Level 6, as Crude Mortality Rate (CMR) remains highest (64.3%) among these IDD individuals in Virginia.

Recommendation 3: The MRC should attempt to decrease repeated emergency department (ED) visits for IDD individuals related to the same health issue/concern, as MRC members noted an upward trend in ED utilization (based on DBHDS incident reporting data) during multiple case reviews.

Recommendation 4: The MRC should explore the incidence of pressure injuries in IDD individuals with increased risk factors for developing serious infection as a result of pressure injuries (i.e., non-ambulatory and non-verbal) in an effort to decrease risk for Sepsis, as Sepsis accounted for cause of death in 26/370 deaths in SFY24. Of the 26 Sepsis deaths (N=370), the number of pressure injuries as a factor can be explored as pressure cases are denoted during case composition.

Status of Recommendations from SFY 2023

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. DBHDS developed an Annual Wellness Toolkit for licensed providers which was posted to the Office of Integrated Health (OIH) website August 2, 2023. A preventive screenings field was also implemented on Individual Supports Plan (ISP) and the Waiver Management System (WaMS) forms, as of July 20, 2023 to ensure accurate documentation of preventive screenings. Review of ISP data showed overall decreases in the number of preventive screenings performed. This is thought to be reflective of an overall increase in the number of waiver recipients. Additional work is underway with WaMS which will inform further data analysis.

Recommendation 2: The MRC should determine if there are patterns of similar or correlating environmental and/or medical components (i.e., 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.

The MRC completed a Retrospective Case Series Cross-Sectional Review (RCSCSR) on Potentially Preventable (PP) Choking deaths. Data analysis showed that the top 3 contributing factors to the PP Choking deaths were: Failure to execute established protocols, 2 or more existing diagnoses that increased choking risk, and 2 or more medications that increased choking risk. The MRC developed recommendations based on these findings and distributed them to DBHDS subcommittees as appropriate 04/09/2024. A retrospective case series cross-sectional review is an observational analysis of pre-existing events that already occurred, collected solely from medical records or other documentation (retrospective). Data from multiple similar IDD cases reviewed by the MRC (case series) at a single point in time (cross sectional) were analyzed to identify potential correlating factors.

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

The MRC developed a potential QII surrounding further investigation of case-specific reasons for failure to adhere to established protocols. During the process of developing this QII, it was discovered that each failure to adhere to established protocols resulted in an Office of Licensing (OL) Corrective Action Plan (CAP), and limited additional data surrounding failure to execute established protocols was available. The only manner for obtaining additional information would be in-person interviews with licensed providers involved, which was not feasible this year due to

available resources. Further research is needed to identify proven strategies to improve compliance in the adherence and execution of established protocols.

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

The MRC developed a potential QII on FTT and PCM in effort to improve care provided to IDD individuals with these diagnoses. During the QII development process, DBHDS determined that additional data was required. This topic will continue to be explored in SFY24.

Background

Purpose

The purpose of the DBHDS IDD MRC is to focus on system-wide quality improvement by conducting mortality reviews of IDD individuals 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 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 QIIs to promote the health, safety, and well-being of IDD individuals 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 2024, the MRC met 24 times, and both membership requirements and quorum were met at each meeting.

For all IDD decedents, and within 90 calendar days of a death, the Mortality Review Office (MRO) compiled 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 2024

The MRC:

- Updated and divided the MRC Charter into two documents, a Policy document and a Standard Operating Procedures (SOP) document, which are now available electronically through PowerDMS, the DBHDS policy management system.
- The MRC continued to monitor use of the electronic Mortality Review Form's data elements for collection, tracking and analysis to ensure continued data reliability and validity
- Expanded collaboration with the Virginia Department of Health and the DBHDS data warehouse in order to identify IDD deaths requiring mortality review for those deaths that occurred outside of Virginia (which in this state fiscal year included Tennessee and West Virginia). These efforts were undertaken to address and decrease gaps in available demographic data.

Key Definitions

- Expected (XP) 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 (UXP) 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 UXP 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 UXP death. An unexplained death is also an UXP death.
- Unknown may be used in two distinct contexts - If there is insufficient information to classify a death as either XP or UXP, OR there is insufficient information to make a determination as to the cause of death (CoD).
- Other (CoD) denotes a CoD 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 related to factors for which an actionable intervention may be taken by DBHDS or within the administrative or regulatory authority 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 then 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 (more than one factor may be identified):
    - 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:
    - CoD cannot clearly be determined, established, or is unknown
    - Any UXP 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 4 criteria exist:
  - CoD 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 are noted.
  - An XP 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 UXP (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 UXP death.

For actions recommended by the MRC, the MRC shall consider if one of the following 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 CoD in 369 out of 370 (99.7%) of cases, with only one death classified as having an unknown cause.

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

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
SFY 2024	1

The Code of Virginia Section § 37.2-314.1 (SB 482, 2020) grants the MRC increased access to information and records, relevant to all IDD deaths reviewed by the MRC. This includes access to Virginia state death certificates through the Virginia Department of Health and autopsy results through the Office of the Chief Medical Examiner.

The decrease in the number of deaths classified as Unknown, are related to the detailed cause of death classification versus the broader category of deaths utilized in previous years.

The number of deaths by cause are displayed in Table 2. The most common CoD for SFY 2024 was cancer with metastasis.

The number of deaths caused by COVID-19 decreased from 16 in SFY 2023 to 8 in SFY 2024.

Table 2: Number of Deaths by Cause, SFY 2024

Cause Of Death	Count
Cancer w/metastasis	31
Sudden Cardiac Death	29
Sepsis	26
Cerebral Palsy	24
Pneumonia	22
Failure to Thrive/Slow Decline	19
Down Syndrome	14
Congestive Heart Failure	12
Acute Respiratory Failure	11
Aspiration Pneumonia	10
COVID-19	8
Dementia	8
Intracranial Hemorrhage	8
Alzheimer's disease	7
Stroke (Cerebrovascular Accident or CVA)	7
Epilepsy	6
Seizure	6
Cancer w/o metastasis	5
Accident	4
Cardiac Arrythmia	4
Choking	4
Coronary Artery Disease (CAD)	4
Myocardial Infarction (MI)	4
Cirrhosis	3
Cornelia de Lange syndrome	3
Gastrointestinal bleed	3
Intestinal Obstruction	3
Aspiration* (pulmonary)	2
Duchenne Muscular Dystrophy	2
Joubert Syndrome	2
Lennox Gastaut Syndrome	2
Muscular Dystrophy	2
Parkinson's disease	2
Protein calorie/energy malnutrition	2
Pulmonary Embolism	2
Pulmonary Fibrosis	2
Rett Syndrome	2
Sanfilippo Syndrome (Mucoploysacchrides Type III or MPSIII)	2
Sudden Unexplained Death in Epilepsy	2
Other (Causes appearing once, listed below)	61
Total	**370**

*Change in Cause of Death Category for Aspiration is based on ICD-10 FY2025 revision released Oct 2024

The following causes of death were found only once in SFY 2024: Achondroplasia, Acute Lymphoblastic Leukemia, Aicardi Syndrome, Airway hemorrhage from tracheo artery fistula 2/2 tracheostomy, Aortic Dissection, Asthma, Biliary cirrhosis, Bohring-Opitz Syndrome, Cerebral Atherosclerosis, Cerebral Hemophagocytic Lymphohistiocytosis, Cerebro-oculo-facio-skeletal (COFS) syndrome, Charcot-Marie Tooth Disease, **C**oloboma, **H**eart defects, **A**tresia choanae, **R**etardation of growth & development, **G**enital abnormalities, **E**ar anomalies (CHARGE syndrome), Chromosome 16p13.11 microduplication, Chronic Respiratory Failure, Chronic Kidney Disease, Dandy Walker Syndrome, Diabetic Ketoacidosis, Drowning, Fragile X Syndrome, Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS), Holoprosencephaly Sequence, Homicide, Human Metapneumovirus Infection, Hypoglycemia, Influenza, Influenza A, Ischemic Cardiomyopathy, Joubert Syndrome, Kearns-Sayre Syndrome, Kleefstra Syndrome, Leukemia, Mediastinal mass/Cancer, Metabolic acidosis, Metabolic Encephalopathy, Microcephaly, Mitochondrial Metabolism Disorder, Mixed Connective Tissue Disorder, Moebius Syndrome, Myasthenia Gravis, Necrotizing fasciitis, Noonan Syndrome, Obesity Hypoventilation Syndrome, Ocular Cancer, Ogilvie syndrome (acute colonic pseudo-obstruction), Other: Hemophagocytic Lymphohistiocytosis (HLH), Partial Trisomy 21 and 22 (Down syndrome w/*Mosaic trisomy 22), Periventricular Leukomalacia, Refsum, Respiratory failure 2/2 unknown infectious source, Stercoral colitis, Subdural Hematoma, Traumatic Brain Injury (TBI), Thrombosed Mechanical Mitral Valve, Treacher-Collins Syndrome, Ulcerative Colitis, Unknown, Variegate Porphyria (complications of), Velocardiofacial Syndrome, Volvulus, Von Willebrand's Disease, and Williams Syndrome.

Current and historical CoD are coded into categories so that trend data can be tracked more easily. Table 3 displays trend data by cause of death category. These categories will be used throughout the report.

Table 3: Number of Deaths by Category, SFY 2018 – SFY 2024

Category	SFY18	SFY19	SFY20	SFY21	SFY22	SFY23	SFY24
Accident	2	1	2	3	4	2	5
Birth injury central nervous system disease						1	1
Cancer	23	30	34	33	33	29	40
Cardiovascular Disease	41	39	71	67	53	48	56
Congenital malformations, deformations, and chromosomal abnormalities	2	13	5	18	28	30	28
Drug Toxicity/Overdose	1		1	7		1	
Endocrine, Nutritional, & Metabolic Disease	31	15	27	17	35	37	27
Gastrointestinal (GI) Disease	11	10	12	13	15	16	14

Category	SFY18	SFY19	SFY20	SFY21	SFY22	SFY23	SFY24
Genetic malformations, deformations, and chromosomal abnormalities	11	9	16	18	29	35	51
Harm to self/Suicide				1			
Hematological Disease	3	1		2	1		1
Infectious Disease	17	19	41	23	26	26	28
Mental, Behavioral and Neurodevelopmental Disorder						1	
Multiple Medical Problems*	10	8					
Musculoskeletal and Connective Tissue Disease	2	1	8	2	2		
Neurodegenerative Disorder	5	18	7	21	10	8	9
Neurological Disorder	9	19	24	36	41	25	40
Post-Operative Complications	6	3	3	3	3	3	
Renal Disease	9	11	6	8	7	4	1
Respiratory Disease	43	72	79	132	120	65	67
Traumatic Disorder	1	1	2	2	8	4	1
Unknown	34	42	16	2	1	1	1
Total	**261**	**312**	**354**	**408**	**416**	**336**	**370**

*Discontinued in SFY 2020

The number of deaths by category for individuals who were not receiving a waiver service are reported in Table 4. Respiratory Disease was also the top category for this group.

Table 4: Cause of Death Category for Non-Waiver Individuals, SFY 2024

Cause of Death Category	Deaths
Respiratory Disease	13
Cancer	11
Genetic malformations, deformations and chromosomal abnormalities	5
Cardiovascular Disease (CVD)	5
Congenital malformations, deformations and chromosomal abnormalities	5
Neurological Disorder	4
Infectious Disease	4
Endocrine, nutritional & metabolic disease	3
Neurodegenerative disorder	2
Accident	1

Cause of Death Category	Deaths
Total	**53**

End of Life Care

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.

If an individual has a Do Not Resuscitate (DNR) order or active hospice care, this does not necessarily mean that the death is XP or not PP per the Committee's definitions.

DNR Status

The number and percentage of individuals who had a DNR in place is displayed in Table 5. The percentage has increased over time, but after reaching a high of 75% in SFY 2023, the number dropped back down to 65% in SFY 2024.

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

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%
SFY 2024	240	130	65%

DNR status by residential setting is displayed in Table 6. Individuals who lived in a group home, Nursing Facility/Skilled Nursing Facility/Assisted Living Facility, or state facility, were most likely to have a DNR in place.

Table 6: DNR by Residential Setting, SFY 2024

Residence	DNR	Total	Percent
Group Home	95	144	66%
Private Residence with Family	56	94	60%
Sponsored Placement	37	51	73%
Nursing Facility/Skilled Nursing Facility/Assisted Living Facility	21	23	91%
Intermediate Care Facility for Individuals with Intellectual Disabilities	17	19	89%
Private Residence Other	10	28	36%
State Facility	3	10	30%
Other	1	1	100%
Total	**240**	**370**	**65%**

Hospice

Of the 370 individuals who died in SFY 2024, 139 were receiving hospice services (38%), a slight decrease from the previous year.

Table 7: Hospice Services by SFY

SFY	Receiving Hospice
SFY 2020	35%
SFY 2021	34%
SFY 2022	34%
SFY 2023	39%
SFY 2024	38%

Hospice services by residential setting are displayed in Table 8. Individuals who lived in a group home, sponsored placement, or Nursing Facility/Skilled Nursing Facility/Assisted Living Facility were most likely to be receiving hospice services.

Table 8: Hospice Services by Residential Setting, SFY 2024

Residence	Hospice	Total	Percentage
Group Home	50	144	35%
Private Residence with Family	34	94	36%
Sponsored Placement	19	51	37%
Nursing Facility/Skilled Nursing Facility/Assisted Living Facility	19	23	83%
Intermediate Care Facility for Individuals with Intellectual Disabilities	9	19	47%
Private Residence Other	5	28	18%
State Facility	3	10	30%
Other		1	0%
Total	**139**	**370**	**38%**

The number and percentage of individuals receiving hospice services by age group is shown in Table 9. As in previous years, hospice services were most common among individuals in the 81+ category, followed by individuals 71-80 years old.

Table 9: Hospice Services by Age Group, SFY 2024

Age Group	Hospice	Total	Percentage
0-17	3	14	21%
18-30	12	48	25%
31-40	10	39	26%
41-50	10	31	32%
51-60	25	80	31%
61-70	38	81	47%
71-80	30	59	51%
81+	11	18	61%
Total	**139**	**370**	**38%**

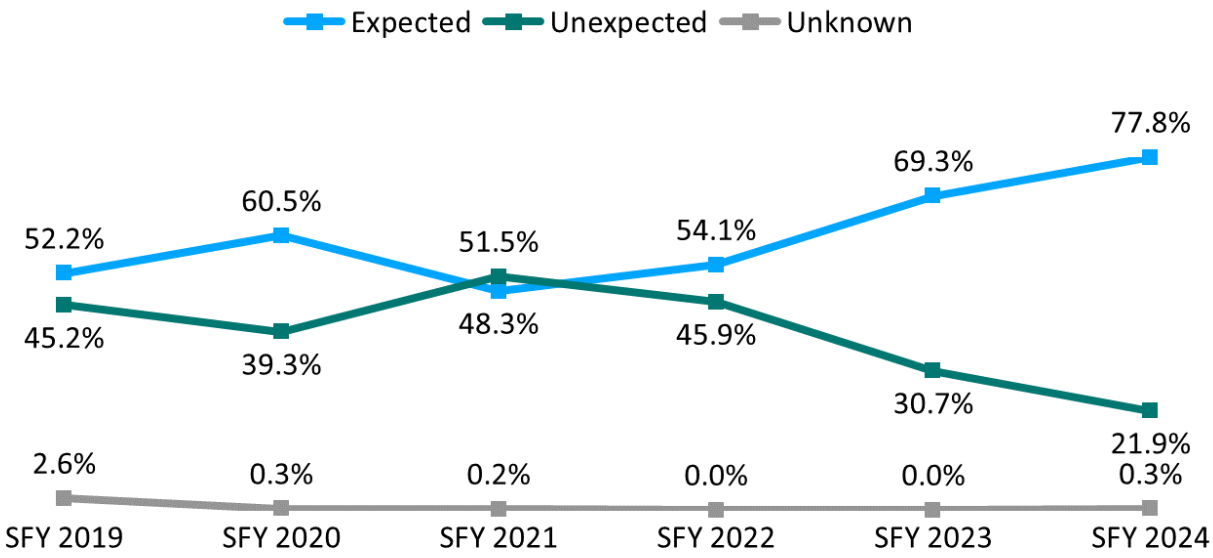
Expected (XP) and Unexpected (UXP) Deaths

The number of XP and UXP deaths by year is shown in Table 10. In SFY 2024, 288 out of 370 deaths (78%) were determined to be XP. This is the highest percentage and absolute number in the past six years. The increase might be attributed to the use of more specific CoD determinations than were previously utilized. The MRC continues to receive more comprehensive and detailed medical records leading to the death of the individual. It has been noted that many IDD individuals have long standing complex medical histories that are notably addressed within their care team. The MRC reviews the timeliness, quality, and individual's choice of care within these reviews to make this determination.

Table 10: XP and UXP Deaths, SFY 2019 – 2024

Year	XP	UXP	Unknown	% XP
SFY 2019	163	141	8	52%
SFY 2020	214	139	1	61%
SFY 2021	197	210	1	48%
SFY 2022	225	191	0	54%
SFY 2023	233	103	0	69%
SFY 2024	288	81	1	78%

Figure 1: XP and UXP Deaths, SFY 2019 - SFY 2024



The top categories for cause of death in expected and unexpected deaths are shown in Table 11. As in the previous year, the top category for expected deaths was 'Genetic malformations, deformations, and chromosomal abnormalities.' The top cause for unexpected deaths was Cardiovascular disease (CVD).

Table 11: Top causes of XP and UXP deaths, SFY 2024

XP	
Category	**Deaths**
Genetic malformations, deformations, and chromosomal abnormalities	50
Respiratory Disease	50
Cancer	40
Infectious Disease	27
Neurological Disorder	27
Congenital malformations, deformations, and chromosomal abnormalities	27

UXP	
Category	**Deaths**
Cardiovascular Disease	34
Respiratory Disease	17
Neurological Disorder	13
Gastrointestinal Disease	6
Accident	5
Endocrine, nutritional, & metabolic disease	2

Potentially Preventable (PP) Deaths

The number of PP Deaths by SFY is displayed in the following table. Four deaths were determined to be PP in SFY 2024. This is the lowest percentage in six years and may be attributed to positive outcomes from effective care and identified supports by DBHDS providers that were influenced over the years by not only the MRC, but by other Offices within DBHDS to promote the health, safety, and well-being of IDD individuals.

Table 12: PP Deaths, SFY 2019 – 2024

SFY	Not PP	PP	Unknown	% PP
SFY 2019	258	11	43	3.5%
SFY 2020	328	17	9	4.8%
SFY 2021	365	39	4	9.6%
SFY 2022	392	22	2	5.3%
SFY 2023	325	11	0	3.3%
SFY 2024	365	4	1	1.1%

The causes of the four PP deaths are listed in Table 13. While choking was the top cause of PP death in SFY 2023 (8 deaths) and SFY 2022 (4), only one death was caused by choking in SFY 2024. This death was classified as unknown CoD since the actual CoD was unable to be determined. This individual was residing in a private residence and information was limited despite interviews, additional records from the primary care provider, personal aides, and other sources that were contacted. The MRC continues to work with the relevant offices at DBHDS to identify and aid in the development of proven strategies to increase provider compliance with adherence and execution of established protocols as this continues to be noted as a PP factor.

Table 13: Top Causes of PP Deaths, SFY 2024

Cause of Death	Number
Accident (fall with head injury)	1
*Aspiration	1
Acute Respiratory Failure	1
Choking	1

*Change in Cause of Death Category for Aspiration is based on ICD-10 FY2025 revision released Oct 2024

Efforts thought to have contributed to the decrease in PP choking deaths are related to the MRC recommendations to the DBHDS Risk Management Review Committee and Office of Integrated Health. The MRC suggested education on awareness of choking risk as a care concern and worked with these two DBHDS Offices to implement education and interventions for DBHDS providers. Educational interventions suggested a focus on: improving consistency of dietary care across all environments, ensuring inclusion of dietary supervision requirements and meal plans in ISP, and enhancing case management manual diet/nutrition components. The frequency of the four factors for deaths determined to be PP are displayed in Table 14. All four PP deaths involved a failure to execute one of the following established protocols: medication management, fall precautions, emergency management, and diet/food consistency protocols (related to providing food that was not part of the individual's diet protocol). Each protocol failure was addressed by the Office of Licensing, the Office of Human Rights, and/or the Department of Medical Assistance Services. This data was a factor for Recommendation #2 of this report. Coordination and optimization of care was an issue in all but one of the PP deaths.

Table 14: Factors in PP Deaths, SFY 2024

Factor	Number
Access to care	1
Assessment of and response to, the individual's needs or changes in status	2
Coordination and optimization of care	3
Execution of established protocols	4

Population Demographics

The Crude Mortality Rate (CMR) for population categories is calculated by dividing the number of deaths in the relevant category by the number of individuals receiving waiver services in the same category, times one thousand, to represent the number of deaths per thousand.

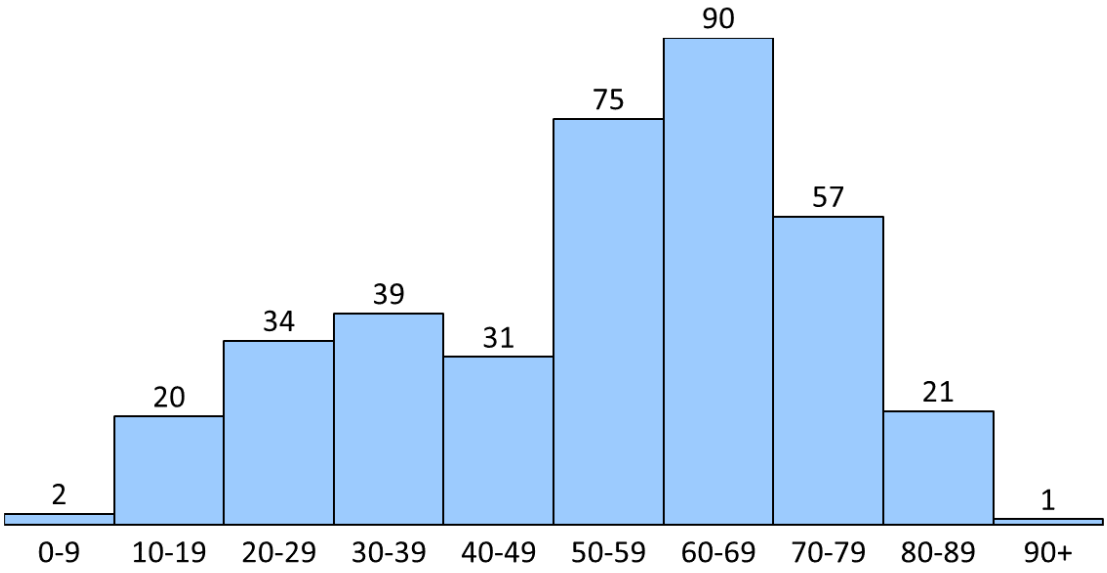
The CMR helps the MRC to see if deaths are disproportionately occurring among certain subpopulations. However, some differences are inevitable because some groups are at greater risk. For example, older individuals are expected to have a higher CMR than younger individuals.

The CMR can be used to detect and investigate trends and outliers; however, it cannot be used to draw conclusions, because there are many confounders. For example, the CMR is higher for individuals who live in group homes and other congregate settings, but this is partly because these individuals are older than those who live independently.

Age

The number of deaths by age group for all deaths reviewed by the MRC is shown in the figure below.

Figure 2: Deaths by Age Group, SFY 2024



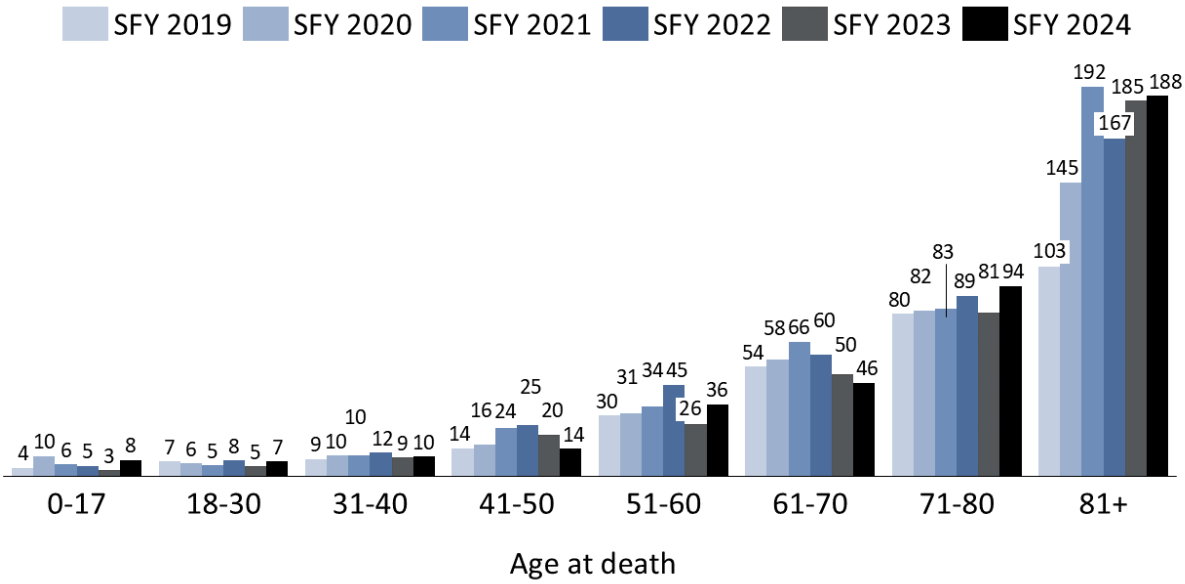
The CMR by age for individuals receiving waiver services is displayed in Table 15. As in previous years, the rates were higher among older age groups, with the highest CMR found for individuals aged 81 or older.

Table 15: CMR by Waiver Service & Age per 1,000 population, SFY 2024

Age Group	Waiver Deaths	Waiver Population	CMR
0 - 17	8	987	8.1
18 - 30	43	5932	7.2
31 - 40	36	3682	9.8
41 - 50	31	2263	13.7
51 - 60	69	1943	35.5
61 - 70	67	1453	46.1
71 - 80	48	512	93.8
81 or Greater	15	80	187.5

The figure below shows the CMR by age over time. The rates for all age groups have remained consistent over the past six years

Figure 3: CMR by Age Group, SFY 2019 - SFY 2024



Gender

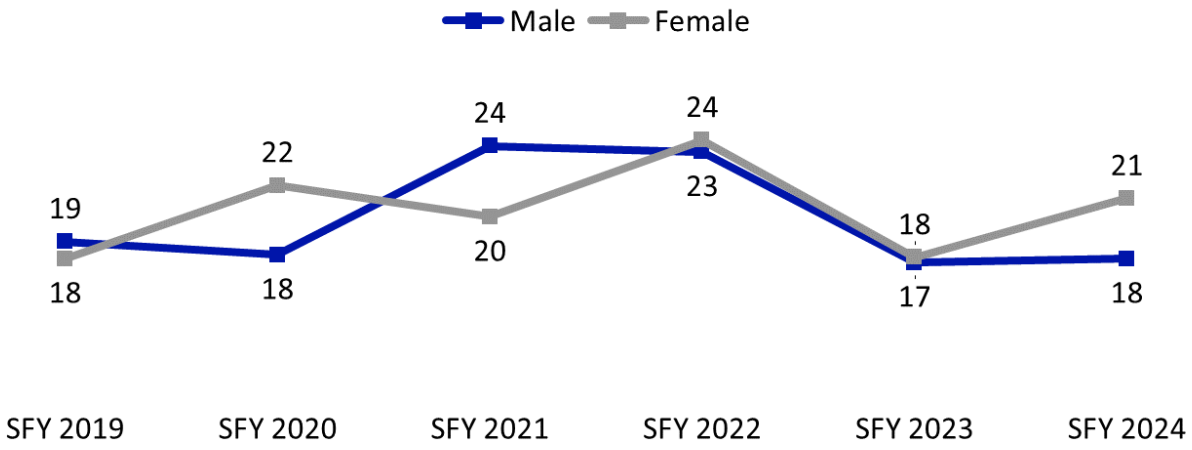
The CMR by gender for waiver recipients is displayed in Table 16. Out of the 317 deaths of individuals receiving waiver services in SFY 2024, 58% were male, which is consistent with the distribution of the waiver population, which was 62% male at the time of the January 2024 snapshot.

Table 16: CMR by Gender per 1,000 population, SFY 2024

Sex	Waiver Deaths	Waiver Population	CMR
Female	133	6391	20.8
Male	184	10459	17.6

The CMR by gender over time is displayed in the figure below. The rates have been consistent over the years, with the rate for males higher in some years and lower in other years, most likely due to the small number of deaths and random variation.

Figure 4: CMR by Gender, SFY 2019 - SFY 2024



The top causes by gender are shown in Table 17. Respiratory Disease was the top category for both groups.

Table 17: Top CoD by Gender, SFY 2024

Female	
Category	**Deaths**
Respiratory Disease	25
Neurological Disorder	25
Cardiovascular Disease	23
Genetic malformations, deformations, and chromosomal abnormalities	21
Cancer	18
Congenital malformations, deformations, and chromosomal abnormalities	12

Male	
Category	**Deaths**
Respiratory Disease	42
Cardiovascular Disease	33
Genetic malformations, deformations, and chromosomal abnormalities	30
Cancer	22
Infectious Disease	18
Endocrine, nutritional, & metabolic disease	16

Race

The number of reviewed deaths by race for SFY 2024 is shown in Table 18. The average age at death for all White/Caucasian individuals was 54.8 years old (a slight decrease from 55.6 years old in SFY 2023), while the average age for Black/African American individuals was 54.5 years old (an increase from 50.9 years old in SFY 2023).

Table 18: All Deaths by Race, SFY 2024

Race	Number	Percentage
White/Caucasian	254	68.7%
Black/African American	104	28.1%
Multi-Race	7	1.9%
Other	3	0.8%
Asian	2	0.5%
Total	**370**	**100.0%**

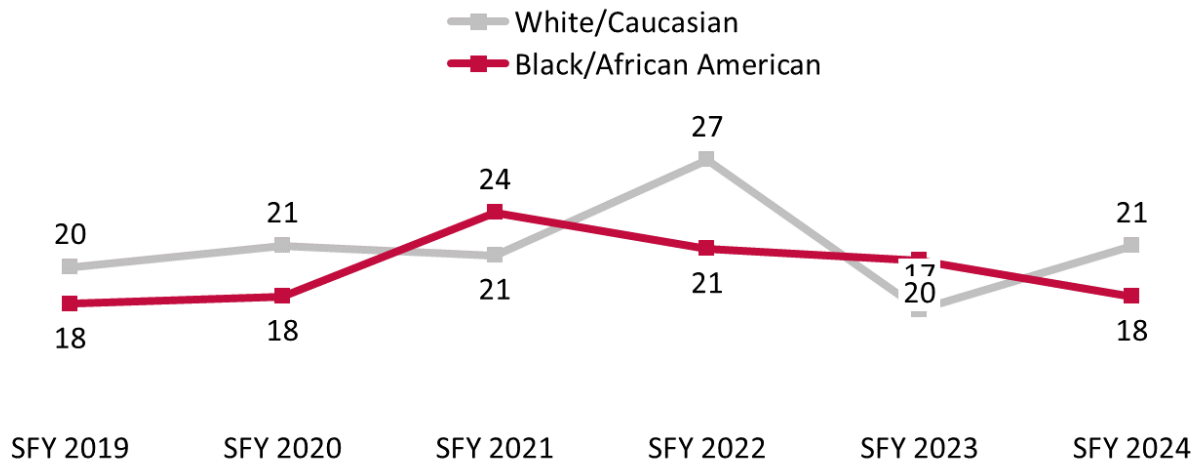
As in the previous year, the CMR for White/Caucasian individuals receiving waiver services was slightly higher than the CMR for Black/African American individuals.

Table 19: Waiver Deaths by Race, SFY 2024

Race	Waiver Deaths	Waiver Population	CMR
Black/African American	89	4920	18.1
White/Caucasian	218	10194	21.4

The chart below shows the trend in CMR by race over time. As with gender, the group with the higher rate fluctuates year to year. This is related to the small number of deaths and random variation.

Figure 5: SFY by Race, SFY 2019 - SFY 2024



The top CoD categories by race for White/Caucasian and Black/African American individuals is shown in Table 20. Respiratory Disease was the top category for White/Caucasian individuals, while Cardiovascular Disease was the top category for Black/African American individuals.

Table 20: Top Cause of Death Categories by Race, SFY 2024

White/Caucasian	
Cause	**Deaths**
Respiratory Disease	50
Cardiovascular Disease	38
Genetic malformations, deformations, and chromosomal abnormalities	37
Cancer	30
Neurological Disorder	23
Congenital malformations, deformations, and chromosomal abnormalities	18

Black/African American	
Cause	**Deaths**
Cardiovascular Disease	18
Neurological Disorder	17
Respiratory Disease	14
Genetic malformations, deformations, and chromosomal abnormalities	11
Cancer	10
Endocrine, nutritional, & metabolic disease	10

Services and Supports

The Supports Intensity Scale (SIS®) is a standardized assessment tool that measures individuals' support needs. The results place individuals on a scale from one to seven, with higher numbers indicating more support is needed[4].

The CMR for individuals receiving waiver services by SIS level is shown in Table 21. As in previous years, the CMR was highest for individuals with a SIS level of 6.

Table 21: Deaths and CMR by SIS level, SFY 2024

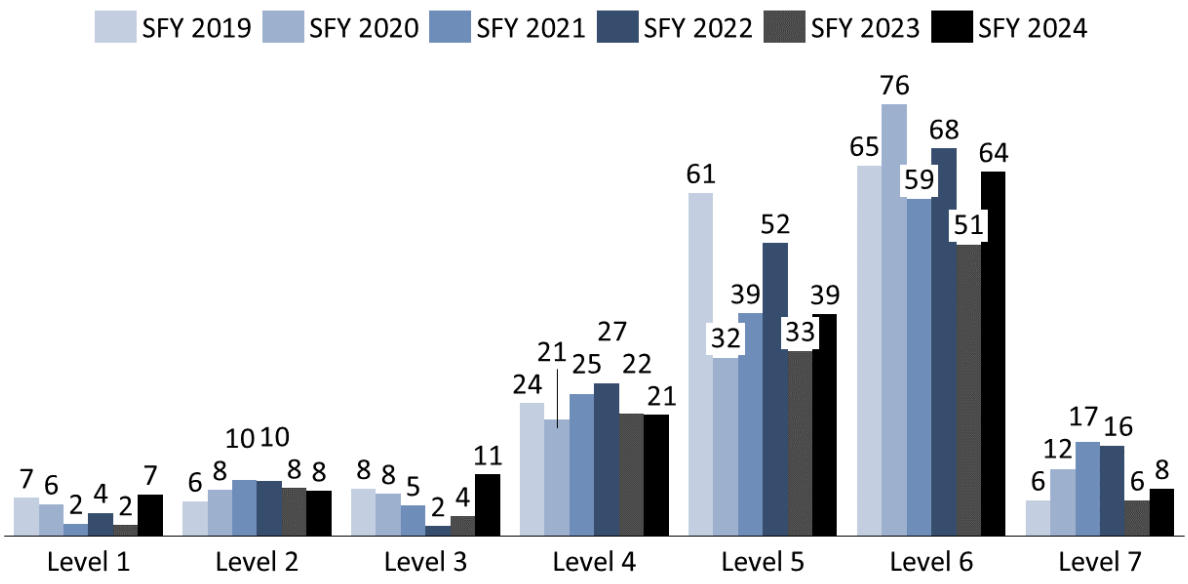
SIS Level	Waiver Deaths	Waiver Population	CMR
1 - Mild Support	7	952	7.4
2 – Moderate Support	47	5879	8.0
3 – Mild/Moderate Support with Some Behavioral Support	6	552	10.9
4 – Moderate to High Support	135	6303	21.4
5 – Maximum Support	23	586	39.2
6 – Intensive Medical Support	89	1384	64.3
7 – Intensive Behavioral Support	10	1194	8.4

[4] https://dbhds.virginia.gov/wp-content/uploads/2024/01/VA-SIS-A-2nd-Edition-FAQs_010924-POST.pdf

CMR by SIS level for the past five years is seen in the following Figure. Individuals with SIS Level 6 have consistently had a higher CMR than individuals at other SIS levels.

In SFY 2024, the top cause of death for individuals with SIS Level 6 was genetic malformations, deformations, and chromosomal abnormalities (12) followed by Pneumonia (9), Sepsis (6), Cancer w/metastasis (5), and Failure to Thrive/ Slow Decline (5). The average age at death for this group was 47 years old, which is slightly lower than the average age for all reviewed deaths (54 years old).

Figure 6: CMR by SIS Level, SFY 2019 - SFY 2024



Residential Setting

Deaths by residential setting is indicated here in Table 22.

Table 22: Deaths by Residential Setting, SFY 2024

Residence	Deaths	Percent
Group Home	144	38.9%
Private Residence with Family	94	25.4%
Sponsored Placement	51	13.8%
Private Residence Other	28	7.6%
Nursing Facility/Skilled Nursing Facility/Assisted Living Facility	23	6.2%
Intermediate Care Facility for Individuals with Intellectual Disabilities	19	5.1%
State Facility	10	2.7%
Other	1	0.3%
Total	**370**	**100.0%**

CMR for individuals receiving waiver services in a congregate or institution setting, verses those living independently (including with family) is shown in Table 23. As in the previous year, the CMR for individuals in congregate or institutional settings was higher.

Table 23: CMR by Living Situation for DD Waiver Recipients, SFY 2024

Residential Living Situation	Deaths	DD Waiver Population	CMR
Congregate or institution	212	4874	43.50
Independent	105	11978	8.77

Conclusion

This mortality review report sheds light on some of the distinct health challenges faced by individuals with intellectual and developmental disabilities (IDD). 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 in the Department of Behavioral Health and Developmental Services are important in addressing existing and potential health risk factors for all IDD 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, both within DBHDS and externally through the communities. 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. To promote positive outcomes and minimize the risk for potential events, training and education on prevention awareness, early recognition, and advocacy actions, were the focal points for the addition of specific mortality prevention strategies to be identified by the MRC at each meeting. 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 to ensure the provision of evidence-based standards of care. The DBHDS IDD MRC 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 intellectual and developmental disabilities.