Virginia Department of Behavioral Health & Developmental Services

SFY 2021 Annual Mortality Report

Presented by the DBHDS Mortality Review Committee

December 2021

Contents

Annual Mortality Report

State Fiscal Year 2021

Executive Summary

This is the seventh 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 the timeframe of July 1, 2020 to June 30, 2021 as reported in the DBHDS incident reporting systems. This report compares state fiscal year (SFY) 2021 mortality review data to that in 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, 2021, there were 15,221 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 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 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.

Over the past year, the MRC saw the impact of two significant events that are woven throughout the data. The first is the impact of legislation that began July 1, 2020, which allowed the MRC access to greater information from providers who are not directly licensed by DBHDS. Legislation resulted in almost triple the amount of documentation for each case reviewed,

[1] Virginia Waiver Management System. Accessed by DBHDS on Aug 13, 2021.

describing more clinical detail, state death certificates, records from medical and rehabilitation centers, hospice, and other community care. This resulted in the increased identification of deaths that were considered to be potentially preventable and fewer deaths where the cause of death was unknown, such that the overall quality and completeness of the data has improved significantly. The other significant event, which began in the middle of state fiscal year 2020, which continues to have significant impact, is the ongoing transmission of COVID-19. However, in this fiscal year, several COVID-19 vaccines and biological therapeutics became available to mitigate the morbidity and mortality of COVID-19. While availability and priority was phased, individuals with developmental disorders, high-risk medical conditions, those in congregate settings and frontline essential workers, received priority during the initial distribution and administration of vaccines. COVID-19 continues to pose a threat in Virginia due to the continued high transmission of novel variants, and the provider community should be commended for their ongoing dedication to serve individuals with I/DD in those critical settings, despite the multiple workforce, financial, and service delivery challenges that have impacted all healthcare providers as a result of the pandemic.

Key Findings

- The DBHDS DD MRC reviewed 408 deaths that occurred during SFY 2021. This is a 15.3 percent increase from the 354 deaths reviewed by the Committee during SFY 2020, and is the highest number of deaths reviewed by the Committee since its creation.
    - The DBHDS DD MRC utilizes a two-tier review process, which allows the DBHDS DD 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 408 deaths reviewed in SFY 2021, 171 (42 percent) deaths were categorized as a Tier 1, and 237 (58 percent) deaths were categorized as Tier 2.
- The median age at time of death was 59 years old; the mean age at death was 55 years old.
- The leading cause of death in SFY 2021 was COVID-19 (60 deaths, 14.7 percent), followed by heart disease (37 deaths, 9.1 percent) and cancer (33 deaths, 8.1 percent).
- The MRC determined more deaths to be Unexpected (210 deaths, 51.5 percent) than Expected (197 deaths, 48.3 percent). In the previous two fiscal years, more deaths were classified as Expected than Unexpected.
    - Forty-eight deaths (23 percent) classified as Unexpected had a cause of death as COVID-19.
    - The DBHDS DD MRC could not determine the cause of death for only two deaths (0.5 percent). This is the lowest percentage of deaths in which the cause is Unknown since the Committee's 2012 inception.

[2] Full definitions of Tier 1 and Tier 2 are on page 10 of this report.

- The DBHDS DD MRC determined 39 deaths (10 percent) to be potentially preventable in SFY 2021. This is a 129 percent increase in the total number of potentially preventable deaths compared to SFY 2020 preventable deaths (17 deaths, 5 percent).
    - Similar to previous years, the majority of deaths determined to be potentially preventable in SFY 2020 (25 of 39) involved a failure to execute established protocols.
- Compared to SFY 2020, the crude morality rates increased for all age groups except for two age groups: 0-17 years old and 18-30 years old. Significant increase in crude mortality rates compared to SFY 2020 were seen in age groups 41-50 years old (52 percent increase) and 81 years old and above (33 percent increase).
- The crude mortality rates for individuals in SIS Levels 2, 4, 5 and 7 increased compared to SFY 2020, while those for Levels 1, 3, and 6 decreased. The crude mortality rate for individuals with a SIS Level of 7 increased 41 percent compared to SFY 2020.
- Average community tenure greatly increased from SFY 2020 (43 months). For SFY 2021, average community tenure was 87 months. Of the deaths reviewed in SFY 2021, compared to prior years, nearly 60 percent of individuals that died in SFY 2021 transitioned from a training center in 2012 or 2013. As only one training center remains open, it is anticipated that community tenure will be a reflection of the timing of the closures nearly 10 years ago.

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, client-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 are as follows:

Recommendation 1: In the 2019 Annual Report, it was recommended that DBHDS should maintain an established target that potentially preventable deaths make up less than 15 percent of the total DD deaths per year. While there was an increase in the percentage of potentially

preventable deaths in SFY 2021 from 5 percent (SFY20) to 10 percent, 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.

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 2021, the MRC collaborated with the Offices of Licensing and Provider Development to increase training and adherence to providers related to emergency response protocols. 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.

Recommendation 3: In the 2019 Annual Report, it was recommended that DBHDS should maintain an established target of less than 10 percent of deaths reviewed to be classified as "Unknown" for the cause of death. In 2020, SB 482 was passed by the General Assembly to legislatively establish the Developmental Disabilities Mortality Review Committee, which provides greater access to information and records for an individual whose death is being reviewed by the Committee, from providers beyond those licensed by DBHDS. This legislation went into effect on July 1, 2020, and has had a significant impact on the DBHDS DD MRC in determining the cause of death, with only two of 408 deaths determined to be cause of death as unknown. Determining the cause of death is a key factor in understanding and developing systemic quality improvement initiatives, and having access to pertinent information and records facilitates that determination. In SFY 2021, DBHDS received 98 percent of death certificates, achieving last year's quality improvement initiative's goal of over 90 percent. DBHDS should continue to monitor this on an annual basis to ensure that this trend is sustained over time.

Recommendation 4: As mentioned previously, COVID-19 continues to impact vulnerable I/DD individuals, and was the cause of death for 23 percent of unexpected deaths in SFY 2021. For the next fiscal year, the MRC will measure COVID-19 mortality among the I/DD population to determine if a decrease to less than10 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.

Recommendation 5: Death due to sepsis represented 5 percent of deaths in this study year compared to 11 percent of deaths in the year prior. While sepsis, once it occurs, can often lead

to mortality, there are a number of contributory illnesses that may benefit from early detection and intervention to prevent the development of sepsis or death. For SFY 2021, DBHDS evaluated underlying causes and conditions that lead to an increase in sepsis deaths in this population, with the primary contributing cause as 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.

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. These activities may include; identifying systemic actions and interventions to increase provider and individual education about disease and treatments, training, and up-to-date recommendations on best practice, and early identification of risk factors or illnesses that contribute to the top causes of deaths in the I/DD population.

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) in order 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 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 2021, 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 2021

- Provided SIS level training for all MRC members on October 8, 2020.
- Provided training and orientation for additional DBHDS DD MRC members to ensure understanding of DBHDS DD MRC mission, scope, and mortality review process. Understanding the cause of death on a death certificate education was provided to all members on November 5, 2020, in addition to application of the principles of continuous quality improvement.
- SB 482 was passed by the 2020 General Assembly and became effective on July 1, 2020. This legislatively established the DBHDS DD MRC and provided greater access to information and records regarding individuals whose deaths are being reviewed by the Committee.
- Established procedures to request, receive, track, and store medical records as a result of the above legislation. Partnering with medical record vendors in the state, an electronic process was developed in order to preserve confidentiality of PHI when requesting and receiving medical records.
- Collaborated with the Virginia Department of Health's Office of Vital Records to obtain death certificates. This process was initiated in May 2020, and for SFY 2021, death certificates were obtained for 98 percent of deaths reviewed by the DBHDS DD MRC. In SFY21, this process became fully electronic, and no longer required in person pick up of hard copy (paper) documents.
- In July 2020, established a process in collaboration with the DBHDS Office of Licensing's Special Investigation Unit (SIU) for the receipt and tracking of required provider documents, including licensing documents.

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. Changes that were implemented in the last quarter of SFY 2020 are reflected in the data analysis for SFY 2021.

Key definitions

- Expected Death denotes a death that was consistent with, and as a result of, an individual's previously diagnosed terminal condition. A death can be expected if the person had a known terminal condition *(e.g., end stage renal disease)* or if the person was elderly and had a period of deterioration and increasing medical frailty. In both cases, the person, family, and caregivers were aware that the condition was terminal, end of the life decisions were in place, and primary health care and palliative care teams, if applicable, were involved. The individual, legally authorized representative, power of attorney or legal guardian *(if the individual lacked capacity to make advance directive*

decisions), and family, were all aware that the illness or condition would result in death and had an opportunity to discuss, if not decide, end of life matters and clinical measures to be taken or not taken.

- Unexpected Death denotes a death that occurred as a result of an acute medical event that was not expected in advance nor based on a person's known medical conditions. Examples might include suicide, homicide, accident, acute medical event, a new medical condition, or sudden and unexpected consequences of a known medical condition. An Unexplained death also is considered an unexpected death.
- Unknown indicates 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 are deaths that are considered to be premature and may have been avoided, based on a combination of known medical, genetic, social, environmental, or other factors *(such as pre- morbid conditions)*. When the DBHDS DD MRC determines a death is potentially preventable, the Committee categorizes factors that might have prevented the death. For a death to be determined potentially preventable, the actions and events immediately surrounding the individual's death must be related to deficits in the timeliness or absence of, at least one of the following factors:
    1. Coordination of care
    2. Access to care, including delay in seeking treatment
    3. Execution of established protocols
    4. Assessment of the individual's needs or changes in status
- A Tier 1 case requires a detailed, comprehensive review of multiple factors and areas of focus by the mortality review Committee. 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)
    - 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
- A Tier 2 case does not require a detailed, comprehensive review as the preliminary review was sufficient. Tier 2 deaths must meet all of the following criteria:
    - Cause of death can clearly be determined or established
    - An Expected death, if no abuse or neglect, involvement of law enforcement or well-defined safety and well-being risks are documented

- An Unexpected (Unexplained) death that occurred as a result of an acute medical event, a new medical condition, or sudden and unexpected (unexplained) consequences of a known medical condition
- 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.

Virginia Deaths

The COVID-19 pandemic, which was first declared globally in early 2020, continues to pose a threat to the health and safety of the population. Community transmission of COVID-19 has occurred in "waves", with peaks in the U.S. in the colder months, and lower rates in the warmer months. Compared to SFY 2020, the significant development to combat the pandemic was a number of COVID-19 vaccines that were approved under Emergency Use Authorization by the Food and Drug Administration (FDA). The first COVID-19 vaccine in the U.S. was first made available in December 2020, however though supply was limited at first, priority populations were able to receive the vaccine including: individuals with I/DD, frontline essential workers, and high-risk settings such as congregate care. DBHDS worked collaboratively across multiple state agencies to enhance vaccine 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 406 of 408 deaths (99.5 percent) reviewed. Only two deaths were classified with an Unknown cause of death in SFY 2021, which is an improvement from SFY 2020 where 16 deaths were classified as Unknown cause of death, and SFY 2019 where Unknown was the leading cause of death. This is a significant improvement after a three-year trend of increasing Unknown cause of death, which peaked in SFY 2019 where 13.5 percent of deaths categorized as Unknown cause. 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 Committee.

Unlike deaths in which the specific cause of death is "Unknown", deaths classified as "Other" causes have known etiologies outside of the DBHDS DD MRC's primary categories for statistical trending. The DBHDS DD MRC classified 15 deaths (3.7 percent) as having "Other" causes of death in SFY 2021. The causes of "Other" deaths in SFY 2021 were: multisystem organ failure, hematological disorder, homicide, accidents, and urinary tract infections, each of which accounted for two deaths. The remaining five deaths were each the result of singular causes of

death: circulatory system disorder, endocrine disorder, drowning, influenza and intent to harm self (suicide).

COVID-19 deaths were first reflected in the MRC data in the fourth quarter of SFY 2020. The number of COVID-19 deaths in SFY 2021 reflects when the highest rates of transmission were occurring in the Commonwealth, therefore resulting in COVID-19 as the number one cause of death for SFY 2021. COVID-19 accounted for 60 deaths (14.7 percent): 10 deaths in Q1, 20 deaths in Q2, 27 deaths in Q3 and three deaths in Q4. While it may be too early to fully determine the impact of the COVID-19 vaccine, the decreased rate of deaths in Q4 due to COVID-19 seem to align with the timing of widespread vaccine uptake, as 42 percent of the DD waiver population was fully vaccinated by end of Q3 (March 2020), reaching a 70 percent vaccination rate by June 1, 2021. The second leading cause of death was heart disease (37 deaths, 9.1 percent), followed by cancer (33 deaths, 8.1 percent). Additionally of note, the MRC reviewed deaths of significant numbers (11) for drug toxicity and overdose, as well as one homicide death and one death related to self harm (suicide). This may reflect the "deaths of despair" that increased during the pandemic due to increased stressors related to issues such as unstable employment, housing, disrupted health care, limited access to typical social supports, and caregiver burnout.

The table below includes a summary of the causes of death. The 2019, 2020 and 2021 columns include two numbers in each row. The first is the total number of deaths for that category and the second indicates the number of those deaths for individuals who were not receiving a DBHDS-licensed residential service.

**Table 1. Number of Annual Deaths by Cause of Death, SFY 2018 – 2021*
(Sorted by Frequency in 2021)**

Cause Of Death	2018	2019	2020	2021	Total
COVID-19	-	-	10/2	60/18	70
Heart Disease	19	17/8	28/15	37/6	101
Cancer	23	30/14	34/20	33/8	120
Sudden Cardiac Death	22	22/9	43/18	29/3	116
Neurodegenerative Diseases	5†	18/2	7/3	21/2	51
Sepsis	14	19/10	41† /15	21/6	95
Pneumonia	21	20/7	22/10	20/2	83
Aspiration Pneumonia	-	13/4	15/2	19/4	47
Complication of Congenital Condition	2	13/10	5/4	18/0	38
Complication of Genetic Condition	11	9/8	16/11	18/3	54
Seizure	6	7/3	12/5	16/6	41
Respiratory Disease	18	29† /17	10/3	12/2	69
Acute Respiratory Failure	3†	8† /3	16/7	12/4	39
FTT/Slow Decline	4	10/4	21/7	11/1	46
Gastrointestinal Disease	4	3/1	8† /3	9/4	24
Choking	0	2/0	5/1	8/0	15
Kidney Disease	9	11† /5	6/4	8/2	34
Stroke	3	7/2	8/4	7/0	25
Drug Overdose/Toxicity	1	0	1/0	7/4	9
Neurological Disorder**	-	-	-	6/1	6
Aspiration	25	5/1	4/0	5/1	39
Bowel Obstruction	7	7/2	4/2	4/0	22
Traumatic Brain Injury	-	4/0	2/0	4/1	10
Anoxic Brain Injury	-	1/0	2/0	4/0	6
Postoperative Complications	6†	3/1	3/2	3/0	15
Unknown	34	42/24	16/14	2/0	94
Other^	24	18/5	15/5	15/4	72

* In Table 1, causes of death marked with a single asterisk (*) were added by the DBHDS DD MRC in SFY 2021.
- 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 Committee determinations.
** Fields marked with ** indicate it was a newly added cause of death.
† The totals marked with a † differ from previously reported totals due to a misclassification of an "Other" deaths.
^ 'Other' is located at the bottom of the table because it comprises several causes of deaths that all include 2 or less deaths.

End of Life Care

The American Association for Individuals with Intellectual and Developmental Disabilities (AAIDD), updated their position statement in January 2020[3], on caring for individuals with I/DD

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

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 did not view that having a Do Not Resuscitate 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 SFY 2021, 224 deaths (55 percent) had a 'Do Not Resuscitate' (DNR) status. In SFY 2020, 42 percent of deaths (148 deaths) had a DNR status. There were 184 deaths (45 percent) in SFY 2021 that had no documented record of a DNR status as compared to SFY 2020 where 58 percent of deaths (206 deaths) had no documented DNR status. For SFY 2021 Tier 1 cases, 76 cases (44 percent) had a DNR status while 95 deaths (56 percent) did not. The residential setting with the highest DNR status was in congregate care (65 percent). The setting with the lowest percentage of documented DNR status was independent living with 38 percent (59 individuals with a DNR). This may be related to familiarity with advance directives in congregate settings.

Do Not Resuscitate Status	Congregate	Facility	Independent	Institution	Unknown	Other
Yes	116	8	59	23	18	0
No	63	6	98	12	4	1
Total	179	14	157	35	22	1

Hospice

Of the 408 individuals who died in SFY 2021, 138 individuals were receiving hospice services (66 percent) while 270 individuals who died were not (34 percent). This is similar to SFY 2020 where 35 percent of individuals who died were receiving hospice services and 65 percent were not. The greatest percentage of individuals receiving hospice services resided in institutions (43 percent, 15 individuals) followed by congregate setting (41 percent, 73 individuals). The lowest percentage of individuals receiving hospice services resided in a facility (14 percent, 2 individuals). The greatest number of individuals receiving hospice care that died in SFY 2021 were between the ages of 61-70 (43 deaths). Fifty-four percent of individuals aged 71-80 that died in SFY 2021 were receiving hospice services. Over 60 percent of deaths of individuals 81 and older were receiving hospice services.

Hospice Services	Congregate	Facility	Independent	Institution	Unknown	Other
Yes	73	2	40	15	8	0
No	106	12	117	20	14	1
Total	179	14	157	35	22	1

Age	Number Of Hospice Deaths	Total Deaths	Percentage of Deaths
0-17	0	12	0%
18-30	6	36	16.7%
31-40	7	35	20.0%
41-50	16	54	29.6%
51-60	28	85	32.9%
61-70	43	118	36.4%
71-80	27	50	54.0%
81 and above	11	18	61.1%

Expected and Unexpected Deaths

Following the cause of death determination, the DBHDS DD MRC determines whether a death was Expected or Unexpected. Unlike the previous two years, in SFY 2021 MRC determined more deaths to be Unexpected than Expected. The percentage of deaths the DBHDS DD MRC determined to be Unexpected increased from 39.3 percent of deaths in SFY 2020 to 51.5 percent of in deaths in SFY 2021 (51 percent increase). The DBHDS DD MRC was unable to determine whether one death was Expected or Unexpected, which was attributed to the large number of COVID-19 deaths that occurred during this review period. The Centers for Disease Control (CDC) indicated that individuals with certain medical conditions were at high risk of severe illness and death from COVID-19. However, the MRC felt that contracting COVID-19 was largely unexpected because of enhanced infection precautions and statewide restrictions that existed throughout most of the year. The MRC recognized 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 was present, the medical risk factors proved to be an accurate reflection of the development of negative outcomes, as supported by literature.

The leading cause of unexpected deaths in SFY 2021 was COVID-19 (48 deaths), followed by sudden cardiac death (28 deaths) and heart disease (26 deaths). The leading causes of Expected deaths were cancer (31 deaths), neurodegenerative diseases (21 deaths), and complications of a genetic condition (12 deaths).

Figure 1. Expected and Unexpected Deaths, SFY 2018-2021

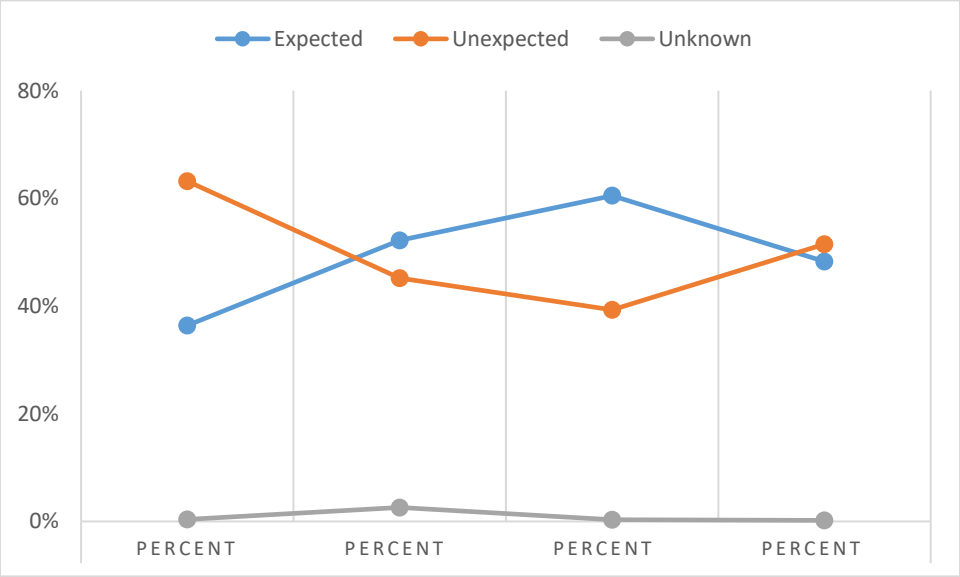


Table 2. Expected and Unexpected Deaths, SFY 2018 – 2021

Determination	2018		2019		2020		2021	
	Deaths	Percent	Deaths	Percent	Deaths	Percent*	Deaths	Percent
Expected	95	36.4%	163	52.2%	214	60.5%	197	48.3%
Unexpected	165	63.2%	141	45.2%	139	39.3%	210	51.5%
Unknown	1	0.4%	8	2.6%	1	0.3%	1	0.2%

* Due to rounding, these column percentages add to more than 100 percent.

Potentially Preventable Deaths

In SFY 2021, 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. Potentially preventable, as defined by the DBHDS DD MRC, is specific to the identification of modifiable factors within the service delivery system, required through regulation, but that may have been missed. For the purposes of the DBHDS DD MRC, this definition does not include preventable risk factors and health behaviors such as smoking or unhealthy diets. These modifiable risk factors are addressed though the Health and Safety Key Performance Area Workgroup whose focus is on health prevention and maintenance of wellness. 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. In previous fiscal years, while the standardized application of the definition was achieved, this definition had identified a relatively small number of individuals. However, SFY

2021 showed a significant increase in the number of potentially preventable deaths as determined by the MRC.

The DBHDS DD MRC classified 39 deaths (10 percent) as potentially preventable in SFY 2021. Of these 39 deaths determined to be potentially preventable, 25 deaths (64 percent) were identified as a failure to execute established protocols, which was the top reason for potentially preventable in the previous two years as well. In SFY 2021, of the 39 potentially preventable deaths, seven were due to choking, six to sudden cardiac death, and four each to sepsis, COVID-19 and drug overdose/toxicity, three to heart disease, two due to homicide, two to aspiration pneumonia, two to bowel obstruction, one to aspiration, one to pneumonia, and one where the cause of death was unknown. In SFY 2021, the DBHDS DD MRC determined that four deaths could not be determined if they were potentially preventable or not and therefore categorized as Unknown.

Table 3. Potentially Preventable Deaths, SFY 2018 – 2021

Determination	2018		2019		2020		2021	
	Deaths*	Percent	Deaths	Percent**	Deaths	Percent**	Deaths	Percent
Not Potentially Preventable	184	71%	258	83%	328	93.0%	365	89%
Potentially Preventable	55	21%	11	4%	17	5.0%	39	10%
Unknown	20	8%	43	14%	9	3%	4	1%

* Two deaths that occurred during SFY 2018 did not include any data for this determination and are therefore omitted from this column.

** Due to rounding, these column percentages add to more than 100 percent.

Population Demographics

This section includes demographic trends for individuals reviewed by the DBHDS DD MRC. For SFY 2021, 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 2021 was 26.8 deaths per 1,000, an increase compared to a rate of 24.5 in SFY 2020. 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)[4] 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.

[4]http://www.dbhds.virginia.gov/library/developmental%20services/mlmc%20support%20levels%20and%20tiers%20adults%206-30-16.pdf

Age

- As observed in the previous three years, the plurality of deaths reviewed by the DBHDS DD MRC in SFY 2021 occurred among individuals aged 61 to 70.
- Nearly 80 percent of all deaths reviewed by the DBHDS DD MRC were for individuals 41 years of age or older.
- For SFY 2021, the median age at time of death was 59 years; the mean age at death was 55 years.

Figure 2. Age at Death, SFY 2021

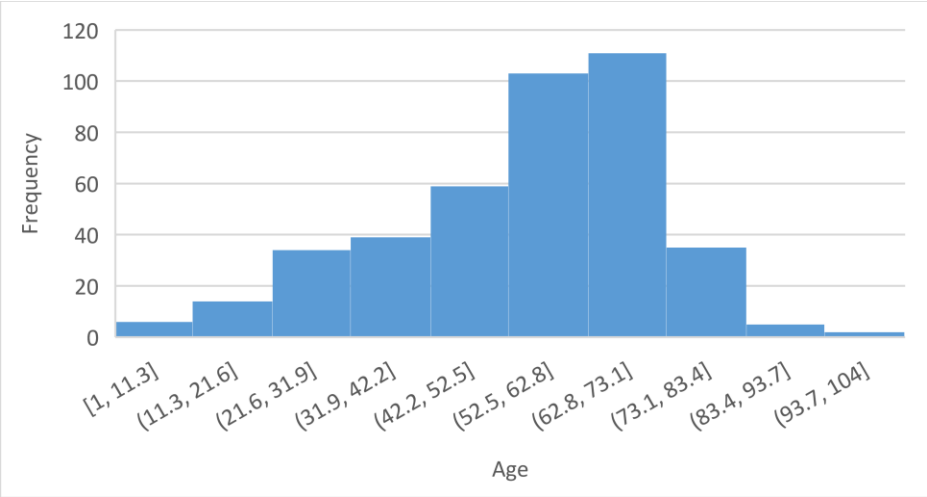
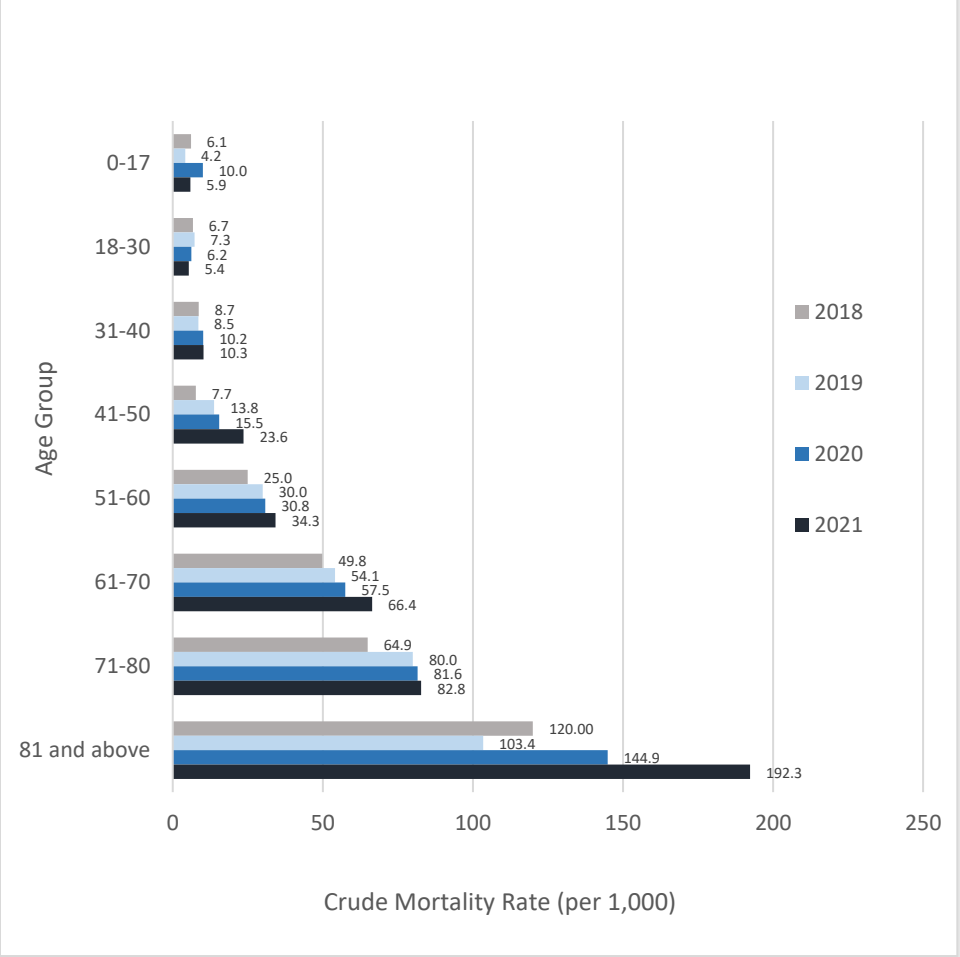


Table 4. Crude Mortality Rates by Age per 1,000 population, SFY 2021

Age Group	Deaths	DD waiver Population	Crude Mortality Rate
0-17	6	1022	5.9
18-30	28	5190	5.4
31-40	32	3120	10.3
41-50	47	1992	23.6
51-60	69	2014	34.3
61-70	91	1370	66.4
71-80	36	435	82.8
81 and above	15	78	192.3
Total	**324**	**15,221**	**21.3**

- Compared to SFY 2020, the crude mortality rate among the DD Waiver population increased for all age ranges except among individuals between the ages of 0 and 17 and 18-30.
- In the DD waiver population, 168 decedents were between the ages of 51-70, and 71 of those individuals (42 percent) were known to be receiving hospice services.

Figure 3. Crude Mortality Rates by Age per 1,000 DD Waiver Population, SFY 2018 – 2021



Gender

Males comprised the majority of individuals whose deaths were reviewed by the DBHDS DD MRC in SFY 2021, consistent with trends from previous fiscal years. The overall gender findings for SFY 2021 was 233 male and 175 female deaths. The leading cause of death among all males in SFY 2021 was COVID-19 (39 deaths, 21 percent), followed by heart disease (27, 15 percent), then sudden cardiac death (16, 9 percent). Among females, the leading cause of death was COVID-19 (21 deaths, 15 percent), followed by cancer (18, 13 percent), then sudden cardiac death (13, 9 percent).

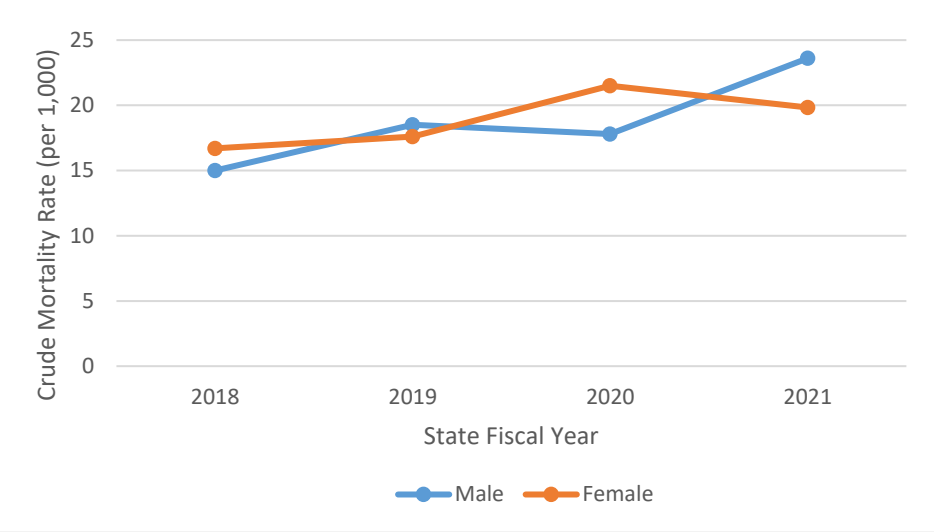
The table below includes the gender analysis of individuals the DBHDS DD MRC reviewed that were in the DD Waiver population.

Table 5. Crude Mortality Rates by Gender per 1,000 population, SFY 2021

Gender	Deaths	DD Waiver Population	Crude Mortality Rate
Female	139	5,889	23.6
Male	185	9,330	19.8
Unknown	0	2	0.0
Total	**324**	**15,221**	**21.3**

The crude mortality rate among females on a DD Waiver, which had consistently increased in previous years, decreased for SFY 2021. The crude mortality rate decreased from 21.5 deaths per 1,000 in SFY 2020 to 19.8 deaths per 1,000 in SFY 2021 (8 percent decrease). In contrast, among males on a DD Waiver, the crude mortality, which decreased in SFY 2020, increased in SFY 2021. For males on a DD Waiver, the crude mortality rate increased from 17.8 deaths per 1,000 population in SFY 2020 to 23.6 per 1,000 population in SFY 2020 (33 percent increase).

Figure 4. Crude Mortality Rates by Gender per 1,000 population, SFY 2018 – 2021



Race

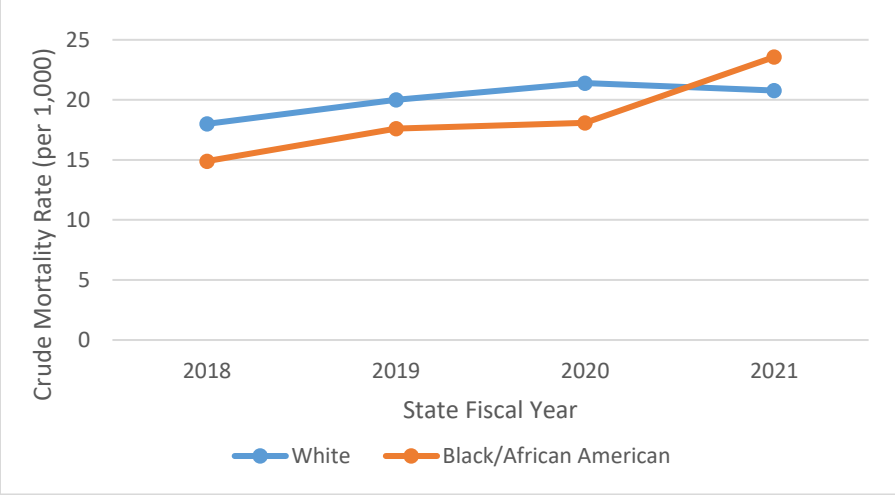
Consistent with data from previous years, the majority of deaths reviewed by the DBHDS DD MRC were of individuals identified as White/Caucasian (246 deaths, 60 percent). Individuals identified as Black/African American accounted for 32 percent of deaths (130 deaths) reviewed by the Committee. Individuals of all other races combined for approximately 7 percent of deaths (27 deaths) reviewed by the Committee.

Table 6. Crude Mortality Rates by Race per 1,000 population, SFY 2021

Race	Deaths	DD Waiver Population	Crude Mortality Rate
White/Caucasian	197	9482	20.8
Black/African American	106	4498	23.6
Other	19	1173	16.2
Unknown	2	68	29.4
Total	**324**	**15221**	**21.3**

The crude mortality rate among individuals identified as White/Caucasian on the DD waiver was 20.8 deaths per 1,000 population in SFY 2021, a 3 percent decrease from 21.4 deaths per 1,000 population in SFY 2020. However, the crude mortality rate among individuals identified as Black/African American on the DD waiver increased from 18.1 deaths per 1,000 population in SFY 2020 to 23.6 deaths per 1,000 population, a 30 percent increase. This is the first year the crude mortality rates for individuals identifying as Black/African American surpassed the rate of those identified as White/Caucasian. Unlike SFY 2020, in SFY 2021 a greater percentage of Black/African American Individuals died (32 percent) than the percentage of Black/African Americans individuals on the waiver (30 percent). Whereas a lower percentage of White/Caucasian deaths occurred (30 percent) than percentage of White/Caucasian individuals on the wavier (62 percent). These rates are impacted by the demographics of the waiver population for that specific year. In SFY 2021, there were fewer Black/African American individuals on the waiver but more Black/African American deaths in SFY 2021 than the previous year.

Figure 5. Crude Mortality Rates by Race per 1,000 population, SFY 2018 – 2021



Services and Supports

As mentioned previously, 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

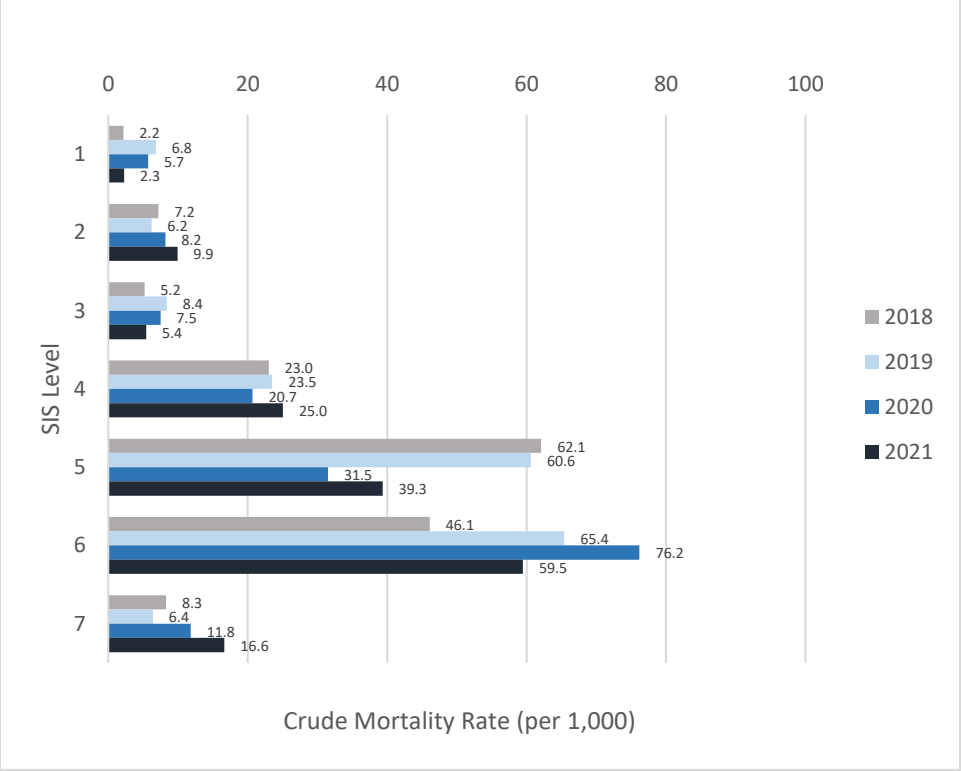
service program includes individuals with the fewest support needs while Levels 6 and 7 includes individuals with an intensive need for medical and behavioral supports and services, respectively. After the initial SIS assessment is completed, SIS levels are re-evaluated and completed every three years 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 6 months in any of two domains or 'Exceptional Medical Behavioral Supports Needs'.

Table 7. Crude Mortality Rates by SIS Level per 1,000 population, SFY 2020

SIS Level	Deaths	DD Waiver Population	Crude Mortality Rate
1	2	885	2.3
2	50	5040	9.9
3	3	552	5.4
4	145	5790	25.0
5	24	610	39.3
6	82	1379	59.5
7	16	961	16.6
Unknown	2	4	500.0
Total	**324**	**15221**	**21.3**

From SFY 2020 to 2021, the crude mortality rate increased for individuals on the DD waiver with SIS Levels 2, 4, 5 and 7 and decreased for those with SIS Levels of 1, 3 and 6. In SFY 2021, the highest crude mortality rate on the waiver by SIS Level was for SIS Level 6, which captures the population of individuals with the highest level of intensive medical needs. However, the crude mortality rate among individuals with a SIS Level of 6 decreased to 59.5 deaths per 1,000 population in SFY 2021 compared to 76.2 deaths per 1,000 in SFY 2020. The most deaths occurred in individuals on DD waiver with SIS level 4, which serves individuals with moderate to high needs and is the SIS level that serves the highest number of individuals on a waiver. SFY 2021 SIS level 4 comprised of 145 deaths and a crude mortality rate of 25.0, which is increased 21 percent compared to SFY 2020 (20.4 deaths per 1,000). Individuals receiving services categorized as SIS level 4, 5 and 6, often have pre-existing chronic diseases as well as medical conditions that contribute to high rates of mortality in this population. Identifying evidence-based practices in mortality prevention strategies may help to further understand the impact resources and activities might have on the vulnerable I/DD population.

Fig. 6. Crude Mortality Rates by SIS Level Group per 1,000 population, SFY 2018 – 2021



Residential Setting

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

- *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 8. Deaths by Residential Setting, SFY 2018 – 2021

Residential Setting	2018		2019		2020		2021	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Congregate	109	41.8%	147	47.1%	165	46.6%	179	43.9%
Facility	15	5.7%	16	5.1%	6	1.7%	14	3.4%
Independent	106	40.6%	127	40.7%	136	38.4%	157	38.5%
Institution	31	11.9%	20	6.4%	45	12.7%	35	8.6%
Unknown	0	0.0%	2	0.6%	2	0.6%	23	5.6%
Total	**261**	**-**	**312**	**-**	**354**	**-**	**408**	**-**

In SFY 2021, the leading cause of death among those living independently was heart disease (19 deaths, 12 percent), followed by COVID-19 (18 deaths, 11 percent), then cancer (12 deaths, 8 percent). Among those individuals who lived in congregate settings, the leading cause of death was COVID-19 (30 deaths, 17 percent), followed by sudden cardiac death (17 deaths, 9 percent), and cancer (16 deaths, 9 percent).

Among individuals who lived independently, 11 deaths (7 percent) were identified as potentially preventable and 22 deaths (12.3 percent) among those in congregate settings were identified as potentially preventable.

In SFY 2021, the percentage of deaths among individuals in state facilities increased, which contrasts the decreasing trend established since SFY 2017. The percentage of deaths for congregate and independent residence are similar in SFY 2021 as the previous year. SFY 2021 institutional deaths decreased slightly compared to SFY 2020.

Table 9 presents the crude mortality rates of individuals on a DD Waiver in SFY 2021. Seven of the individuals who died in a congregate setting and 30 of the individuals who died in an independent setting were not receiving a licensed service on a DD Waiver; thus, they are not included in the calculation of this rate.

Table 9. Crude Mortality Rates by DD Waiver Residential Setting per 1,000 population, SFY 2021

Residential Living Group	Deaths	DD Waiver Population*	Crude Mortality Rate
Congregate	172	4,526	38.0
Independent	127	10,695	11.9
Total	**299**	**15,221**	**19.6**

* 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 10 presents the crude mortality rates of individuals in non-waiver settings.

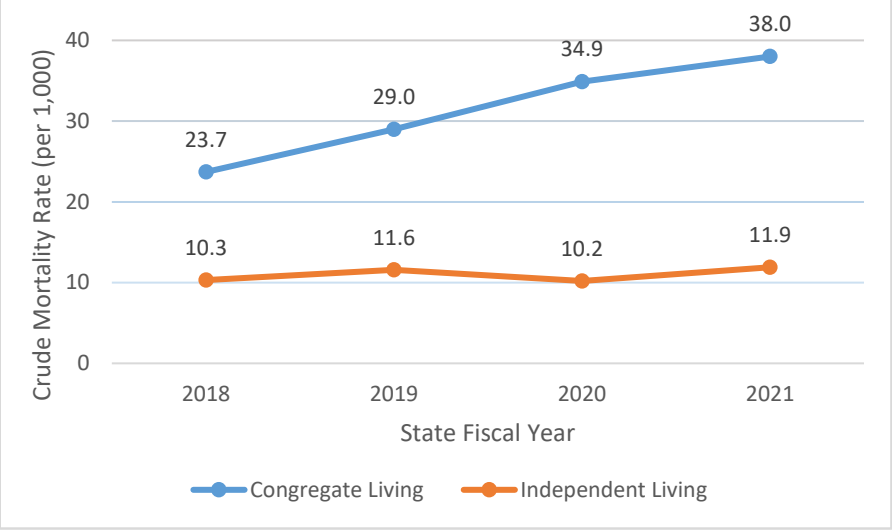
Table 10. Crude Mortality Rates by Non-Waiver Residential Setting per 1,000 population, SFY 2021

Residential Living Group	Deaths	Estimated Population*	Crude Mortality Rate
Facility	11	360	30.6
Institutional	35	4,066	8.6

*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 (SFY 2020) is added to the maximum bed capacity for adult and child ICF/IIDs.

In SFY 2021, the crude mortality rate among those living in congregate settings was 38 deaths per 1,000 population, a nine percent increase from 34.9 deaths per 1,000 population in SFY 2019. The crude mortality rate among those living independently increased from 10.2 deaths per 1,000 population in SFY 2019 to 11.9 deaths per 1,000 population in SFY 2020, a 17 percent increase. The crude mortality rate for both congregate and independent living are at their highest since 2017. Again, these congregate settings were particularly vulnerable to the impact of COVID-19.

Figure 7. Crude Mortality Rates by Residential Grouping per 1,000 population, SFY 2018 – 2021



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.

In SFY 2021, the DBHDS DD MRC reviewed 47 deaths among individuals discharged from a training center into the community. Sudden cardiac death was the leading cause of death among individuals discharged from TCs (eight deaths, 17 percent), followed by both aspiration pneumonia and COVID-19 (four deaths, 9 percent). Eight deaths (17 percent) among those discharged from TCs 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 11. 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

The average community tenure for 2021 increased 84 percent compared to SFY 2020. The median community tenure among these individuals also increased from 48 months in SFY 2020 to 91 months in SFY 2021. Nearly 60 percent of the deaths in SFY 2021 were from individuals discharged from training centers eight or nine years ago. Only one death occurred from an individual discharged from a training center within the past three years. This is a significant contrast compared to SFY 2020 where21 deaths occurred from individuals discharged from a training center within three years, with 10 of those being discharged within one year. One state operated training center remains, with no anticipated plans for closure at this time. 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. Now as the services and supports through the waiver are better established, community tenure is anticipated to continue to increase as the majority of individuals who previously resided in the training centers now live in the community and overall, less individuals transition from institution to a community setting.

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. Individuals with I/DD experience a higher mortality than the general population[5]. 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

[5] Reppermund S, Srasuebkul P, Dean K, Trollor JN. Factors associated with death in people with intellectual disability. J Appl Res Intellect Disabil. 2020 May;33(3):420-429. doi: 10.1111/jar.12684. Epub 2019 Dec 1. PMID: 31786826.

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. However, these past two years have been particularly challenging due to the COVID-19 pandemic's impact on the service delivery system and ongoing uncertainty of ongoing transmission. 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. These factors will be evaluated as the DBHDS DD MRC implements, tracks, and analyzes resulting data from mortality case initiatives and recommendations. 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 Committee will continue to revise and update its processes as needed, to incorporate evidence, best practices, in data driven initiatives.