Virginia Department of Behavioral Health & Developmental Services

SFY 2020 Annual Mortality Report

Presented by the DBHDS Mortality Review Committee
November 2020

Contents

Annual Mortality Report

State Fiscal Year 2020

Executive Summary

This is the sixth 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, 2019 to June 30, 2020 as reported in the DBHDS incident reporting systems. This report compares state fiscal year (SFY) 2020 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, 2020, there were 14,834 individuals enrolled on a Virginia Developmental Disability (DD) Home and Community Based Services (HCBS) waiver[1]. DBHDS authorizes approximately ninety 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 and analyzed. 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.

In the midst of this state fiscal year, the world was introduced to a novel coronavirus, COVID-19, which has resulted in a global pandemic and declaration of a public health emergency in the Commonwealth. This respiratory illness quickly impacted congregate care settings as public health leaders fought to study and contain the virus. Research has grown indicating that the

[1] Virginia Waiver Management System. Accessed by DBHDS on Aug 13, 2020.

elderly and those with chronic medical conditions were the most susceptible to severe illness, and thousands across the United States have died from the disease. When the COVID-19 pandemic was declared a state of emergency in March 2020 by Governor Ralph Northam, there was significant concern regarding the impact that the pandemic would have on the DD population. DBHDS licenses a number of congregate settings, which were the settings of many COVID-19 outbreaks across the country. This report does not include the total number of individuals with DD who were infected with COVID-19; however, COVID-19 accounted for approximately ten percent of deaths in quarter four of this study period, rivaling sudden cardiac death, which is the leading cause of death overall in this population. COVID-19 continues to pose a threat in Virginia, and the provider community should be commended for their ongoing dedication to serve individuals with 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.

Finally, one of the most monumental events of this study year for the Commonwealth's developmental disabilities system of care was the closure of Central Virginia Training Center (CVTC) in the spring of 2020. Only one training center will remain open, Southeastern Virginia Training Center. CVTC opened in 1910 and at its peak in 1972, 3,686 individuals resided there. Its closure signified tremendous effort and commitment toward transitioning individuals from four training centers into the community to live and prosper.

Key Findings

- The DBHDS DD MRC reviewed 354 deaths that occurred during SFY 2020. This is a 13.5 percent increase from the 312 deaths reviewed by the Committee during SFY 2019. This is the highest number of deaths reviewed by the Committee since its creation.
    - In SFY 2019, the DBHDS DD MRC commenced a two-tier review process which allowed the DBHDS DD MRC to focus more specifically on unexpected or unexplained deaths. These deaths were categorized as Tier 1, and all others fell into Tier 2[2]. Of the 354 deaths reviewed in SFY 2020, 116 deaths were categorized as a Tier 1, and 238 deaths were categorized as Tier 2.
- The median age at time of death was 58 years; the mean age at death was 54 years.
- Sudden cardiac death was the leading cause of death in SFY 2020 (43 deaths, 12%), followed by sepsis (40 deaths, 11%), cancer (34 deaths, 10%), and heart disease (28 deaths, 8%).
- The DBHDS DD MRC determined COVID-19 to be the cause of 10 deaths between April and June of 2020, making up 10% of deaths for that quarter.
- In earlier years after inception of the DBHDS DD MRC, there were significant challenges to obtaining key data to inform causes of death and, therefore, the increased the

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

difficulty of determining whether deaths were Expected or Unexpected. This has improved significantly in SFY19 and SFY 20 such that the Committee determined more deaths to be Expected than Unexpected.

- The DBHDS DD MRC could not determine the cause of death in 16 deaths (5%). This is the lowest percentage of deaths in which the cause is Unknown since the Committee's 2012 inception.
- The DBHDS DD MRC determined 17 deaths (5%) to be potentially preventable in SFY 2020. Similar to SFY 2019, the majority of deaths determined to be potentially preventable in SFY 2020 (14 of 17) involved a failure to execute established protocols. Potentially preventable as defined by the DBHDS DD MRC is specific to identifying modifiable factors within the service delivery system that are required through regulation but may have been missed. However over the past two years, while the standardized application of the definition has been achieved, this definition has identified a relatively small number of individuals. The Committee will continue to evaluate what is considered to be potentially preventable in order to adequately identify potentially preventable deaths in order to reduce mortality rates to the fullest extent practicable and improve quality of services for individuals with DD.
- Compared to SFY 2019, the crude morality rates increased for all age groups, except among individuals aged 18-30. Increases were observed in the crude mortality rate among individuals aged 0-17, which had decreased in SFY 2018 and SFY 2019, and among those aged 81 or over, which had decreased in SFY 2019.
- The crude mortality rates for individuals in SIS Levels 2, 6, and 7 increased from SFY 2019, while those for Levels 1, 3, 4, and 5 decreased. The crude mortality rate for individuals with a SIS Level of 5 decreased from 60.6 to 31.5 per 1,000 population.
- For the first time since SFY 2015, average community tenure decreased among individuals discharged from training centers. However, the median community tenure among these individuals increased from 44 months in SFY 2019 to 48 months in SFY 2020.

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

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% of the total DD deaths per year. Similar to last year, the SFY 2020 data indicated that 5% of deaths were determined to be potentially preventable and again, the primary reason was due to failure to adhere to established protocol. Failure to adhere to established 911 protocol was identified by the DBHDS DD MRC as the major contributor to the potentially preventable factor of 'Execution of Established Protocols.' The DBHDS DD MRC implemented a quality improvement initiative to improve providers' adherence to 911 protocols, for which the baseline data determined that an average of 30% of deaths where 911 was a factor, properly followed the correct protocol. In SFY 2021, DBHDS should implement a quality improvement initiative to increase the number of mortality review cases in which 911 protocol was followed to greater than 60%.

Recommendation 2: In the 2019 Annual Report, it was recommended that DBHDS should maintain an established target of less than 10% of deaths reviewed to be classified as "Unknown" for the cause of death. The DBHDS DD MRC established improved processes, such that only 5% (16 deaths) in SFY20 were determined to be Unknown. Determining the cause of death is a key factor to understand and develop systemic quality improvement initiatives, and having access to pertinent information and records facilitates that determination. In 2020, SB482 was passed by the General Assembly to legislatively establish the Developmental Disabilities Mortality Review Committee, which provides greater access to information and records regarding 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 DBHDS should track the impact on the DBHDS DD MRC for determining the cause of death, to maintain the established target.

Recommendation 3: Death certificates are a critical piece of information for understanding mortality trends and data. For SFY21, DBHDS should increase the number of death certificates available for DBHDS DD MRC review and establish a baseline for the number of I/DD individuals with a death certificate available for mortality review to >90%.

Recommendation 4: Death due to sepsis represented 11% of deaths in this study year. 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 death. For SFY21, DBHDS should further evaluate underlying causes and conditions that lead to increase in sepsis deaths in this 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 disability 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, which is updated annually, the DBHDS DD MRC must convene as frequently as necessary to ensure that deaths are reviewed within 90 days of the date of death, and must have attendance by required members. During SFY 2020, the DBHDS DD MRC met 23 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 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 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 Augmentations in SFY 2020

- Provided training and orientation for all DBHDS DD MRC members to ensure understanding of DBHDS DD MRC mission, scope and mortality review process. Application of the principles of continuous quality improvement was also included in the March 2020 training.
- SB482 was passed by the 2020 General Assembly and became effective on July 1, 2020. This legislatively established the DBHDS DD MRC and provides greater access to information and records regarding individuals whose deaths are being reviewed by the Committee.

- Collaborated with the Virginia Department of Health Office of Vital Records to obtain death certificates. This process was initiated in May 2020, and for the last quarter of SFY 2020, death certificates were obtained for 99% of deaths reviewed by the DBHDS DD MRC.
- Implemented a tier process in June 2019 whereby the Chief Clinical Officer or Clinical Manager screens all I/DD cases and refers to the DBHDS DD MRC any case where there is a finding of abuse, neglect or other documented circumstances that may have impacted the individual's death or warrants further review.
- Established a process in collaboration with the DBHDS Office of Licensing Special Investigation Team for the receipt of required provider documents, including licensing documents. This process was implemented in July 2020.

The goal of these process enhancements was 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 will be 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 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 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

In the fall of 2019, a novel virus, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) emerged in Wuhan, China. By February of 2020, the virus had expanded globally, and the World Health Organization (WHO) named the disease "COVID-19". In March of 2020, the first death due to COVID-19 was reported in Virginia[3].

The DBHDS DD MRC also made nomenclature changes to three diseases in alignment with ICD-10 coding, retrospective clinical and health records, and medical terminology, which had no effect on the cause of death classifications.

SFY 2019 Name	Name change in SFY 2020
Chronic lower respiratory disease	Respiratory Disease
Flu	Influenza
Septicemia	Sepsis

The DBHDS DD MRC determined a cause of death in 338 of 354 (95.5%) deaths reviewed. In SFY 2019, the leading cause of death was Unknown. The leading cause of death in SFY 2020 was sudden cardiac death (43 deaths, 12.1%), followed by sepsis (40 deaths, 11.3%) and cancer (34 deaths, 9.6%). This is a significant improvement after a three-year trend of increasing Unknown cause of death, which peaked in SFY2019 of 13.5% of deaths categorized as Unknown cause. Individuals who live in private residences, as opposed to settings licensed by DBHDS, continue to pose challenges to making determination of the cause of death; however, these determinations have improved due to greater access to death certificates and other information and records.

In the fourth quarter of SFY 2020, the DBHDS DD MRC noted 100 total deaths, and during this time period, of those 100, the DBHDS DD MRC determined COVID-19 as cause of death in 10 cases (10%). This was determined via death certificate in nine of the ten cases; one death attributed to COVID-19 occurred out of state, and the documentation submitted for that review supported and also listed cause of death due to COVID-19. Early during the pandemic, Virginia, like many states across the country, experienced a rapid rise in cases coupled with limited resources related to a national PPE shortage, testing supplies, and healthcare services, coupled with the many individuals with DD who have co-morbid chronic medical conditions.

[3] https://www.vdh.virginia.gov/coronavirus/

Consideration of these factors were reviewed, such that the COVID-19 deaths reviewed in SFY 2020 were determined to not be potentially preventable based on the DBHDS DD MRC's definition[4]. However, the deaths due to COVID-19 in the DD population reported here is significant, rivaling sudden cardiac death, which is the top cause of death overall. As resources and more robust public health guidance becomes available, DBHDS will continue to monitor the impact of COVID-19 in SFY 21, and continue to utilize this data to advocate for prioritization of the needs of individuals with DD.

Unlike deaths in which the specific cause of death is "Unknown", deaths classified as "Other" causes have known etiologies that exist outside of the DBHDS DD MRC's primary categories for statistical trending. The DBHDS DD MRC classified 15 deaths (4.2%) as having "Other" causes of death in SFY 2020. The most common causes of "Other" deaths in SFY 2020 were trauma, nutritional deficiencies, traumatic brain injuries, anoxic brain injuries, and accidents, each of which accounted for two deaths. The remaining five deaths were each the result of singular causes.

The table below includes a summary of the causes of death. The 2019 and 2020 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 where the individual was not receiving a DBHDS-licensed residential service.

Table 1. Number of Annual Deaths by Cause of Death, SFY 2017 – 2020[5]
(Sorted by Frequency in 2020)

Cause of Death	2017	2018	2019	2020	Total
Sudden Cardiac Death	35	22	22/9	43/18	122
Sepsis	14	14	19†/10	40/15	88
Cancer	14	23	30/14	34/20	101
Heart Disease	22	19	17/8	28/15	86
Pneumonia	27	21	20/7	22/10	90
FTT/Slow Decline	7	4	10/4	21/7	42
Acute Respiratory Failure**	-	-	7/3	16/7	23
Complications of a Genetic Condition	6	11	9/8	16/11	42

[4] DBHDS DD MRC definition of Potentially Preventable is found on page 10 of this report.

[5] In Table 1, causes of death marked with a single asterisk (*) were added by the DBHDS DD MRC in SFY 2020. 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. The totals marked with two asterisks (**) differ from previously reported totals due to differentiation of deaths due to "acute respiratory failure" and "respiratory disease" per ICD-10 classification and death certificate delineation. Finally, the totals marked with a dagger (†) differ from previously reported totals due to a misclassification of an "Other" deaths as caused by "sepsis."

Unknown	31	34	42/24	16/14	123
Aspiration Pneumonia	-	-	13/4	15/2	28
Other	21	34	18[†]/5	15/5	87
Seizure	10	6	7/3	12/5	35
COVID-19	-	-	-	10/2	10
Respiratory Disease**	22	18	30/17	10/3	80
Stroke	3	3	7/2	8/4	21
Multi-system Organ Failure*	-	-	-	8/6	8
Neurodegenerative Diseases	3	4	18/2	7/3	32
Gastrointestinal Disease	-	-	3/1	6/3	9
Kidney Disease	9	9	10/5	6/4	34
Choking	1	0	2/0	5/1	8
Complications of a Congenital Condition	-	2	13/10	5/4	20
Aspiration	13	25	5/1	4/0	47
Bowel Obstruction	4	7	7/2	4/2	22
Postoperative Complications	6	5	3/1	3/2	17
Total	**248**	**261**	**312/140**	**354/163**	**1,175**

Expected and Unexpected Deaths

Following the cause of death determination, the DBHDS DD MRC determines whether a death was Expected or Unexpected. The leading cause of Unexpected deaths in SFY 2020 was sudden cardiac death (37 deaths), followed by "Unknown" (14 deaths) and "Other" (12 deaths). The leading causes of Expected deaths were cancer (34 deaths), sepsis (33 deaths), and failure to thrive (21 deaths). The DBHDS DD MRC was unable to determine whether one death was Expected or Unexpected.

Fig. 1. Expected and Unexpected Deaths, SFY 2017 – 2020

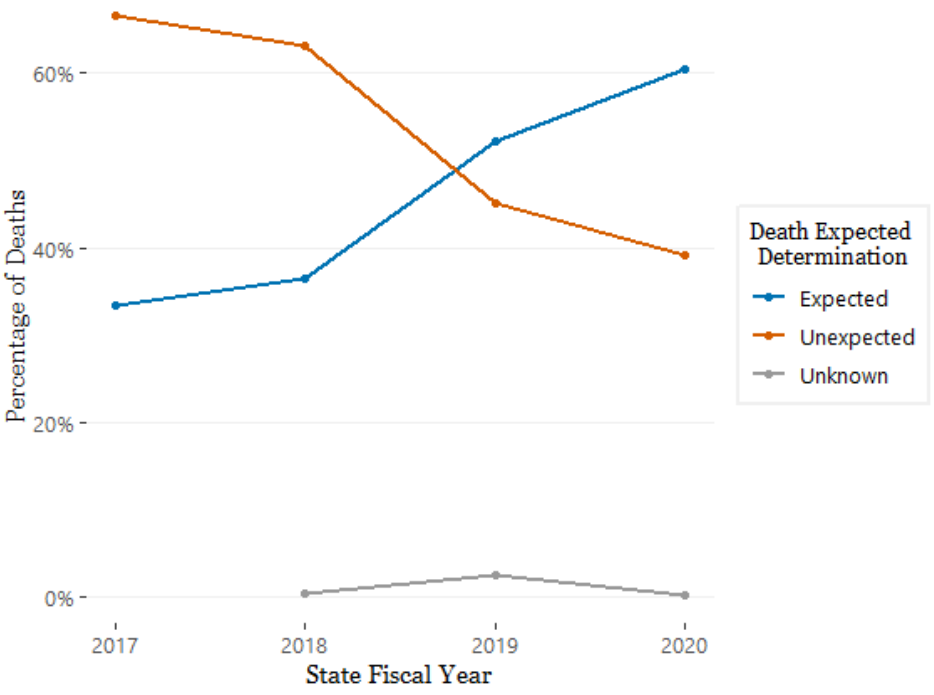


Table 2. Expected and Unexpected Deaths, SFY 2017 – 2020

Determination	2017		2018		2019		2020	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent[6]
Expected	83	33.5%	95	36.4%	163	52.2%	214	60.5%
Unexpected	165	66.5%	165	63.2%	141	45.2%	139	39.3%
Unknown	0	0	1	0.4%	8	2.6%	1	0.3%

As was observed for the first time in SFY 2019, the DBHDS DD MRC determined more deaths to be Expected than Unexpected in SFY 2020. The percentage of deaths the DBHDS DD MRC determined to be expected increased from 52.2 percent of deaths in SFY 2019 to 60.5 percent of in deaths in SFY 2020.

Potentially Preventable Deaths

In SFY 2020, 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 identifying modifiable factors within the service delivery system that are required through regulation but

[6] Due to rounding, these column percentages add to more than 100 percent.

may have been missed. However over the past two years, while the standardized application of the definition has been achieved, this definition has identified a relatively small number of individuals. The Committee will continue to evaluate what is considered to be potentially preventable in order to adequately identify potentially preventable deaths in order to reduce mortality rates to the fullest extent practicable and improve quality of services for individuals with DD. 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 not only whether actions leading to the death itself were preventable, but also whether there was an opportunity to improve quality of care regardless of whether or not the death was potentially preventable, as defined above.

The DBHDS DD MRC classified 17 deaths (5%) as potentially preventable in SFY 2020. Of these 17 deaths determined to be potentially preventable, 14 (82%) were identified as a failure to execute established protocols. Similarly, in SFY 2019 the failure to execute established protocols was associated with nine of the 11 potentially preventable deaths (82%). In SFY 2020, of the 17 potentially preventable deaths, four were due to choking, two were due to bowel obstruction, and one each were due to nutritional deficiency, traumatic brain injury, and anoxic brain injury. In SFY 2019, the DBHDS DD MRC determined that 14% of the deaths reviewed were Unknown related to potentially preventable. By contrast, in SFY 2020, the DBHDS DD MRC determined 'Unknown' related to potentially preventable status for 3%.

Table 3. Potentially Preventable Deaths, SFY 2018 – 2020

Determination	2018		2019		2020	
	Deaths[7]	Percent	Deaths	Percent[8]	Deaths	Percent[9]
Not Potentially Preventable	184	71%	258	83%	328	93%
Potentially Preventable	55	21%	11	4%	17	5%
Unknown	20	8%	43	14%	9	3%

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

[8] Due to rounding, these column percentages add to more than 100 percent.

[9] 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 2020, 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 time-frame divided by the mid-interval population, adjusted per 1000. Crude mortality rate here is reported for the DD waiver population as the denominator can be validated and compared from year to year. There are a number of factors that impact crude mortality rate such as age, gender, and race, which are further broken down within this section. Additional breakdown is conducted for the individual's service program. In Virginia, the Supports Intensity Scale 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 previously observed in SFYs 2018 and 2019, the plurality of deaths reviewed by the DBHDS DD MRC in SFY 2020 occurred among individuals aged 61 to 70.
- Slightly more than two thirds of all deaths reviewed by the DBHDS DD MRC were for individuals 51 years of age or older.
- As in SFY 2019, the median age at time of death was 58 years; the mean age at death was 54 years.

Fig. 2. Age at Death, SFY 2020

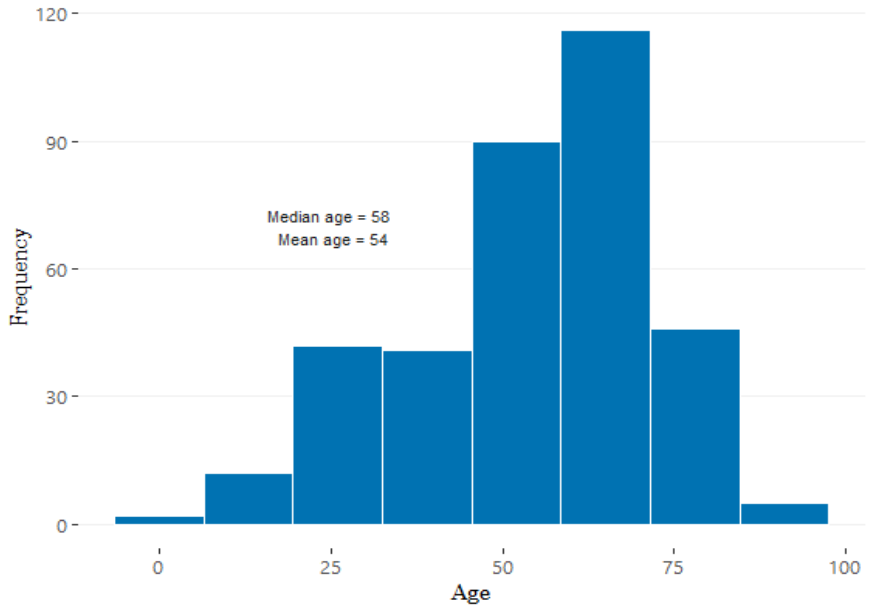
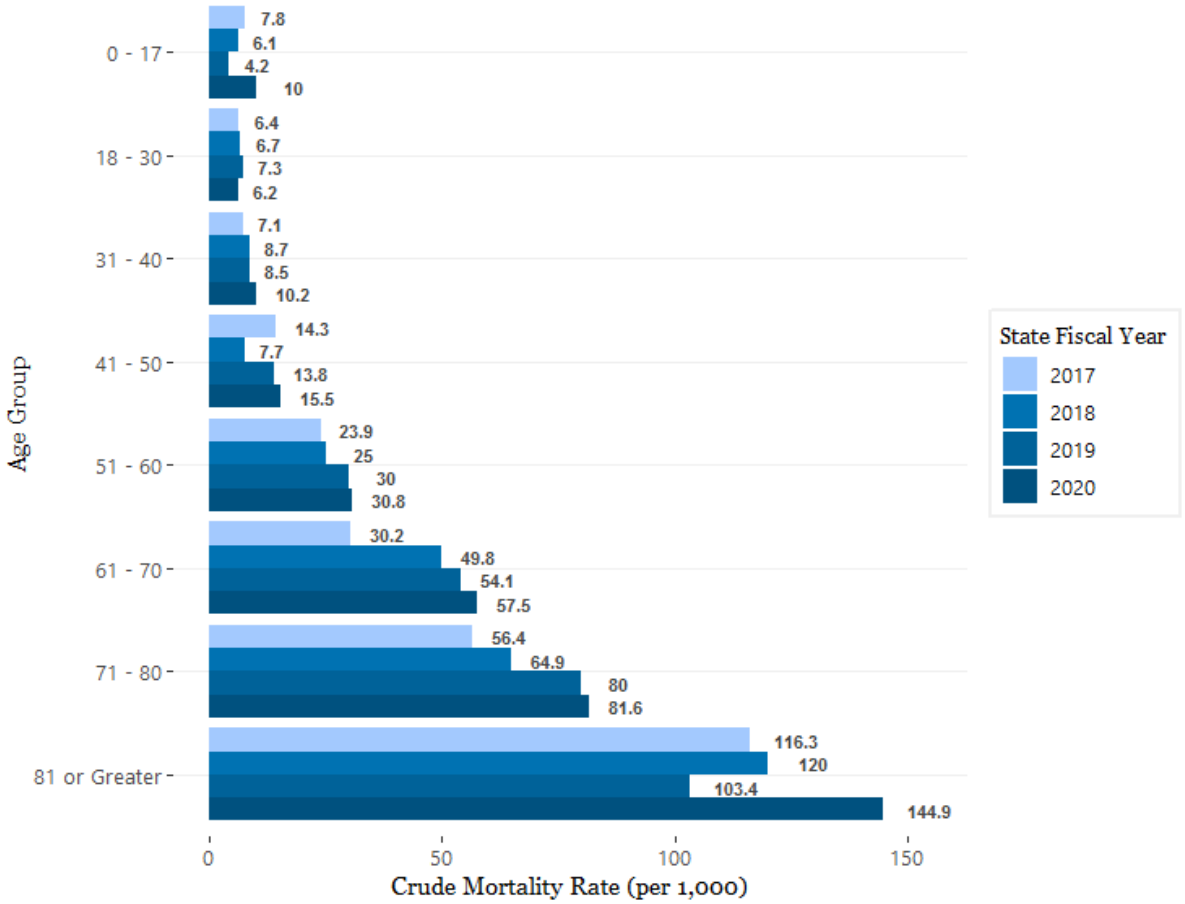


Table 4. Crude Mortality Rates by Age per 1,000 population, SFY 2020

Age Group	Deaths	DD Waiver Population	Crude Mortality Rate
0 - 17	10	997	10.03
18 - 30	30	4,820	6.22
31 - 40	30	2,936	10.22
41 - 50	30	1,941	15.46
51 - 60	62	2,014	30.78
61 - 70	75	1,305	57.47
71 - 80	31	380	81.58
81 or Greater	10	69	144.93
Total	**278**	**14,462**	**19.22**

- Between SFYs 2017 and 2020, the crude mortality rate among individuals on a DD Waiver increased for all age groups between 51 and 80 years of age.
- Compared to SFY 2019, the crude mortality rate among the DD Waiver population increased for all age ranges except among individuals between the ages of 18 and 30.
- In the DD waiver population, 137 decedents were between the ages of 51-70, and 54 of those individuals (39%) were known to be receiving hospice services.

Fig. 3. Crude Mortality Rates by Age per 1,000 DD Waiver Population, SFY 2017 – 2020



Gender

Males comprised the majority of individuals whose deaths the DBHDS DD MRC reviewed in SFY 2020, consistent with trends from previous fiscal years. The table below includes the gender breakdown of individuals the DBHDS DD MRC reviewed that were in the DD Waiver population.

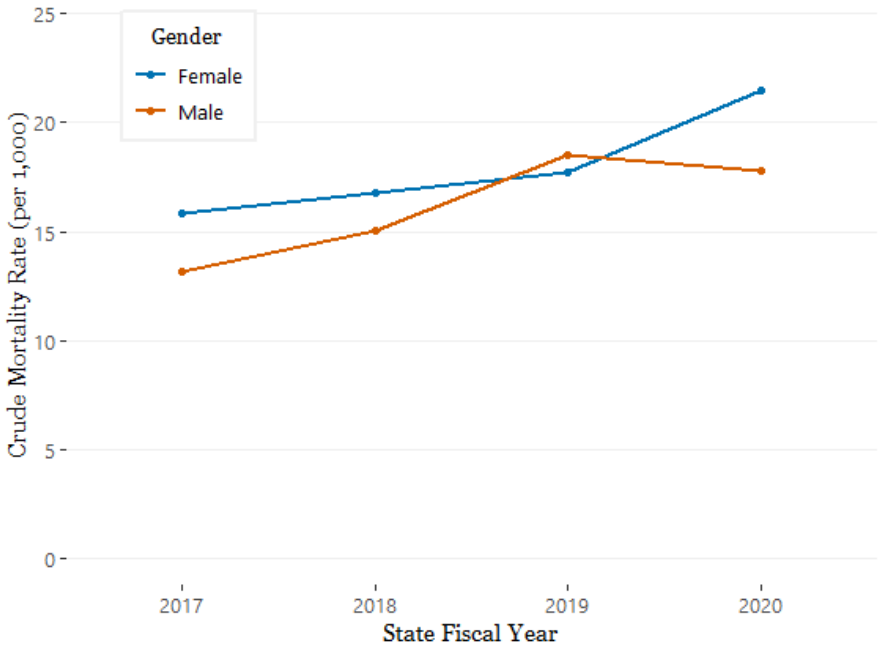
Table 5. Crude Mortality Rates by Gender per 1,000 population, SFY 2020

Gender	Deaths	DD Waiver Population	Crude Mortality Rate
Female	122	5,675	21.50
Male	156	8,785	17.76
Unknown	0	2	0
Total	**278**	**14,462**	**19.22**

Since SFY 2017, the crude mortality rate among females on a DD Waiver has consistently increased, from 15.9 deaths per 1,000 population in SFY 2017 to 21.5 deaths per 1,000 population in SFY 2020. In contrast, among males on a DD Waiver, the crude mortality rate has fluctuated in recent years: increasing from SFY 2017 to SFY 2019 before decreasing in the

current fiscal year. For males on a DD Waiver, the crude mortality rate increased from 13 deaths per 1,000 population in SFY 2017 to 18.5 per 1,000 population in SFY 2019, and then decreased to 17.8 deaths per 1,000 population in SFY 2020.

Fig. 4. Crude Mortality Rates by Gender per 1,000 population, SFY 2017 – 2020



The overall gender breakdown for SFY 2020 was 201 male and 153 female deaths. The leading cause of death among all males in SFY 2020 was sudden cardiac death (26 deaths, 13% of male deaths), followed by sepsis (24, 12%), then heart disease (17, 8%). Among females, the leading cause of death was cancer (18 deaths, 12% of female deaths), followed by sudden cardiac death (17, 11%), sepsis (16, 10%), heart disease and pneumonia (each accounting for 11 deaths, 7%).

Race

Consistent with data from previous years, the majority of deaths reviewed by the DBHDS DD MRC were of individuals identified as White/Caucasian (238 deaths, 67%). Individuals identified as Black/African American accounted for 29 percent of deaths reviewed by the Committee. Individuals of all other races combined for approximately 4 percent of deaths reviewed by the Committee.

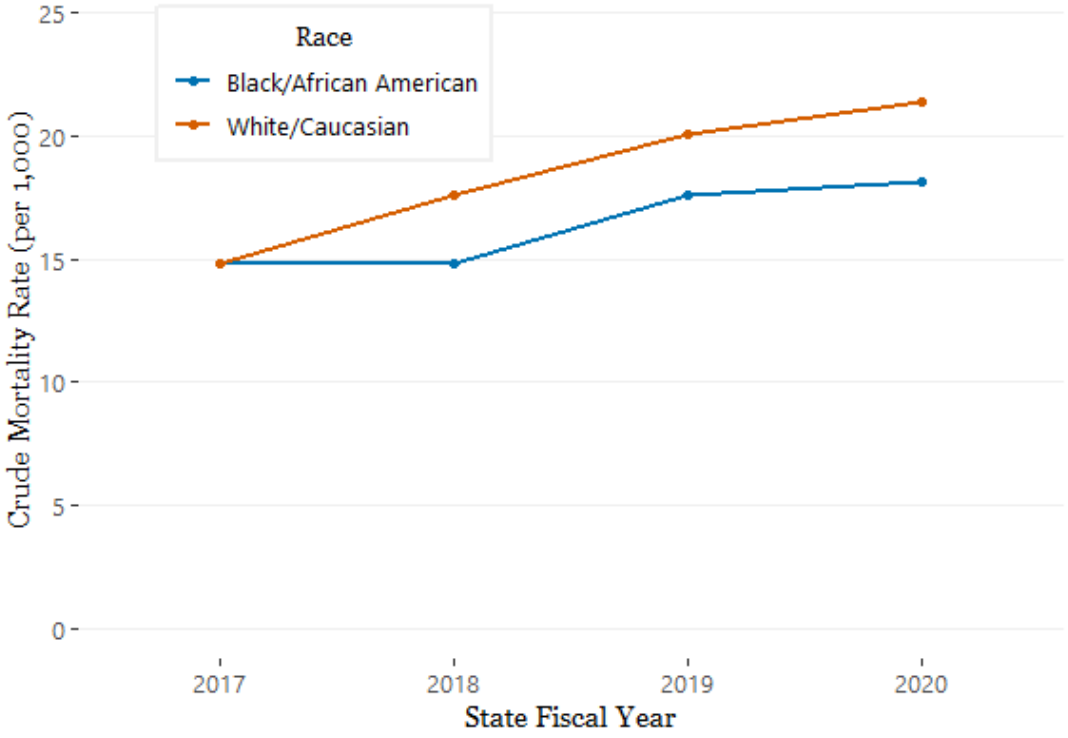
Table 6. Crude Mortality Rates by Race per 1,000 population, SFY 2020

Race	Deaths	DD Waiver Population	Crude Mortality Rate
White/Caucasian	193	9,022	21.39

Black/African American	77	4,250	18.12
Other	8	1,132	7.07
Unknown	0	58	0
Total	**278**	**14,462**	**19.22**

The crude mortality rate among individuals identified as White on the DD waiver was 21.4 deaths per 1,000 population in SFY 2020—an increase from 20 deaths per 1,000 population in SFY 2019. Similarly, the crude mortality rate among individuals identified as Black/African American on the DD waiver also increased from 17.6 deaths per 1,000 population in SFY 2019 to 18.1 deaths per 1,000 population.

Fig. 5. Crude Mortality Rates by Race per 1,000 population, SFY 2017 – 2020



Services and Supports

DBHDS uses the Supports Intensity Scale (SIS)[10] to assign individuals on a DD waiver to one of seven levels. Each level includes an array of services and supports, reflecting a service program

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

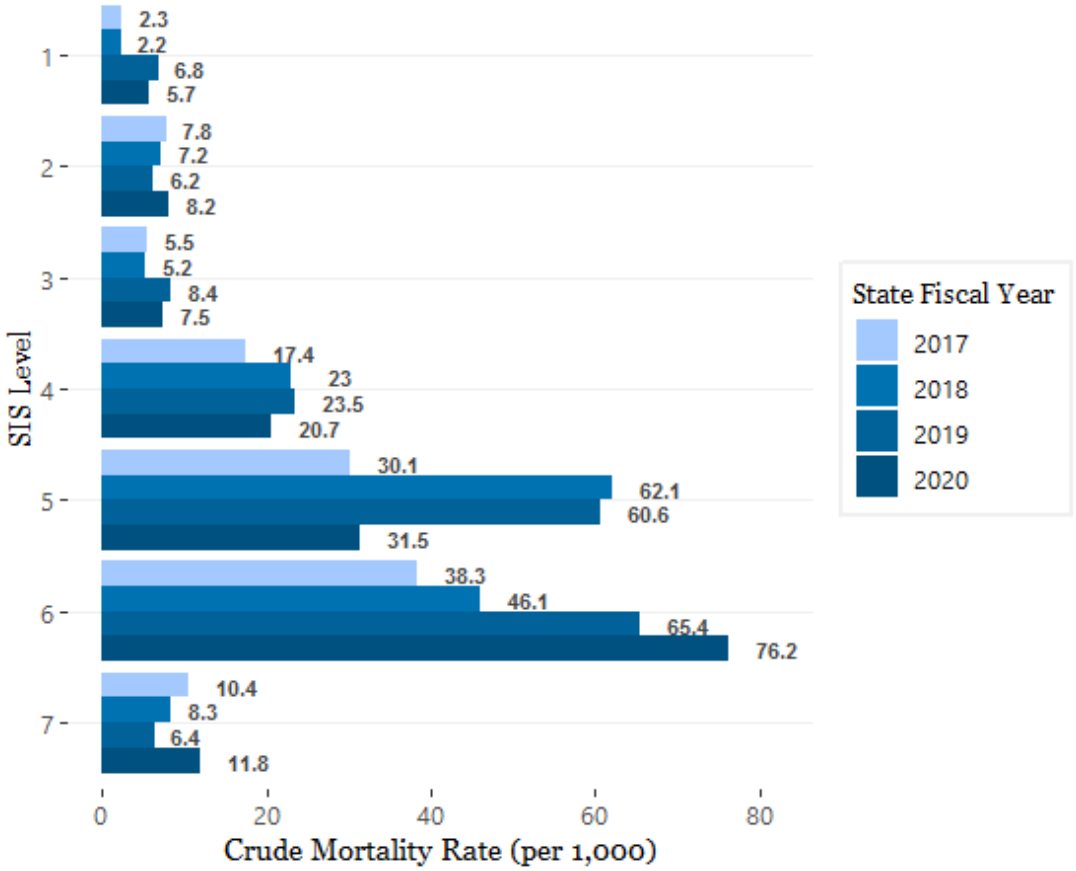
that meets the individuals' needs. Individuals categorized within a Level 1 service program includes individuals with the fewest support needs and Levels 6 and 7 includes individuals with an intensive need for medical and behavioral supports and services, respectively. After the initial SIS assessment is completed, SIS levels are re-evaluated and completed every three years for those over age 16, and every two years for those age 5-15. A SIS level may be re-evaluated before that time if there is a 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	5	873	5.73
2	45	5,503	8.18
3	4	533	7.50
4	104	5,029	20.68
5	13	413	31.48
6	96	1,260	76.19
7	10	844	11.85
Unknown	1	7	142.86
Total	**278**	**14,462**	**19.22**

From SFY 2019 to 2020, the crude mortality rate increased for individuals on the DD waiver with SIS Levels 2, 6, and 7 and decreased for those with SIS Levels of 1, 3, 4, and 5. In SFY 2020, 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. The crude mortality rate among individuals with a SIS Level of 6 increased to 76.2 deaths per 1,000 population in SFY 2020. For individuals with a SIS Level of 5, the crude mortality rate decreased from 60.6 deaths per 1,000 population in SFY 2019 to 31.5 deaths per 1,000 population in SFY 2020.

Fig. 6. Crude Mortality Rates by SIS Level Group per 1,000 population, SFY 2017 – 2020



Residential Setting

Due to the low number of individuals in certain residential settings, the DBHDS DD MRC analyzed death reviews using the following groupings for residence type for the purposes 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* include Commonwealth-operated training centers, Hiram Davis Medical Center, and state hospitals where an individual had a 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 2017 – 2020

Residential Setting	2017		2018		2019		2020	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Congregate	82	33.1%	109	41.8%	147	47.1%	165	46.6%
Facility	20	8.1%	15	5.7%	16	5.1%	6	1.7%
Independent	100	40.3%	106	40.6%	127	40.7%	136	38.4%
Institutional	40	16.1%	31	11.9%	20	6.4%	45	12.7%
Unknown	6	2.4%	0	0%	2	0.6%	2	0.6%
Total	**248**	**-**	**261**	**-**	**312**	**-**	**354**	**-**

In SFY 2020, the leading cause of death among those living independently was sudden cardiac death (22 deaths, 16%), followed by cancer (15, 11%), and heart disease, pneumonia, and "Unknown" (each 10 deaths, 7%). Among those individuals who lived in congregate settings, the leading cause of death was sepsis (25, 15%), followed by sudden cardiac death (17, 10%), and failure to thrive/slow decline (14, 8%).

In SFY 2020, the percentage of deaths among individuals in state facilities continued to decrease, a trend established in SFY 2017. By contrast, the percentage of deaths in Community Institutional settings increased to 12.7 percent of deaths reviewed by the DBHDS DD MRC, from a low of approximately six percent in SFY 2019; however, based on trend analysis, the data from SFY 2019 appears to be the outlier, as previous years have ranged from 11.9 to 16.1%.

Table 9. Crude Mortality Rates by DD Waiver Residential Setting per 1,000 population, SFY 2020

Residential Living Group	Deaths	DD Waiver Population[11]	Crude Mortality Rate
Congregate Living	159	4,551	34.9
Independent Living	101	9,911	10.2
Total	**260**	**14,462**	**18.0**

Table 9 presents the crude mortality rates of individuals on a DD Waiver in SFY 2020. Six of the individuals who died in a congregate settings and 35 of the individuals who died in an

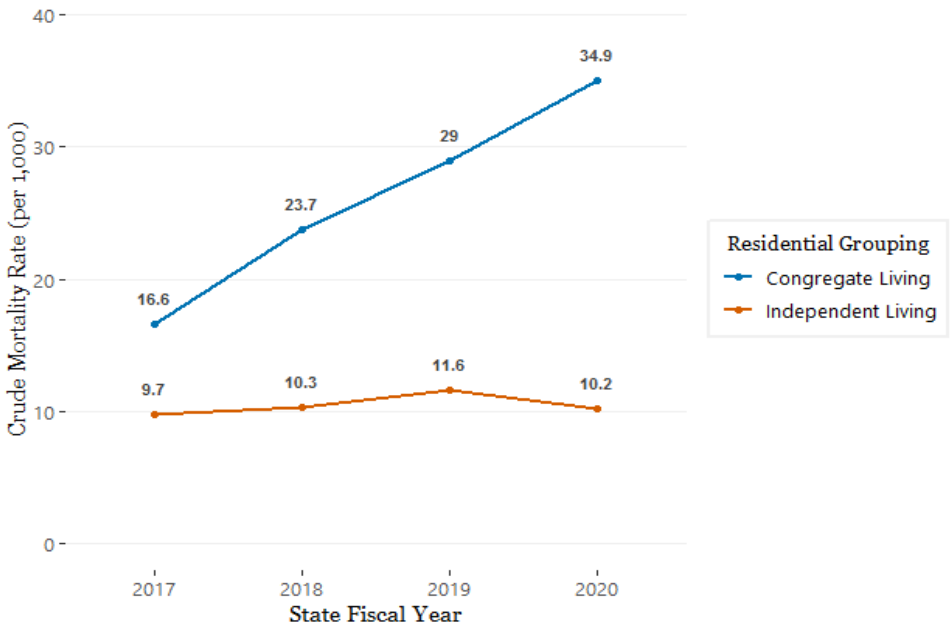
[11] Population estimates for the congregate living and independent living groups utilize the "Living Situation on Waiver" field in the Waiver Management System (WaMS) enrollment data.

independent setting were not receiving a licensed service on a DD Waiver; thus, they could not be included in the calculation of this rate. 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 2020

Residential Living Group	Deaths	Estimated Population[12]	Crude Mortality Rate
Facility	6	400	15.0
Institutional	29	8,401	3.4

Fig. 7. Crude Mortality Rates by Residential Grouping per 1,000 population, SFY 2017 – 2020



In SFY 2020, the crude mortality rate among those living in congregate settings was 34.9 deaths per 1,000 population, an increase from 29 deaths per 1,000 population in SFY 2019. In contrast, the crude mortality rate among those living independently decreased from 11.6 deaths per 1,000 population in SFY 2019 to 10.2 deaths per 1,000 population in SFY 2020. The crude mortality rate for individuals living independently decreased to its lowest point since SFY 2017.

[12] 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 2019) is added to the maximum bed capacity for adult and child ICF/IIDs.

None of the deaths reviewed by the DBHDS DD MRC among individuals who lived independently were considered potentially preventable, while approximately 10 percent of deaths among those in congregate settings were potentially preventable (16 deaths).

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. The pace of this shift has increased dramatically since 2011, prompted by the Commonwealth's decision to close four training centers. Deaths among individuals discharged from training centers within two years receive an additional review by the DBHDS Community Integration Project Team.

In SFY 2020, the DBHDS DD MRC reviewed 46 deaths among individuals discharged from a training center into the community. Sepsis was the leading cause of death among individuals discharged from TCs (8, 17%), followed by sudden cardiac death (7, 15%) and COVID-19 (5, 11%). Four deaths (9%) that occurred among those discharged from TCs were 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[13]

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

For the first time, average community tenure decreased among individuals discharged from training centers. Nonetheless, the median community tenure among these individuals increased from 44 months in SFY 2019 to 48 months in SFY 2020. While both mean and median are

[13] The totals marked with an asterisk (*) differ from previously reported totals. Previously, 28 deaths were reported among this population in SFY 2016; 31 in SFY 2018. These discrepancies were identified during quality reviews of the source data.

measures of central tendency, the mean is more likely than the median to be influenced by outliers. In SFY 2020, there were nine individuals who were discharged from a training center (20%) within less than or equal to 12 months of their deaths. From July 1, 2019 to June 30, 2020, only two TCs remained open, and there were no TC deaths that occurred within 30 days of discharge to a congregate or independent living 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[14]. Addressing persistent health risk factors through early recognition and intervention by DBHDS licensed providers for all I/DD individuals is a priority. The DBHDS DD MRC support 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. This report is an important contribution towards those efforts.

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 and 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 shifting to also include identification of risk factors versus contributory factors that predispose individuals with I/DD to negative outcomes and the role those factors play in implementing interventions. These will be evaluated as the DBHDS DD MRC implements and tracks resulting data from these initiatives and recommendations.

[14] 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.