Virginia Department of Behavioral Health & Developmental Services

SFY 2022 Annual Mortality Report

Presented by the DBHDS Mortality Review Committee

December 2022

Contents

Annual Mortality Report

State Fiscal Year 2022

Executive Summary

This is the eighth 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) 2022, as reported in the DBHDS incident reporting systems. SFY 2022 covers July 1, 2021 to June 30, 2022.

This report compares SFY 2022 mortality review data to data from previous years. The interpretation of information presented in this report is not intended to be used for direct comparison with the mortality reviews and reports of other states. Each state utilizes its own specified population, definitions, processes, and different methods or analyzed data which is relevant to their need or state requirements, and generalized findings or comparisons of mortality rates is limited.

As of June 30, 2022, there were 15,480 individuals enrolled on a Virginia Developmental Disability (DD) Home and Community-Based Services (HCBS) waiver[1]. 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, DBHDS and the Developmental Disabilities Mortality Review Committee (MRC) 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 at the time of death and diagnosed with an intellectual disability and/or developmental disability (I/DD) are reviewed.

Analysis of the mortality trends, patterns, and problems can identify opportunities for system improvements to reduce risks to all individuals with developmental disabilities receiving behavioral health and/or developmental services. 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] Virginia Waiver Management System. Accessed by DBHDS on December 12, 2022.

Key Findings

- The DBHDS DD MRC reviewed 416 deaths that occurred during SFY 2022. This is a two percent increase from the 408 deaths reviewed by the MRC during SFY 2021, and it is the highest number of deaths reviewed since the MRC's creation.
    - The MRC utilizes a two-tier review process, which allows the MRC to focus more precisely on unexpected or unexplained deaths. These deaths are categorized as Tier 1, and all others are categorized as Tier 2[2]. Of the 416 deaths reviewed in SFY 2022, 201 (48 percent) deaths were categorized as a Tier 1, and 215 (52 percent) deaths 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.
- For the second year in a row, the leading cause of death in SFY 2022 was COVID-19 (46 deaths, 11 percent), but the number of COVID-19 deaths declined from 60 deaths (15 percent) from SFY 2021.
- The MRC determined more deaths to be expected (225 deaths, 54 percent) than unexpected (191 deaths, 46 percent).
    - The top cause of unexpected deaths was COVID-19 (43 unexpected deaths) followed by heart disease (23 unexpected deaths).
    - Only one death for which the cause was unknown.
- The DBHDS DD MRC determined 22 deaths (five percent) to be potentially preventable in SFY 2022, with two deaths where the MRC could not determine if the death was potentially preventable and therefore categorized as unknown. This is a 44 percent decrease in the total number of potentially preventable deaths compared to SFY 2021 preventable deaths (39 deaths, 10 percent).
    - Similar to previous years, the majority of deaths determined to be potentially preventable in SFY 2022 (20 of 22) involved a failure to execute established protocols.
    - Eight of the deaths determined to be potentially preventable were caused by choking.
- The Crude Mortality Rate increased from 34 to 45 for the 51-60 age group and decreased from 192 to 167 for the 81+ age group.
- As in the previous year, the rate was lowest for individuals with SIS Levels 1-3 and highest for individuals with a SIS Level of 6. The rate for Level 6 increased from 59.5 in SFY 2021 to 68.4 in SFY 2022.

[2] Full definitions of Tier 1 and Tier 2 can be found in the Key Definitions section.

Recommendations

An important component of health and safety oversight within DBHDS involves the analysis and review of mortality data to identify important patterns and trends that may help to decrease risk factors; provide information to guide system enhancements through process improvements; and determine recommendations in response to these findings.

The DBHDS DD MRC documents recommendations for systemic quality improvement initiatives coming from patterns of individual reviews on an ongoing basis, to ensure the provision of safe, effective, person-centered, timely, efficient, and equitable care to all I/DD individuals. From this analysis, including a review of the data presented in this report, the DBHDS DD MRC also makes at least four recommendations annually for systemic quality improvement initiatives, and reports these recommendations to the QIC and the DBHDS Commissioner. Recommendations in this report build upon the recommendations of previous years as well as integrate new findings and data from the current study year.

The recommendations for SFY 2022 are as follows:
Recommendation 1: Frailty may play a decisive role in increasing adverse health outcomes within the I/DD population. Frailty awareness and its role in health outcomes may be a predictor of mortality, particularly in individuals in SIS level 6. SIS assessments are used to determine the type of services and supports needed and MRC data indicates increased rates of mortality in SIS level 6. There is a myriad of complex medical and behavioral conditions, and the use of a standardized and objective tool, such as a frailty assessment, may further predict mortality in the I/DD population. Assessment of needs or change in status is a major factor the MRC identified as related to potentially preventable deaths. The MRC should utilize and collect frailty data for I/DD 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.

Recommendation 2: Failure to execute establish protocols remains a major factor in the role of potentially preventable deaths as identified by the MRC. A specific area noted was related to delays in calling 911 at the first sign of a medical emergency. There is an opportunity for systemic improvement in training and implementation of practices to support staff in the event of a medical emergency, which may positively affect the outcomes in the I/DD population. Currently, there are limited standards for what must be included in emergency management policies and procedures for DBHDS licensed providers, and no standards for processes to track emergency preparedness training. There are also no requirements regarding medical emergencies and use of medical emergency scenario drills to train for medical emergencies. Review of data from SFY 2021 determined that the baseline of cases reviewed by the MRC where 911 was initiated and a standard protocol was adhered to was 63 percent. DBHDS should work

to increase the percentage of adherence to the execution of provider established protocols for medical emergencies to >70 percent for I/DD individuals residing in DBHDS licensed provider residences.

Recommendation 3: In 2021, Virginia experienced a 15 percent increase in drug overdose related deaths across the population, and 76.5 percent of those deaths were determined that opioids were the cause or a contributing factor. In SFY 2021, the MRC noted seven deaths related to drug overdose or toxicity, and while there were no deaths related to drug overdose in SFY 22, the MRC monitored the need for opiate use disorder training for individuals with I/DD and DD providers. Statewide efforts have increased to reverse this opiate overdose mortality trend and there are opportunities to be specifically inclusive of the I/DD population in these efforts. The Virginia Board of Pharmacy requires that naloxone (NARCAN®) be prescribed and offered with every opioid prescription in Virginia. REVIVE! is the opioid overdose and naloxone education program for the Commonwealth of Virginia (community based opioid overdose emergency treatment). REVIVE! provides training on recognition and response to an opioid overdose emergency using naloxone (NARCAN®). Increasing knowledge of substance use disorders (SUD), and training in REVIVE! should promote health and safety outcomes for high risk I/DD individuals with SUD and/or experiencing an opioid overdose. DBHDS should work to achieve that 30 percent of DBHDS DD licensed providers complete REVIVE! Training in the next year.

Recommendation 4: Data from the MRC over the past four years shows an increase in the number of deaths caused by choking (SFY 2018 = 0 deaths; SFY 2019 = two deaths [0.64 percent]; SFY 2020 = five deaths [1.41 percent]; SFY 2021 = eight deaths [1.96 percent]; SFY 2022 =11 deaths [2.6 percent]), and the top cause of when the MRC determines a death to be potentially preventable. Choking is one of the 12 serious incidents that the Risk Management Review Committee (RMRC) monitors. DBHDS should review the choking events reported through their incident management system to work collaboratively across the RMRC and MRC to identify potential systemic factors that can mitigate choking risks.

Recommendation 5: Although the MRC has improved upon identifying causes of death, the classification of deaths based on organ system may have limited impact toward understanding underlying specific disease or illness course. 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 I/DD.

Status of Recommendations from SFY 2021

Recommendation 1: The MRC should continue to examine if the definition of potentially preventable needs revision, clarification, or updates, to better capture opportunities that may improve the rates of mortality in the I/DD population. As of December 2, 2021, the key definitions utilized by the MRC to categorize deaths have been updated for additional clarity to capture additional factors and opportunities to improve mortality rates. Additionally, the MRC adopted new definitions incorporate the standardized use of mortality prevention strategies within the actions taken by the MRC.

Recommendation 2: In SFY 2020, failure to adhere to established 911 protocol was identified by the DBHDS DD MRC as a major contributor to the potentially preventable factor of 'Execution of Established Protocols.' In SFY 2021, the DBHDS DD MRC began implementation of a quality improvement initiative to increase providers' adherence to protocols related to calling 911, as baseline data indicated that follow through with their own protocols in calling 911, was only followed for an average of 30 percent of deaths where calling 911 was a factor. In SFY 2022, DBHDS should establish a metric to increase the number of mortality review cases in which 911 protocol was followed to greater than 60 percent. The MRC collaborated with the DBHDS offices of Integrated Health, Licensing, and Provider Development to increase training and adherence of licensed providers and staff related to emergency response protocols. During SFY 2022 Quarter 1, 48 percent of deaths in which 911 protocol was a factor also had 911 protocols followed appropriately. In the course of reviewing deaths, the MRC noted that following emergency response protocols were needed not only to address delays in calling 911 but also including following protocols after 911 is called. The MRC utilized the Plan-Do-Study-Act model for quality improvement to revise this initiative to encompass following medical emergency response protocols more broadly, which is part of the recommendations for SFY 2022.

Recommendation 3: DBHDS should continue to monitor the percent of deaths where the cause is unknown on an annual basis to maintain a target of less than ten percent of deaths reviewed. The MRC has sustained this percentage to over 98 percent in the past two years, largely as a result to legislation allowing for greater access to pertinent clinical information.

Recommendation 4: The MRC should measure COVID-19 mortality among the I/DD population to determine if a decrease to less than 10 percent is noted by raising awareness of the need for vaccines, maintaining infection control measures, and surveillance for COVID-19 symptoms in these at-risk individuals. The MRC developed a quality improvement initiative related to COVID-19 and precautions for high-risk I/DD individuals. This initiative is still in progress with a focus on enhanced vaccination rates, continued support for execution of infection control measures, and enhanced surveillance and early detection of COVID-19. While COVID-19 continues to be a

leading cause of death in the I/DD population, COVID-19 deaths declined from 15 percent (SFY 21) to 11 percent (SFY 22), not yet meeting the intended metric of less than 10 percent of deaths.

Recommendation 5: In SFY 2021, DBHDS evaluated underlying causes and conditions that lead to an increase in sepsis deaths in this population, with the primary contributing cause being urinary tract infection (UTI). This information was shared with the DBHDS Risk Management Review Committee (RMRC), to examine interventions further upstream from the event resulting in mortality. The DD MRC should continue to monitor if interventions and quality improvement initiatives taken by the RMRC, will decrease rates of sepsis due to UTI. In SFY 2022, the DBHDS RMRC began to collect, track, and analyze data related to sepsis and UTIs. DBHDS MRC will continue to monitor if interventions and quality improvement initiatives taken by the RMRC, have decreased rates of sepsis due to UTI in the I/DD mortality cases.

Recommendation 6: The DD MRC should consider aligning the actions taken when a potentially preventable death is identified, with best practices in mortality prevention strategies to further understand the resources and activities that may achieve a greater impact on reducing mortality to the greatest extent practicable. As noted above, starting in December 2021, the MRC adopted new definitions incorporating the standardized use of mortality prevention strategies within the actions taken by the MRC.

Background

Purpose

The purpose of the DBHDS Developmental Disabilities (DD) Mortality Review Committee (MRC) is to focus on system-wide quality improvement by conducting mortality reviews of individuals who were receiving a service licensed by DBHDS at the time of death and diagnosed with an intellectual and/or developmental disability (I/DD), 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 unexplained and unexpected deaths.

At each meeting the DBHDS DD 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 DD MRC member(s) as appropriate.
- Reviews and tracks the status of previously assigned recommended actions to ensure implementation and completion.

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

Process

As described in the DBHDS DD MRC Charter (updated annually), the DBHDS DD MRC convenes at least monthly, and as frequently as necessary to ensure that deaths are reviewed within 90 days of the date of death and must have attendance by specific members. During SFY 2022, the DBHDS DD MRC met 24 times, and the membership requirements were met at every meeting.

For all I/DD 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 the preceding three months' worth of documentation received. For each case review, the DBHDS DD 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 DBHDS DD MRC will then make and document relevant recommendations and/or interventions

Mortality Review Process Enhancements in SFY 2022

- The MRC revised and updated key definitions, updated the MRC charter, and applied to the review of deaths and trained all members of the MRC on these new definitions on December 2, 2021. These changes were made to clarify and be more inclusive of specific characteristics of deaths that may better identify potentially preventable deaths and develop individual and systemic quality improvement initiatives.
- The MRC 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. Starting on December 2, 2021, for actions taken by the MRC, the MRC considered and identified one of three prevention strategies further described in the Key Definitions. It is important to note that these 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. 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.
- The procedures to request, receive, track, and store medical records that were established in SFY 2020 were streamlined in SFY 2021. This allows a timelier receipt of requested records while assuring consistency.
- Effective July 2021, the MRC established a process in collaboration with the DBHDS Office of Licensing's Special Investigation Unit (SIU) to revise their mortality review checklist for licensed providers. This was done in collaboration with the Mortality Review Office and DBHDS licensed providers in order to promote a more thorough mortality review.

The goal of these process enhancements is to obtain additional information and provide more relevant documentation for the retrospective case reviews in order to augment clinical validity and utility related to the DBHDS DD MRC determinations. Significant changes that were implemented in the middle of the fiscal year, related to the adoption of the definitions of prevention strategies, will not be analyzed until the SFY 2023 annual report to better account for adoption of a new practice.

Key definitions

- Expected Death denotes a death that 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 DBHDS DD MRC for data trending.
- Potentially Preventable Deaths (PP) 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 potentially preventable. 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 requires a detailed, comprehensive review of multiple factors and areas of focus by the MRC. Tier 1 deaths may meet any one of the following criteria:
    - 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 does not require a detailed, comprehensive review as the preliminary review was sufficient. Tier 2 deaths, may be expected or unexpected, but in addition must meet all of the following criteria:
    - 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.
- For actions recommended by the MRC, the MRC shall consider if one of the following prevention strategies 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. Examples include:
        - Reducing falls through education, strategies, or safety initiatives
        - Supporting healthy lifestyles through education and practice programs such as weight management (exercise and improved nutrition/diet)
    - Secondary Prevention Strategies – Focus on early detection and timely treatment of conditions or injuries to minimize harmful effects and prevent further morbidity or mortality. Examples include:
        - Training direct-support staff and providers to realize signs and symptoms of serious medication side effects and illness
        - Implementing programs that support and advocate for preventive cancer screenings (e.g., colonoscopy, immunizations/vaccines, mammograms, prostate cancer screening)
    - Tertiary Prevention Strategies – Optimization of the treatment and management of conditions or injuries, in order to reduce mortality rates. Examples include:
        - Education on chronic disease management to direct-support staff and providers (e.g., diabetes, hypertension, obesity)

- Establishing aspiration prevention and management protocols through intensive education that trains staff in the prevention of aspiration and/or aspiration pneumonia

Virginia Deaths

SFY 2022 continued to be impacted by the COVID-19 pandemic. The continued medical developments and greater access to vaccines and other therapeutics allowed for lesser restrictions in the community, and July 1, 2021 marked the end of the declared COVID-19 public health emergency in Virginia. However, on January 10, 2022, there was a state declaration of a 30-day limited state of emergency due to the Omicron variant, and the Federal Public Health Emergency has been extended into January 2023. COVID-19 continues to pose a threat to the health and safety of vulnerable populations, including those with developmental disorders.

The Commonwealth continues to support efforts to enhance vaccine and treatment access to individuals with I/DD. While significant efforts were made from a public health perspective to mitigate the morbidity and mortality of COVID-19, during this mortality review period, COVID-19 was the top cause of death.

The DBHDS DD MRC determined a cause of death in 415 of 416 deaths (99.8 percent) reviewed, with only one death where the cause could not be determined and classified as unknown. After the number of deaths classified as unknown (cause) peaked in SFY 2019 with 42 deaths, the MRC reduced the number each year (Table 1).

Table 1: Number of deaths classified as Unknown

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

This improvement is largely attributed to SB 482 which was passed by the 2020 General Assembly and became effective on July 1, 2020. This legislatively established the DBHDS DD MRC to greater access to information and records, particularly in settings that are not licensed by DBHDS, regarding individuals whose deaths were reviewed by the MRC as well as direct access to Virginia state death certificates. Table 2 displays the causes of death for SFY 2022 and the four previous years.

Table 2. Number deaths by cause, SFY 2019 – 2022
(Sorted by Frequency in SFY 2022)

Cause Of Death	SFY 2019	SFY 2020	SFY 2021	SFY 2022
Covid-19	-	10	60	46
Heart Disease	17	28	37	40
Cancer	30	34	33	33
Complication of Genetic Condition	9	16	18	29
FTT Slow Decline	10	21	11	29
Complication of Congenital Condition	13	5	18	28
Seizure	7	12	16	26
Sepsis	19	40	21	25
Aspiration Pneumonia	13	15	19	18
Pneumonia	20	22	20	18
Respiratory Disease	30	10	12	15
Acute Respiratory Failure	7	16	12	12
Gastrointestinal Disease	3	6	9	12
Choking	2	5	8	11
Sudden Cardiac Death	22	43	29	11
Neurodegenerative Diseases	18	7	21	10
Stroke	7	8	7	8
Trauma	1	2	0	8
Kidney Disease	10	6	8	7
Other^	12	16	15	7
Traumatic Brain Injury	4	2	4	6
Accidents				4
Bowel Obstruction	7	4	4	3
Diabetes				3
Postoperative Complications	3	3	3	3
Aspiration	5	4	5	2
Neurological Disorder**	-	-	6	1
Unknown	42	16	2	1
Anoxic Brain Injury	1	2	3	0
Drug Overdose Toxicity	0	1	7	0
Total	**312**	**354**	**408**	**416**

* Diabetes is a new cause added this year.
- Fields marked with a hyphen (-) do not have measurable values because the categories used to classify deaths did not exist at the time of the MRC determinations.
† Trauma and Accidents were grouped in the "other" category in previous years due to the number of deaths falling below three, but these causes have been pulled out due to the value increasing in SFY2022.
^ 'Other' includes categories with fewer than 3 deaths in both SFY 2022 and SFY 2021. Categories with three or more deaths in SFY 2021 that fell below three in SFY 2022 are shown in the table.

Unlike deaths in which the specific cause of death is "unknown," deaths classified as "other" causes have known etiologies outside of the MRC's primary categories for statistical trending.

This year, categories that had fewer than 3 deaths in both SFY 2022 and SFY 2021 are grouped in the "other" category. The seven deaths coded as "other" in SFY 2022 were circulatory system disorder (2), endocrine disorder (1), hematological disorder (1), infectious disease (1), multi-system organ failure (1), and musculoskeletal disease (1).

Due to the additional clinical information now received by the MRC, causes of death and disease course are more easily identified and understood by the MRC. This may explain the significant percent increases in the number of deaths caused by failure to thrive/slow decline which increased by 164 percent, from 18 deaths in SFY 2021 to 29 in SFY 2022; 61 percent increase in deaths caused by complication of a genetic condition and a 63 percent increase in deaths caused by seizure.

An increase in deaths caused by drug overdose/toxicity was noted in the previous year (seven deaths in SFY 2021), coinciding with a national increase in the number of "deaths of despair" during the COVID-19 pandemic. However, none of the deaths reviewed in SFY 2022 were determined to be caused by drug overdose/toxicity.

Deaths due to COVID-19

Provisional Mortality Data[3] published by the CDC cited that the top three overall causes of death in the United States in 2021 were: 1) heart disease; 2) cancer; and 3) COVID-19. The DBHDS MRC determined similar findings in the I/DD population in Virginia with respect to the top causes of death; however, COVID-19 was the leading cause in Virginia. The second leading cause of death was heart disease (40 deaths, 10 percent), followed by cancer (33 deaths, eight percent). COVID-19 deaths were first reflected in the MRC data in the fourth quarter of SFY 2020 and was the leading cause in SFY 2021. While the number of deaths declined from 60 to 46 in SFY 2022, COVID-19 was the most common cause of death for a second year in a row, with 11 percent of deaths determined to be caused by COVID-19.

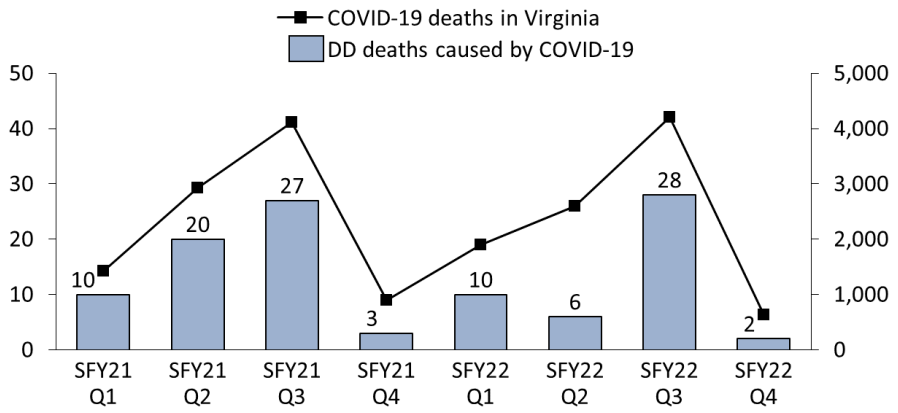
The Centers for Disease Control (CDC) indicated that individuals with I/DD were at high risk of severe illness and death from COVID-19 because of co-occurring chronic medical conditions, living in congregate settings, or systemic health and social inequities. The MRC felt that contracting COVID-19 was largely unexpected because of enhanced infection precautions and availability of vaccines. The MRC recognizes the importance of further understanding additional risks that may exist in the I/DD population as they relate to COVID-19 and preventing transmission. Unfortunately, once the disease is present, the medical risk factors proved to be an accurate reflection of the development of negative outcomes, as supported by literature.

[3] Ahmad FB, Cisewski JA, Anderson RN. Provisional Mortality Data — United States, 2021. MMWR Morb Mortal Wkly Rep 2022;71:597-600.

Individuals with I/DD age 50 years and older were disproportionately affected, comprising 67 percent (31 deaths) of the COVID-19 deaths in this fiscal year. Males (31 deaths) were also disproportionally affected as compared to females (15 deaths). Place of residence was also reviewed, and 26 individuals were residing in congregate care or institution and 20 individuals were residing independently. 43 of the 46 deaths due to COVID-19 were determined to be unexpected, and the MRC determined that none of these deaths due to COVID-19 in this fiscal year were potentially preventable. In addition to the criteria for which a death is determined to be potentially preventable as defined under Key Definitions in this report, this determination with respect to COVID-19, was made in consideration with reviewing documentation of the presence of underlying known chronic medical conditions, vaccination status (including personal choice), access to available therapeutics, and timely identification and medical care received.

The number of COVID-19 deaths by quarter is displayed in Figure 1. The columns represent deaths in the DD population determined to be caused by COVID-19 (plotted on the left axis), while the black line shows COVID-19 deaths in Virginia (plotted on the right axis).

Figure 1. Deaths caused by COVID-19, SFY 2021 and SFY 2022



The number of COVID-19 deaths in the DD population follows the trend in Virginia, with peaks in Q3 of SFY 2021 and Q3 of SFY 2022. The third quarter of the SFY covers January through March, which are winter months associated with high rates of transmission.

Of the deaths reviewed, there are a smaller number of individuals who do not reside in a setting licensed by DBHDS. Table 3 shows the total number of deaths and cause of death for individuals in a DBHDS-licensed residential setting, is in contrast to Table 2, which is all deaths and residence types.

Table 3. Cause of death for DD individuals in a DBHDS licensed residential setting SFY 2019 - SFY 2022, sorted by frequency in SFY 2022

Cause Of Death	SFY 2019	SFY 2020	SFY 2021	SFY 2022
Covid-19		8	42	43
Cancer	16	14	25	30
Heart Disease	9	13	31	29
Complication of Genetic Condition	1	5	15	28
FTT / Slow Decline	6	14	10	26
Sepsis	9	25	15	24
Complication of Congenital Condition	3	1	18	23
Seizure	4	7	10	23
Pneumonia	13	12	18	15
Aspiration Pneumonia	9	13	15	14
Respiratory Disease	13	7	10	13
Choking	2	4	8	11
Gastrointestinal Disease	2	3	5	11
Acute Respiratory Failure	4	9	8	10
Sudden Cardiac Death	13	25	26	10
Neurodegenerative Diseases	16	4	19	9
Stroke	5	4	7	8
Kidney Disease	5	2	6	6
Trauma	1	2	0	6
Traumatic Brain Injury	4	2	3	6
Other^	7	5	11	5
Accidents	0	0	0	3
Bowel Obstruction	5	2	4	3
Diabetes	0	0	0	3
Postoperative Complications	2	1	3	3
Aspiration	4	4	4	1
Neurological Disorder**	0		5	1
Unknown	18	2	0	1
Anoxic Brain Injury	1	2	3	0
Drug Overdose / Toxicity	0	1	3	0
Total	**172**	**191**	**324**	**365**

End of Life Care

The American Association for Individuals with Intellectual and Developmental Disabilities (AAIDD) updated their position statement in January 2020[4], on caring for individuals with I/DD at the end of life. The DBHDS DD MRC acknowledged that conversations and choice related to the type of end-of-life care can be reflective of the interventions and actions related to contributing factors to mortality 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 that the MRC does not view that having a Do Not Resuscitate (DNR) order or being in hospice as equating to determining that a death was to be expected or not potentially preventable.

Do Not Resuscitate Status

In SFY2022, 251 deaths (60 percent) had a "do not resuscitate" (DNR) status. This number represents an increase from SFY2021 and SFY2020 (See Table 4).

Table 4: 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%

For SFY 2022 Tier 1 cases, 92 deaths (46 percent) had a DNR status while 102 deaths (54 percent) did not.

The DNR status of deaths by residential setting is displayed in Table 5. Aside from "other" and "unknown" settings, the percent with a DNR was highest in the facility setting (83 percent); however, the total number of facility deaths (six) is too small to draw conclusions. Sixty-nine percent of deaths occurring in an institution had a DNR status, and 60 percent in congregate care had a DNR status. As in the previous year, the percent was lowest in the independent living setting (43 percent).

Table 5. Do Not Resuscitate by Residential Setting, SFY 2022

DNR Status	Congregate	Facility	Independent	Institution	Unknown	Other
Yes	111	5	78	20	13	0
No	75	1	102	9	1	1
Total	186	6	180	29	14	1
Percent with DNR	60%	83%	43%	69%	93%	0%

[4] https://www.aaidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life (accessed Dec 22, 2021)

Hospice

Of the 416 individuals who died in SFY 2022, 141 individuals were receiving hospice services (34 percent) while 275 individuals who died were not (66 percent). The percent receiving hospice has been steady for the past three years (34 percent in SFY 2021, and 35 percent in SFY 2020).

The number and percent receiving hospice services is displayed in Table 6. In SFY 2022, hospice services were most common in the institution setting (48 percent).

Table 6. Hospice services by residential setting, SFY 2022

	Congregate	Facility	Independent	Institution	Unknown	Other
Hospice	68	1	52	14	6	0
No hospice	118	5	128	15	8	1
Total	186	6	180	29	14	1
Percent in hospice	37%	17%	29%	48%	43%	0%

Table 7 displays the number and percent of individuals receiving hospice by age. The percentage of individuals receiving hospice increases with age, with hospice most common for individuals aged 81 and above.

Table 7. Hospice services by age group, SFY 2022

Age	Hospice deaths	Total deaths	Percent receiving hospice
0-17	1	11	9%
18-30	7	43	16%
31-40	6	39	15%
41-50	16	58	28%
51-60	41	96	43%
61-70	39	98	40%
71-80	23	56	41%
81+	8	15	53%

Expected and Unexpected Deaths

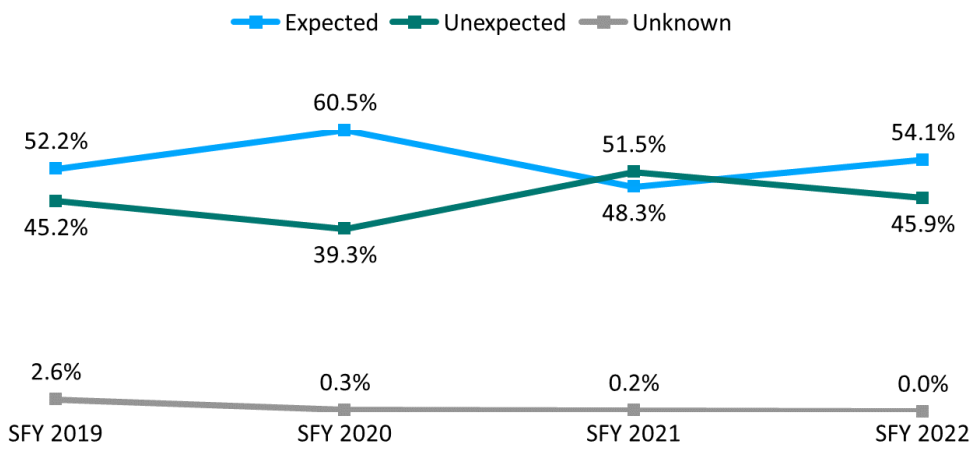
Following the cause of death determination, the MRC determines whether a death was expected or unexpected. Table 8 shows the number and percentage of deaths in each category for SFY 2022 and the previous three years.

Table 8. Expected and Unexpected Deaths, SFY 2019 – 2022

Determination	2019		2020		2021		2022	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Expected	163	52.2%	214	60.5%	197	48.3%	225	54.1%
Unexpected	141	45.2%	139	39.3%	210	51.5%	191	45.9%
Unknown	8	2.6%	1	0.3%	1	0.2%	0	0.0%

While a slight majority of deaths were unexpected in the previous year, the majority of deaths in SFY 2022 (54 percent) were expected. There were no cases in which the MRC was unable to determine whether a death was expected or not.

Figure 2. Expected and Unexpected deaths, SFY 2019 - 2022



The top causes of expected and unexpected deaths are displayed in Table 9.

Table 9. Top Causes of Expected and Unexpected Deaths, SFY 2022.

Expected	
Cause	**Expected Deaths**
Cancer	32
Failure to Thrive/Slow Decline	29
Complication of Congenital Condition	25
Complication of Genetic Condition	23
Heart Disease	17

Unexpected	
Cause	**Unexpected Deaths**
COVID-19	43
Heart Disease	23
Seizure	20
Sepsis	12
Choking	11

The leading cause of unexpected deaths in SFY 2022 was COVID-19 (43 deaths). COVID-19 was also the leading cause of unexpected deaths in SFY 2021 (48 deaths). Heart disease was the second-highest cause of unexpected deaths, in addition to being the fifth-highest cause of expected deaths.

Potentially Preventable Deaths

In SFY 2022, the DBHDS DD MRC continued a process first implemented in SFY 2018 to identify potentially preventable deaths and collect information related to contributing factors in these deaths. Additional language was added this fiscal year to the state definition of potentially preventable as described under key definitions above, which includes clarification that the MRC may identify a potentially preventable death where a violation of a regulatory requirement may not have occurred, the death may have occurred in a setting that is not licensed by DBHDS such as a medical hospital, or the actions necessary to prevent such death may not be within the purview of DBHDS. Through this process, the DBHDS DD MRC assessed whether actions leading to the death itself were preventable. In addition, the MRC identified opportunities to improve overall quality of care regardless of whether the death was determined to be potentially preventable, as defined above.

Table 10 shows the number and percent of deaths that were determined to be potentially preventable in SFY 2022 and the previous three years.

Table 10. Potentially Preventable Deaths, SFY 2019 – 2022

Determination	2019		2020		2021		2022	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Not potentially preventable	258	83%	328	93.0%	365	89%	392	94%
Potentially preventable	11	4%	17	5.0%	39	10%	22	5%
Unknown	43	14%	9	3%	4	1%	2	0%

After increasing in the previous SFY, the percent of deaths determined to be potentially preventable declined from 39 deaths (10 percent) in SFY 2021 to 22 deaths (five percent) in SFY 2022. Given that the definition was updated in the middle of the fiscal year, the MRC will continue to monitor the impact these changes have on categorization of deaths.

Of the 22 deaths determined to be potentially preventable, 20 deaths (91 percent) were identified as a failure to execute established protocols, which was the top reason for potentially preventable in the previous three years as well.

The top five causes of deaths ruled potentially preventable are displayed in Table 11.

Table 11: Top causes of Potentially Preventable deaths, SFY 2022

Cause	Deaths
Choking	8
Pneumonia	2
Seizure	2
Trauma	2
Accidents	1

As in the previous SFY, the top cause of potentially preventable deaths was choking. All other causes varied from the previous year and a trend cannot be established. However, while there is a relatively small number of potentially preventable deaths, it may be important to gain the perspective that these deaths may be more representative of a sentinel death, a death that may signify that repeat occurrences of the same type if individuals are exposed to the same situation or conditions. Healthcare literature describes that sentinel events are significant to understand as the opportunity for prevention has a greater impact through systemic changes as compared to at the individual provider level. The MRC aims to support the overall culture of quality to empower providers in the system to continually self-identify and improve upon practices. Through the adoption of additional definitions related to the categorization of MRC actions as prevention strategies, the intention is to identify system gaps and develop more robust systemic improvements.

Population Demographics

This section includes demographic trends for individuals reviewed by the DBHDS DD 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 2022 was 23.6 deaths per 1,000, a decrease compared to the rate of 26.8 in SFY 2021. 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)[5] 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

- As observed in the previous four years, the plurality of deaths reviewed in SFY 2022 occurred among individuals in their sixties.
- Nearly two thirds of deaths (66 percent) occurred among individuals aged 50 or older.

[5]Link: Supports Intensity Scale: Support Levels & Tiers, 2016.

- For SFY 2022, the median age at time of death was 57 years; the mean age at death was 54 years.

Figure 3. Age at death, SFY 2022

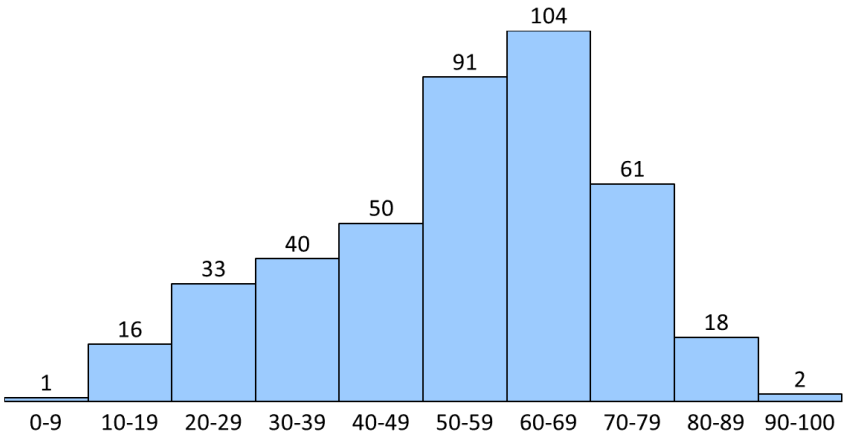
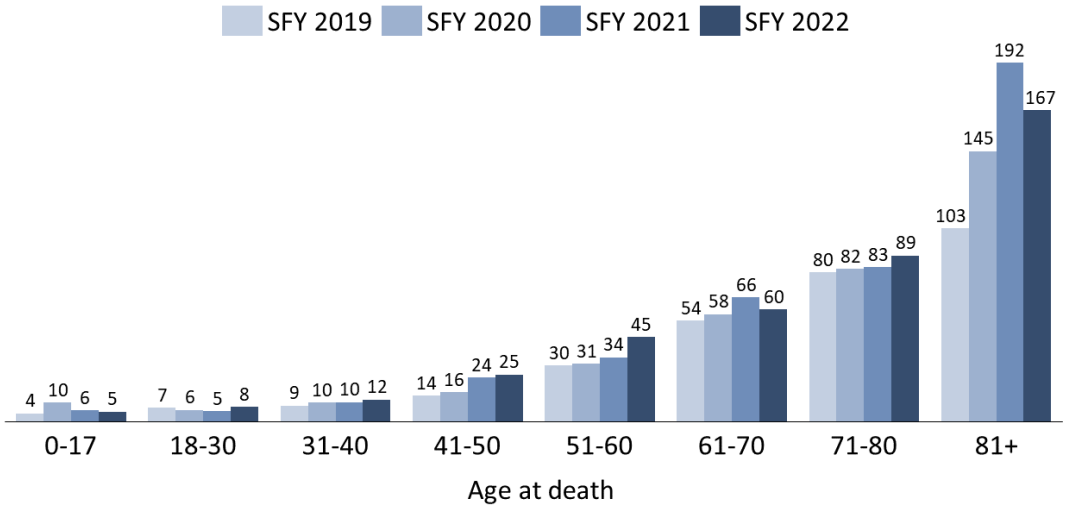


Table 12. Crude Mortality Rates by Age per 1,000 population, SFY 2022

Age Group	Waiver Deaths	DD waiver Population	Crude Mortality Rate
0-17	5	973	5.1
18-30	41	5231	7.8
31-40	38	3273	11.6
41-50	51	2037	25.0
51-60	91	2016	45.1
61-70	84	1400	60.0
71-80	42	472	89.0
81+	13	78	166.7
Total	**365**	**15480**	**23.6**

- The crude mortality rate among the DD Waiver population increased for some groups and decreased for others, with most of the differences in the single digits.
- The rate decreased from 192 to 167 for the 81+ age group.
- The rate increased from 34 to 45 for the 51-60 age group with the top five causes of death being: cancer (12), COVID-19 (11), sepsis (nine), heart disease (six), seizure (six). Of 22 deaths determined to be potentially preventable in this fiscal year, six were in this age group.

Figure 4. Crude Mortality Rate by age group, SFY 2019 - 2022



Gender

The majority of deaths were male in SFY 2022 (244 males vs. 171 females), consistent with previous years and population demographics.

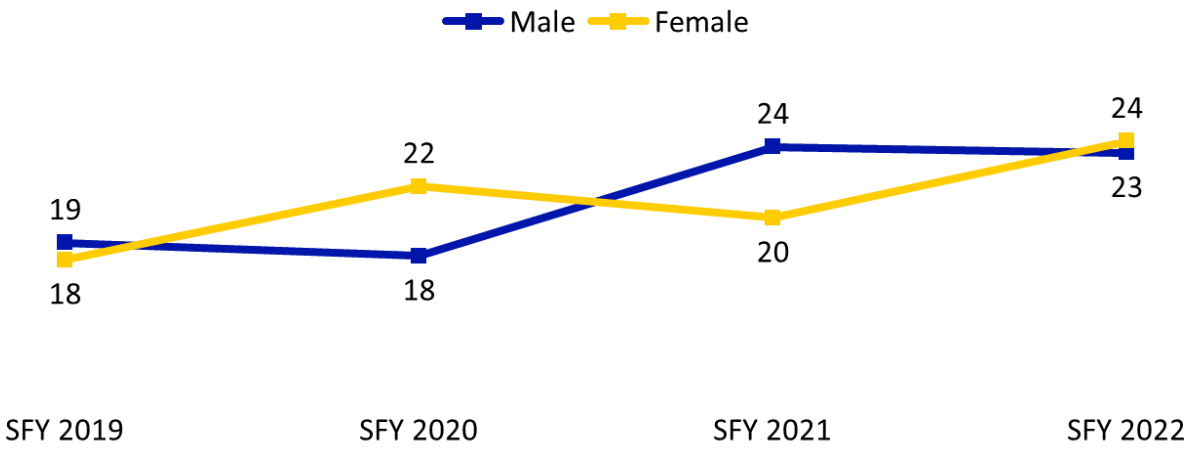
Table 13 displays the gender for reviewed deaths in the DD Waiver population.

Table 13. Deaths by gender, DD Waiver Population, SFY 2022

Gender	Deaths	DD Waiver Population	Crude Mortality Rate
Female	142	5,941	23.9
Male	223	9,537	23.4
Unknown		2	
Total	**365**	**15,480**	**23.6**

Figure 5 shows the CMR trend by gender from SFY 2019 – SFY 2022.

Figure 5. Crude Mortality Rate by gender, SFY 2019 - 2022



After a decrease in SFY 2021, the CMR for female individuals on a DD Waiver increased again in SFY 2022. The rate for male individuals on a DD Waiver remained stable.

Table 14. Top causes of death by gender, SFY 2022

Female	
Cause	**Deaths**
Cx. of Congenital Condition	16
FTT/Slow Decline	16
Cancer	15
COVID-19	15
Heart Disease	15

Male	
Cause	**Deaths**
COVID-19	31
Heart Disease	25
Cx. of Genetic Condition	21
Cancer	18
Seizure	16

Table 14 shows the top five causes of death for female and male individuals. COVID-19 was the leading cause of death for male individuals, while it ranked fourth for female individuals. Among female individuals, the leading cause was Complications of Congenital Condition.

Race

Consistent with data from previous years, the majority of deaths reviewed by the DBHDS DD MRC were of individuals identified as White/Caucasian (68 percent). Table 15 displays the breakdown for all deaths.

Table 15. All deaths by race, SFY 2022

Race	Deaths	Percent of total
White/Caucasian	284	68%
Black/African American	116	28%
Other	12	3%
Unknown	4	1%
Total	**416**	100%

Table 16 shows the race of individuals on a DD Waiver and the Crude Mortality Rate for each group.

Table 16. CMR for DD Waiver Population by race

Race	Deaths	DD Waiver Population	Crude Mortality Rate
White/Caucasian	257	9532	27.0
Black/African American	96	4523	21.2
Other	11	1360	8.1
Unknown	1	65	15.4
Total	**365**	**15480**	**23.6**

For White/Caucasian individuals, the CMR increased from 20.8 in SFY 2021 to 27.0 in SFY2022. For Black/African American individuals, the rate decreased from 23.6 to 21.2.

Figure 6 displays the trend in CMR for White/Caucasian and Black/African American individuals over the past for years. The CMR for White/Caucasian individuals fell below the rate for Black/African American individuals in SFY 2021, but in SFY 2022 the rate was higher for White/Caucasian individuals, as it was in SFY 2019 and SFY 2020.

Figure 6. Crude Mortality Rate by race, SFY 2019 - 2022

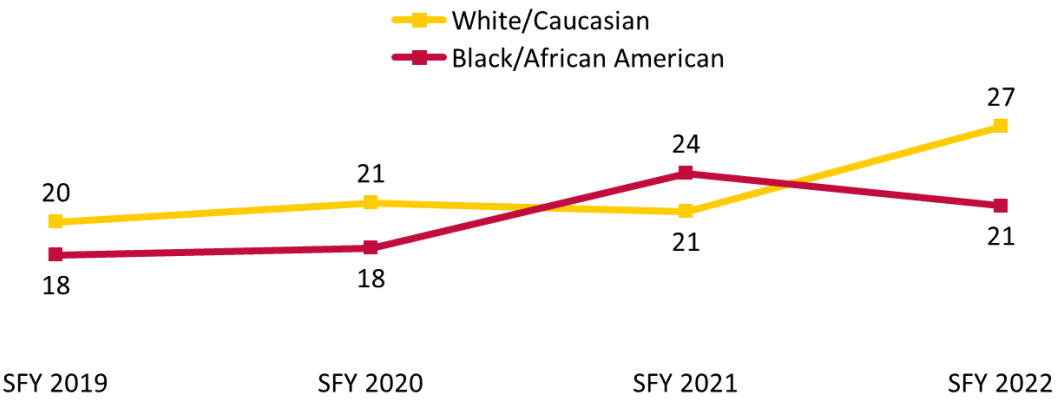


Table 17 shows the top five causes of death for White/Caucasian and Black/African American individuals. The top causes are similar for both groups; however, COVID-19 was the top cause

for White/Caucasian individuals and the third-highest cause for Black/African American individuals.

Table 17. Top Causes of Death by Race, SFY 2022

White/Caucasian	
Cause	**Deaths**
COVID-19	34
Heart Disease	26
Cancer	22
Complication of Genetic Condition	21
Failure to Thrive/Slow Decline	20

Black/African American	
Cause	**Deaths**
Complication of Congenital Condition	13
Heart Disease	12
COVID-19	11
Cancer	10
Failure to Thrive/Slow Decline	9

Services and Supports

Each SIS level includes an array of services and supports, reflecting a service program that meets the individual's needs. Individuals categorized within a Level 1 service program includes individuals with the fewest support needs while Levels 6 and 7 includes individuals with an intensive need for medical and behavioral supports and services, respectively. After the initial SIS assessment is completed, SIS levels are re-evaluated and completed every three years for those over age 16 years old, and every two years for those age 5-15 years old. A SIS level may be re-evaluated before that time if there is documented significant and sustained change over six months in any of two domains or "Exceptional Medical Behavioral Supports Needs."

Table 18 shows the number of deaths and the CMR for each SIS Level.

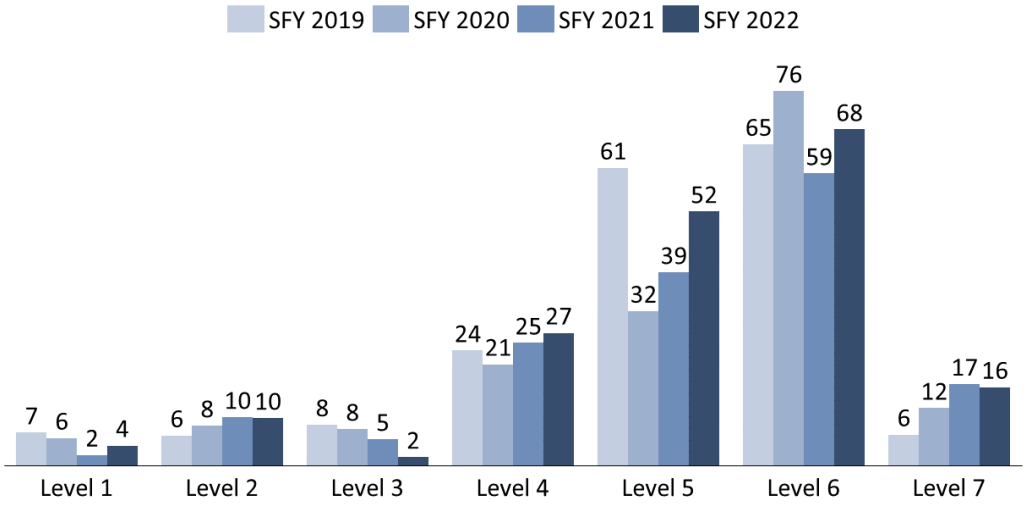
Table 18. Deaths and CMR by SIS level, SFY 2022.

SIS Level	Deaths	DD Waiver Population	Crude Mortality Rate
1	4	957	4.2
2	46	4719	9.7
3	1	550	1.8
4	165	6096	27.1
5	35	677	51.7
6	97	1418	68.4
7	17	1061	16.0
Unknown	0	2	0.0
Total	**365**	**15480**	**23.6**

As in the previous year, the rate was lowest for individuals with SIS Levels 1-3 and highest for individuals with a SIS Level of 6. The rate for Level 6 increased from 59.5 in SFY 2021 to 68.4 in

SFY 2022. The top five causes of death in SIS Level 6 were: complications of a congenital condition (19), complications of a genetic condition (14), sepsis (12), failure to thrive/slow decline (eight); seizure (six), and cancer (six). The majority of deaths that occurred for this SIS Level were in individuals aged 51-80 years old. As compared with SFY 2021 where nine deaths were determined to be potentially preventable, the MRC determined only one death to be potentially preventable in SFY 2022. Continued monitoring of this data by is needed to determine trends and opportunities for targeted intervention for this age group and SIS level given that medical frailty may be a significant factor.

Figure 7. Deaths by SIS Level, SFY 2019 - 2022



Residential Setting

Due to the low number of individuals in certain residential settings, the MRC analyzes mortality reviews using the following residence type groupings for reporting purposes:

- *Independent Living* includes family homes, sponsored placement, supported living, supervised living, and private residences where the individual may be living independently or with less than 24-hour supervision.
- *Congregate Living* is a residential service that provides 24-hour supervision in a community-based home with other residents. Settings include group homes and congregate community residential settings.
- *Community Institutional Living* is a non-state operated setting in the community that provides comprehensive and individualized health care and rehabilitation services to individuals. Institutional settings include inpatient care, nursing home/physical rehabilitation, residential ICF-IID, residential treatment/alcohol and drug rehabilitation, and other institutional settings.

- *State Facility* includes Commonwealth-operated training centers, Hiram Davis Medical Center, and state facilities where an individual had an I/DD diagnosis at the time of death based on ICD-10 codes.
- *Unknown* means the residence type was unknown at the time of death and DBHDS DD MRC review.

Table 19. Deaths by residential setting, SFY 2022

Residential Setting	2019		2020		2021		2022	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Congregate	147	47.1%	165	46.6%	179	43.9%	186	44.7%
Facility	16	5.1%	6	1.7%	14	3.4%	6	1.4%
Independent	127	40.7%	136	38.4%	157	38.5%	180	43.3%
Institution	20	6.4%	45	12.7%	35	8.6%	43	10.3%
Unknown	2	0.6%	2	0.6%	23	5.6%	1	0.2%
Total	**312**		**354**		**408**		**416**	

After an increase in SFY 2021, the number of deaths in facilities decreased from 14 to six in SFY 2022. The causes of the facility deaths were heart disease (three), aspiration pneumonia (one), failure to thrive/slow decline (one), and trauma (one).

The leading cause of death for the congregate setting was COVID-19 (23 deaths) followed by heart disease (18 deaths). For individuals living independently, the top two causes were COVID-19 (20 deaths) and complications of genetic (20 deaths). The top cause of death for individuals in the Institution setting was sepsis (six deaths) followed by failure to thrive/slow decline (five deaths).

Only two deaths (one percent) among individuals living independently were determined to be potentially preventable. However, 20 deaths (12 percent) that occurred in the congregate setting were determined to be potentially preventable. The causes are listed in Table 20.

Table 20. Causes of potentially preventable deaths in Congregate setting, SFY 2022

Cause	Deaths
Choking	8
Trauma	2
Seizure	2
Accidents	1
Aspiration Pneumonia	1
Sepsis	1
Sudden Cardiac Death	1
Diabetes	1
Traumatic Brain Injury	1

Cause	Deaths
Heart Disease	1
Pneumonia	1
Total	**20**

Table 21 presents the crude mortality rates of individuals on a DD Waiver in SFY 2022.

Table 21. CMR for DD Waiver Population by residence, SFY 2022

Residential Living Group	Deaths	DD Waiver Population	Crude Mortality Rate
Congregate or Institution	209	4,403	47.5
Independent	156	11,077	14.1
Total	**365**	**15,480**	**23.6**

* Population estimates for the congregate living and independent living groups utilize the "Living Situation on Waiver" field in the Waiver Management System (WaMS) enrollment data.

Table 22 displays the crude mortality rates of individuals in facility and institutional settings.

Table 22. Crude Mortality Rates for Facility and Institutional Settings, 1,000 population, SFY 2022

Residential Living Group	Deaths	Estimated Population*	Crude Mortality Rate
Facility	6	341	17.6
Institutional	43	4,120	10.4

* Death count includes all individuals regardless of waiver status. Estimated populations for facilities are based on a mid-year snapshot. For the Institutional estimate, the total number of individuals with a DD diagnosis from the most recent private hospital census data is added to the maximum bed capacity for adult and child ICF/IIDs.

Individuals Discharged from Training Centers

For decades, DBHDS has worked to transition individuals residing in state-funded training centers (TCs) into more inclusive, community-based supports. Currently there is only one training center open, Southeastern Virginia Training Center, with no plans for closure at this time.

In SFY 2022, the DBHDS DD MRC reviewed 44 deaths among individuals discharged from a training center into the community. The leading causes of death for these individuals were failure to thrive/slow decline (seven) followed by heart disease (five) and seizure (four). Six of the deaths in this population (13 percent) were determined to be potentially preventable.

Community tenure is defined as the length of time an individual spent in the community between the date of discharge from a training center (under the Commonwealth's settlement

agreement with the United States Department of Justice) and the individual's date of death. Individuals who transfer to another facility or out-of-state are not included in these calculations.

Table 23. Age at Death and Community Tenure for Individuals Discharged from Training Centers

SFY	Deaths	Average Age at Death	Median Age at Death	Average Community Tenure (Months)	Median Community Tenure (Months)
2015	16	60	59	17	18
2016	31	60	60	24	25
2017	23	62	61	31	34
2018	30	60	62	40	44
2019	36	64	64	45	44
2020	46	64	65	43	48
2021	47	63	62	79	91
2022	44	62	62	70	63

The average community tenure decreased from 79 to 70 months in SFY 2022. As only one training center remains open, there are considerably less individuals actively transitioning to a community setting. During the years where significant numbers of individuals were transitioning from the training centers to the community, community tenure was a significant metric to ensure that this shift in care environment did not result in increased mortality, particularly in the year post-discharge. While several factors play a role in community tenure, such as age, medical and behavioral status, adequate supports and services, this population has been closely monitored to ensure their needs are met and in the past five years, individuals have lived on average three years or longer in the community prior to the time of death.

Conclusion

Individuals with disabilities in Virginia and across the country continue to experience significant differences in health characteristics and management compared to those without disabilities. Addressing existing or potential health risk factors through early recognition and intervention by DBHDS licensed providers for all I/DD individuals is a priority. The DBHDS DD MRC supports efforts to include individuals with disabilities in disease prevention, health promotion, and emergency response activities, while working to remove barriers to health care and improve access to routine preventive services for these individuals. This report is an important contribution towards those efforts.

As more individuals with I/DD are living in community settings more, the Commonwealth continues to work toward achieving the highest quality of life for individuals with developmental disorders, through ensuring access to the services and supports that allow them to meet their fullest potential. The COVID-19 pandemic continues to have a serious public health impact on individuals with I/DD. Nonetheless, the quality management process, consisting of a planned,

systemic, organization-wide approach to designing and improving initiatives, has improved over the past several years. The current plan is comprehensive, interdisciplinary, and addresses critical functions such as health and safety, person-centered service planning, access to services, human rights/freedom from abuse and neglect, and outcome management. The focus is also shifting to include identification of risk factors versus contributory factors, that predispose individuals with I/DD to negative outcomes, and the role those factors have in implementing interventions. With the adoption of new definitions to identify and develop system wide improvement, the intention is for the Commonwealth to implement improvements at a systemic level. The DBHDS DD MRC has continued to improve upon and make significant advances to the process it uses to identify and report on deaths for this population. The MRC will continue to revise and update its processes as needed, to incorporate evidence, best practices, in data driven initiatives.