Virginia Department of
Behavioral Health &
Developmental Services

SFY 2019 ANNUAL MORTALITY REPORT

PRESENTED BY THE DBHDS
MORTALITY REVIEW COMMITTEE
May 2020

Annual Mortality Report

Executive Summary

This is the fifth Annual Mortality Report of the Virginia Department of Behavioral Health and Developmental Disabilities (DBHDS). DBHDS conducts mortality reviews of individuals with intellectual or developmental disability who received services in a state-operated facility or in the community through a DBHDS-licensed provider. The information contained within this report is based on reviews of deaths during the timeframe July 1, 2018 through June 30, 2019 as reported to the DBHDS via its incident reporting systems, and is scheduled for release to the public by the end of each year. The information presented compares mortality results in SFY 2019 to data collected in previous years. The interpretation of the information presented in this report is not intended to be used as a direct comparison with other states' mortality reviews and reports as those reports may have utilized different methods or analyzed data from different populations. Generalizing findings or comparing mortality rates is limited due to difference in population definitions, waiver programs, and requirements of other state agencies.

The Commonwealth's estimated population in 2018 was over 8.5 million residents (UVA Weldon Cooper Center, Demographics Research Group, 2019), and an estimated 123,080 have an intellectual or developmental disability (SA Larson, 2013). The Community Living Waiver, Family and Individual Supports Waiver, and Building Independence Waivers are providing twenty-seven different services to thousands of Virginia residents (rbha.org/services). As of June 30, 2019, there were 13,861 individuals on a Virginia Developmental Disability (DD) waiver.

Since the inception of the Mortality Review Committee in 2012, the system of care has significantly shifted to community integration from institutional and congregate care settings. A strong, effective system of community support and services is a major factor for a successful transition. This shift is the result of the collaboration, support and partnership of the individuals and families who receive care, dedicated service providers, state sister agencies, and the Virginia General Assembly. The body of evidence on effective medical and psychosocial interventions grows, and this is important to maintain as the community system continues to evolve. Understanding factors that contribute to preventable deaths and utilizing positive advances in public health improves the life expectancy and quality of life of individuals. This report reflects the commitment to continuous quality improvement initiatives within the Virginia system of care.

Key Findings

- In SFY 2019, the MRC reviewed 312 deaths. This is the highest number of deaths reviewed by the committee since its creation, and may be due to the revised case summary development process which decreased a reservoir of cases. According to a 2018 study conducted by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), the population of individuals with disabilities has increased from 2008 to 2017 from 12.7 percent to 13.2 percent. This may be reflected in the number of deaths reviewed for this target population.

- The median age at time of death was 58 years; the mean age at death was 54 years. While other states' mortality review reports may not directly equate to the Virginia population being reported on through this report, these median ages of death fall within similar ranges reported by other states (*e.g.*, 2018 Annual Report, GA Dept. of Behavioral Health and Developmental Disabilities; 2017 Mortality Data Review, Indiana Division of Disability and Rehabilitative Services).

- As the committee processes for obtaining and reviewing pertinent information for aggregate analysis and outcomes of MRC recommendations have improved, for the first time since 2012 when the MRC first began reviewing deaths, the committee determined more deaths to be expected than unexpected. Prior to SFY 2019, the highest percentage of expected deaths was 36.4 percent in SFY 2018. In SFY 2019, the committee determined 163 deaths (52%) were expected, 141 (45%) were unexpected, and 8 (3%) were not able to be determined by the committee as expected or unexpected and therefore classified as unknown. This represents a 44 percent increase in the percentage of deaths determined to be expected. An analysis of the quality of the data and the challenges of accuracy and completion of data collection is needed to provide interpretation of the submitted information.

- The MRC determined 11 deaths (4%) to be potentially preventable in SFY 2019 – a decrease from 56 deaths (21%) in SFY 2018. Nine of the 11 deaths determined to be potentially preventable involved a failure to execute established protocols.

- The crude mortality rates in SFY 2019 are the highest they have been for individuals on the DD waiver with SIS Levels of 1, 3, 4, 5, and 6 since DBHDS began reporting this data in SFY 2017. From SFY 2018 to 2019, the crude mortality rate increased for individuals on the DD waiver with all SIS Levels except those of 2 and 7. By contrast, the crude mortality rate decreased slightly for those individuals with a SIS Level of 2 or 7, continuing a trend from SFY 2017 through SFY 2018.

- Between SFY 2017 and 2019, the crude mortality rate for individuals living in congregate settings increased faster than the rate for those living independently. In SFY 2019, the crude mortality rate among those living in congregate settings was 29 deaths per 1,000 population, compared to SFY 2017's rate of 16.6 deaths per 1,000 population. In contrast, the crude mortality rate among those living independently increased from 9.6 deaths per 1,000 population in SFY 2017 to 11.6 deaths per 1,000 population in SFY 2019.

Recommendations

The recommendations of the Mortality Review Committee for the SFY 2019 Annual Mortality Report build from the recommendations of the previous year utilizing data from this report. DBHDS recognizes that continued efforts are needed to address strategies in meeting these targets. Quality and process improvement initiatives to address these recommendations were in the planning and implementation phase at the time this report was prepared. The recommendations are as follows:

Recommendation 1: DBHDS should maintain an established target of less than 10% of deaths reviewed to be classified as "Unknown" for the cause of death and continue to utilize the process improvement plan that better identifies causes of death through the mortality review process. DBHDS did not meet this target for FY19, and further process improvements are needed to achieve this, specifically for individuals living in private residences.

Recommendation 2: DBHDS should maintain an established target that potentially preventable deaths make up less than 15% of the total DD deaths per year. DBHDS determined that less than 4% of deaths in FY19 were potentially preventable, and of those, failure to adhere to established protocol was determined to be the reason in 82% of cases, whereas in FY18, this was the cause in only 52% of deaths. The data indicates that this recommendation should be renewed and that additional quality improvement initiatives are needed to specifically address this.

Recommendation 3: For FY19, 11 deaths were classified as potentially preventable, and each different cause of death was only represented by one or two individual cases (i.e., one due to pneumonia, one due to motor vehicle accident, two due to cardiac arrest). Targeting one of these causes of death for a quality improvement initiative based on the FY19 data would not be reflective of the known causes of death common for individuals with developmental disabilities as was reported in previous years. Thus, based on cumulative past data related to causes of death in the potentially preventable category, DBHDS should review system incident report data for potentially preventable causes of death that did not lead to mortality in the rates as per previous years.

Recommendation 4: DBHDS should evaluate the contributory factors leading to the increased crude mortality rates of individuals on the waiver with respect to SIS level.

Background

Purpose and Approach

The purpose of the DBHDS Developmental Disabilities Mortality Review Committee (MRC) is to contribute to system-wide quality improvement through the conduction of mortality reviews of deaths of individuals with an intellectual disability and/or developmental disability (I/DD) diagnosis who received services in a state-operated facility or in the community through a DBHDS-licensed provider. The MRC provides ongoing monitoring and data analysis to identify trends, patterns and problems at the individual service-delivery and systems levels. Once identified, development and implementation of quality improvement initiatives are determined in order to promote the health, safety and well-being of said individuals and reduce mortality rates to the fullest extent practicable.

DBHDS quality improvement involves reviewing performance trends and determining quality improvement priorities. Quality improvement efforts should respond to trends by ensuring corrective actions and regulatory reforms are implemented if necessary to address weaknesses/service gaps in the system.

Quality improvement is a continuous process that involves:

- Data collection
- Data analysis
- Evaluating the effectiveness of the overall systems
- Determining findings and conclusions
- Identifying trends that need to be addressed
- Identifying corrective actions or remedies as needed
- Implementing corrective actions or remedies, and
- Evaluating the effectiveness of implemented corrective actions or remedies

DBHDS' quality improvement office partners with and assists divisions in ensuring that quality improvement activities, including best practices and evidence-based outcomes, are coordinated and integrated into the primary functions of the organization. The programmatic divisions (e.g. Community Behavioral Health, Developmental Services, and Office of Integrated Health) retain ultimate responsibility for and control over the quality improvement work occurring in their respective divisions.
DBHDS is committed to Continuous Quality Improvement (CQI) which is an ongoing cycle of collecting data and using it to make decision to improve programs and processes. The MRC makes recommendations on quality improvement initiatives to the DBHDS Quality Improvement Committee and the specific actions of the MRC and status of these initiatives are reported in further detail in the Annual Quality Management Plan Annual Report and Evaluation.

Model for Quality Improvement
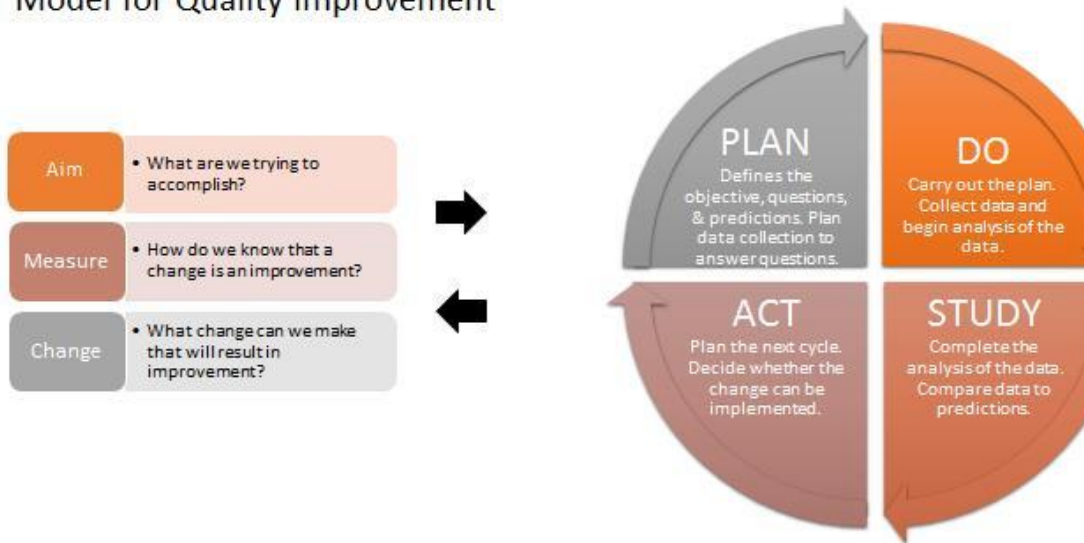
DBHDS requires all state-operated facilities and DBHDS-licensed community providers to report deaths within 24 hours of discovery. From the DBHDS incident reporting systems, reports of deaths for anyone receiving a licensed DD service, has a DD diagnosis, and/or is in a state-operated facility is referred to the MRC for case review. Cases are to be reviewed by the committee within 90 days of the death of the individual. The committee reviews unexplained and unexpected deaths and, to the best ability, determines the cause of an individual's death and whether the death was potentially preventable. A mortality review is not intended to assess clinical competence or violations of regulations. The DBHDS Office of Licensing conducts licensing investigations when notified of deaths by licensed providers. Issues of staff competency are addressed through administrative means identified by applicable professional licensure boards, state laws, and regulatory requirements.

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 made, and primary health care and/or palliative care teams were involved.
- *Unexpected Death, which includes unexplained deaths,* denotes a death that occurred as a result of an acute medical event, accident, or other event that was not expected within the context of a person's known medical conditions or not attributable to an identified cause.
- *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 not attributable to one of the major causes of death used by the MRC for data trending.

- *Potentially Preventable Deaths* are deaths that are considered premature and may have been avoided based on a combination of known medical, genetic, social, environmental, or other factors.

Virginia Deaths

In SFY 2019, the MRC revised the categories it uses to classify causes of death. Most notably, the committee added acute respiratory failure and aspiration pneumonia as causes of death for SFY 2019, distinguishing them from respiratory disease and aspiration, respectively. One possible explanation for the decline in deaths due to aspiration and respiratory disease during SFY 2019 is the added clarity of the new categories used for cause of death.

The MRC classified more deaths as "unknown" in SFY 2019 (42 deaths, 13.5%) than in any fiscal year prior to 2016. Approximately 22 percent of all decedents who resided in private residences had unknown causes of death. Obtaining documentation related to the circumstances leading up to the death of individuals living in private residences poses a challenge as medical and other pertinent clinical information is often not provided through the DBHDS incident reporting system. The challenge of lack of data for the deaths classified as "unknown" may have impacted the validity of the unexpected death classification, and could impact the number and rate of potentially deaths.

Unlike deaths in which the specific cause of death is "unknown", deaths classified as "other" causes have known etiologies that exist outside of the MRC's primary categories for statistical trending. The MRC classified 14 deaths as having "other" causes of death in SFY 2019. The most common causes of "other" deaths in SFY 2019 were traumatic brain injury (4 deaths) and GI disease (3 deaths). The remaining seven cases were comprised of one or two occurrences of each.

Table 1 Number of Annual Deaths by Cause of Death, SFY 2016 – 2019[1]
(Sorted by Frequency in 2019)

Cause of Death	2016	2017	2018	2019	Total
Unknown	47	31	34	42/24	154
Acute Respiratory Failure*	-	-	-	31/16	31
Cancer	41	14	23	30/14	108
Sudden Cardiac Death	39	35	22	22/9	118
Pneumonia	27	27	21	20/7	95
Sepsis	30	14	14	20/10	78

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1 In Table 1, causes of death marked with a single asterisk (*) were added by the MRC in SFY 2019. Fields marked with a hyphen (-) do not have measureable values because the categories used to classify deaths did not exist at the time of the committee determinations. Finally, the totals marked with two asterisks (**) differ from previously reported totals due to unreported deaths that were recently identified by DBHDS – one in SFY 2017 and one in SFY 2018.

| Cause of Death	2016	2017	2018	2019	Total
Neurodegenerative Disease	3	3	4	18/2	28
Heart Disease	23	22	19	17/8	81
Other	21	15	24	14/3	61
Aspiration Pneumonia*	-	-	-	13/4	13
Complications of a Congenital Condition	-	-	2	13/10	15
FTT/Slow Decline	6	7	4	10/4	27
Kidney Disease	10	9	9	10/5	38
Complications of a Genetic Condition	-	6	11	9/8	26
Multiple Medical Problems	-	7	10	8/3	25
Bowel Obstruction	8	4	7	7/2	26
Seizure	0	10	6	7/3	23
Stroke	10	3	3	7/2	23
Respiratory Disease	17	22	18	6/4	63
Aspiration	14	13	25	5/1	57
Postoperative Complications	15	6	5	3/1	29
Total	**311**	**248****	**261****	**312/140**	**1,132**

For the SFY 2019 column in Table 1 above, the first number is the total number of deaths for that category and the second number indicates that number of those deaths where the individual was not receiving a DBHDS-licensed residential service. This number is an estimate based on the groupings that were available at the time of the review. In SFY 2020, the MRC will incorporate a process within the mortality review deliberations wherein a definitive determination as to whether the individual was receiving a DBHDS-licensed service is made.

Expected and Unexpected Deaths

Immediately following the cause of death determination, the MRC determines whether a death was expected or unexpected. The leading causes of unexpected deaths in SFY 2019 were "unknown" (34) and cardiac arrest (15). The leading cause of expected deaths was cancer (27).

Fig.1 Expected and Unexpected Deaths, SFY 2016-2019
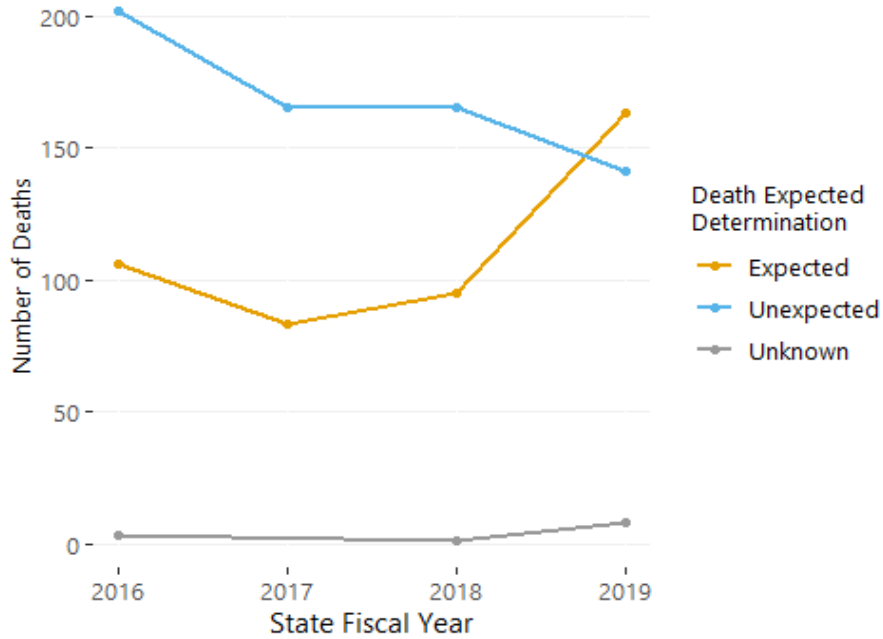
Table 2 Expected and Unexpected Deaths, SFY 2016-2019

Determination	2016		2017		2018		2019	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Expected	106	34.1%	83	33.5%	95	36.4%	163	52.2%
Unexpected	202	65.0%	165	66.5%	165	63.2%	141	45.2%
Unknown	3	1.0%	0	0	1	0.4%	8	2.6%

For the first time since the MRC began reviewing deaths in 2013, the committee determined more deaths to be expected than unexpected. This increase from SFY 2018 is attributed to the expanded MRC membership that included; a broader range of clinical subject matter experts, increased attendance and participation of committee members, clarification of expected and unexpected (unexplained) definitions and identification of contributing factors to that individual's death. The additional 71.5% increase in the number of deaths may also have been a factor.

Potentially Preventable Deaths

In SFY 2019, the MRC continued a process first implemented in SFY 2018 to identify potentially preventable deaths and collect information related to contributing factors in these deaths. In addition, the MRC ensures one of the following factors is always identified for each potentially preventable case. The MRC may also identify one of these four factors for deaths that were not potentially preventable, if circumstances warrant. Through this process, the MRC assessed not only whether actions leading to the

death itself were preventable, but also whether co-morbid conditions existed that were potentially preventable.

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 (including medication management)
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

In SFY 2018, the MRC classified 56 deaths (21%) as potentially preventable. By contrast, in SFY 2019, the MRC classified only 11 deaths (4%) as potentially preventable. The MRC notes this dramatic change in year to year data may be due to; In SFY 2019, the MRC made significant changes to improve the processes of the committee and its structure. Changes included increased membership to include a broader range of clinical and systems subject matter experts, increased participation of committee members and attendance, clarification of definitions of potentially preventable and identifying contributing factors to the individuals death. These changes have likely contributed to the committee's ability to more clearly make determinations related to potentially preventable deaths. However, since the definition of a potentially preventable death was only first introduced in SFY 2018 and multiple changes have occurred in SFY 2019, ongoing monitoring of the effect of these changes is needed in subsequent years.

When the MRC determines a death is potentially preventable, the committee categorizes factors that might have prevented the death. In SFY 2019, nine of the 11 deaths classified as potentially preventable (82%) involved a failure to adhere to established protocols. This contrasts with findings from SFY 2018, but given the small number of potentially preventable deaths in SFY 2019 these differences may be epiphenomenal. The causes of these eleven deaths include one each for sepsis, pneumonia, intracranial hematoma, motor vehicle accident, multisystem organ failure, traumatic brain injury, and complications secondary to impaction, and two each for cardiac arrest and choking.

Table 3 Potentially Preventable Deaths, SFY 2018-2019

Determination	2018		2019	
	Deaths	Percent	Deaths	Percent[2]
Not Potentially Preventable	184	71%	258	83%
Potentially Preventable	55	21%	11	4%
Unknown	20	8%	43	14%

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

Population Demographics

This section includes demographic trends for individuals reviewed by the MRC. For SFY 2019, a separate comparison shows mortality rates for individuals receiving DD waiver services.

Age

Prior to SFY 2018, the plurality of deaths reviewed by the MRC occurred among individuals 51 to 60 years old. However, in both SFY 2018 and 2019, the plurality of deaths occurred among individuals aged 61 to 70. Approximately two-thirds of all deaths reviewed by the MRC occurred among individuals aged 51 or older.

Table 4 Crude Mortality Rates by Age per 1,000 population, SFY 2019

Age Group	Deaths	DD Waiver Population	Crude Mortality Rate
0 - 17	4	945	4.2
18 - 30	31	4,218	7.3
31 - 40	23	2,710	8.5
41 - 50	26	1,885	13.8
51 - 60	61	2,032	30
61 - 70	65	1,202	54.1
71 - 80	28	350	80
81 or Greater	6	58	103
Unknown	0	3	0
Total	**244**	**13,403**	**18.20**

- Between SFY 2017 and 2019, the crude mortality rate increased for all age groups between 51 and 80 years of age. Among individuals 0 to 17 years of age, the crude mortality rate has decreased from 8.9 deaths per 1,000 population in SFY 2017 to 4.2 deaths per 1,000 population in SFY 2019. The median age at time of death was 58 years; the mean age at death was 54 years. While other states' mortality review reports may not directly equate to the Virginia population being reported on through this report, these median ages of death fall within similar ranges reported by other states (*e.g.*, 2018 Annual Report, GA Dept. of Behavioral Health and Developmental Disabilities; 2017 Mortality Data Review, Indiana Division of Disability and Rehabilitative Services).

Fig. 2 Crude Mortality Rates by Age per 1,000 population, SFY 2017-2019
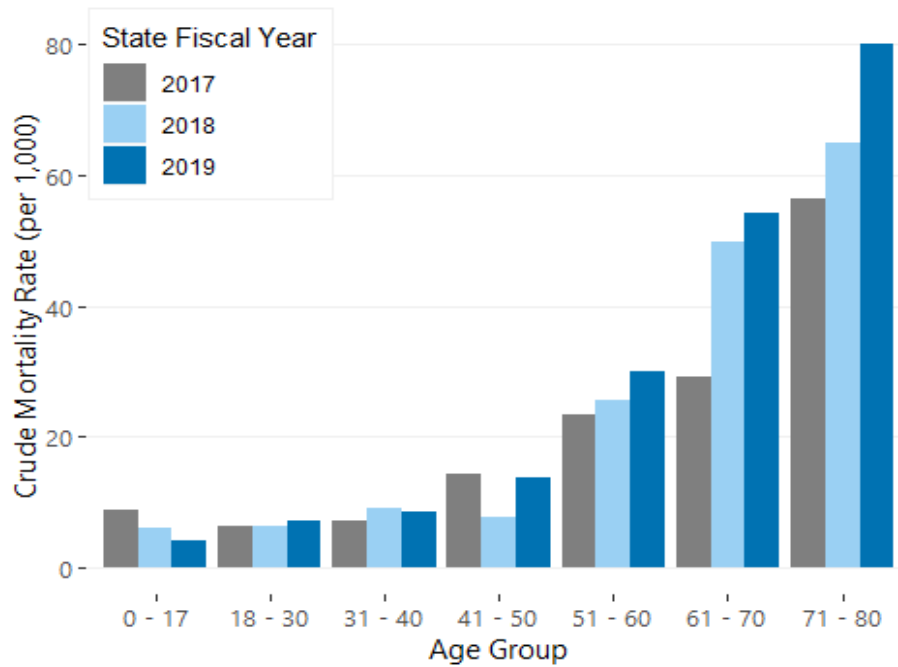

Gender

Males comprised the majority of individuals whose deaths were reviewed by the MRC in SFY 2019, consistent with trends from previous fiscal years.

Table 5 Crude Mortality Rates by Gender per 1,000 population, SFY 2019

Gender	Deaths	DD Waiver Population	Crude Mortality Rate
Female	94	5,304	17.7
Male	150	8,093	18.5
Unknown	0	6	0
Total	**244**	**13,403**	**-**

Between SFY 2017 and 2019, the crude mortality rates increased within both gender groups on the DD waiver. The crude mortality rate among females on the DD waiver increased from 15.9 deaths per 1,000 population in SFY 2017 to 17.7 deaths per 1,000 population in SFY 2019. Among males on the DD waiver, the crude mortality rate increased from 13 deaths per 1,000 population in SFY 2017 to 18.5 deaths per 1,000 population in SFY 2019. For the first time since DBHDS began reporting crude mortality rates in SFY 2017, the crude mortality rate among males on the DD waiver surpassed the rate for females.

Fig. 3 Crude Mortality Rates by Gender per 1,000 population, SFY 2017-2019
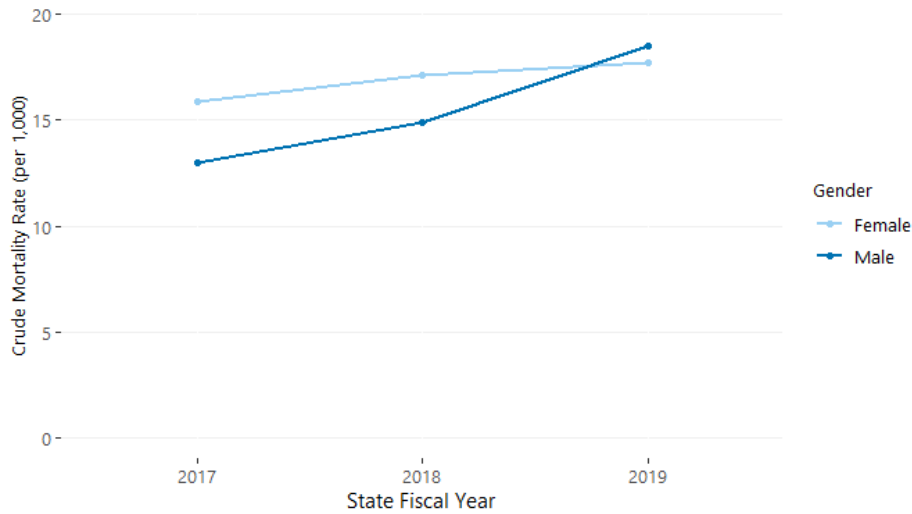
The leading cause of death among males in SFY 2019 was "unknown" (22, 11%), followed by cancer (16, 8%), and then cardiac arrest and septicemia (both accounting for 15 deaths). Among females, the leading cause of death in SFY 2019 was also "unknown" (20, 17%), followed by cancer (14, 12%), and then respiratory failure (10, 8%).

Race

Consistent with data from previous years, the majority of deaths reviewed by the MRC were of individuals identified as White (225 deaths, 72%). Individuals identified as Black/African American accounted for 26 percent of deaths reviewed by the committee. Individuals of all other races combined for approximately 2 percent of deaths reviewed by the committee. Racial disparity of deaths warrant a closer examination of the psychosocial contributing factors.

Table 6 Crude Mortality Rates by Race per 1,000 population, SFY 2019

Race	Deaths	DD Waiver Population	Crude Mortality Rate
Caucasian	170	8,482	20
African American	69	3,928	17.6
Other	5	931	5.4
Unknown	0	62	0
Total	**244**	**13,403**	**-**

The crude mortality rate among individuals identified as Caucasian on the DD waiver was 20 deaths per 1,000 population in SFY 2019 – an increase from 17.8 deaths per 1,000 population in SFY 2018. Similarly, the crude mortality rate among individuals identified as African American on the DD waiver also increased from 14.6 deaths per 1,000 population in SFY 2018 to 17.6 deaths per 1,000 population.

Fig. 4 Crude Mortality Rates by Race per 1,000 population, SFY 2017-2019
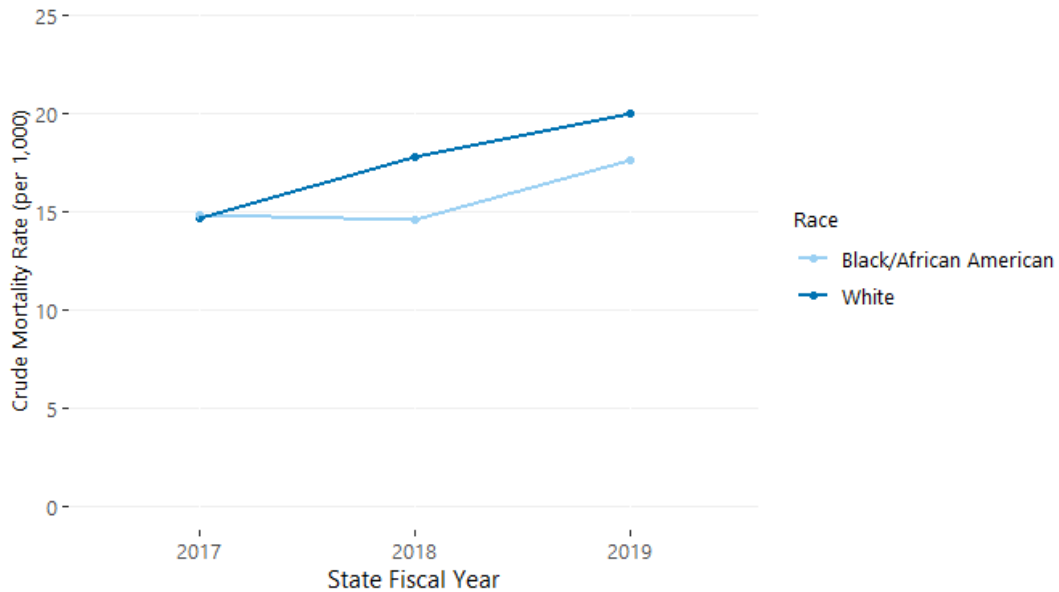
SIS Level

DBHDS uses the Supports Intensity Scale (SIS) to assign individuals on a DD waiver to one of seven levels, labeled 1 through 7, related to their support needs. These levels were developed by DBHDS and its consultants, with Level 1 representing individuals with the fewest support needs while Levels 6 and 7 represent individuals with the greatest need for support. While a plurality of all individuals reviewed by the MRC in SFY 2018 were on SIS Level 4, the plurality of DD waiver recipients during that time were on SIS Level 2.

Table 7 Crude Mortality Rates by SIS Level per 1,000 population, SFY 2019

SIS Level Group	Deaths	DD Waiver Population	Crude Mortality Rate
1	6	882	6.8
2	33	5,345	6.2
3	5	596	8.4
4	103	4,382	23.5
5	14	231	60.6
6	77	1,178	65.4
7	5	784	6.4
Total	243	13,398	_

From SFY 2018 to 2019, the crude mortality rate increased for individuals on the DD waiver with all SIS Levels except those of 2 and 7. In fact, the crude mortality rates in SFY 2019 are the highest they have been for individuals on the DD waiver with SIS Levels of 1, 3, 4, 5, and 6 since DBHDS began reporting this

data in SFY 2017. By contrast, the crude mortality rate decreased slightly for those individuals with a SIS Level of 2 or 7, continuing a trend from SFY 2017 through SFY 2018. SIS level 6 captures the population of individuals with the highest level of intensive medical needs, which correlates with the highest crude mortality rate of all individuals on the waiver; however, additional data analysis is needed to better understand potential contributing factors associated with each SIS level.

Fig. 5 Crude Mortality Rates by SIS Level Group per 1,000 population, SFY 2017-2019
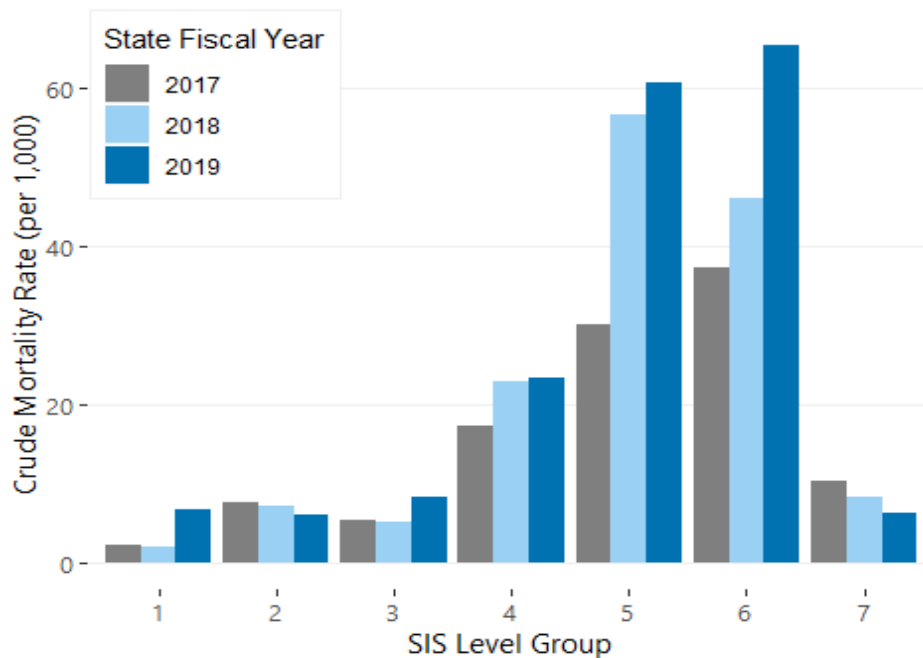
Residential Setting

Due to the low number of individuals in certain residential settings, the MRC analyzed death reviews using the following groupings for residence types: independent living, congregate living, institutional living, state facility, and unknown.

For the purposes of this report:

- *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 Facilities* include training centers, including 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 MRC review.

Table 8 Deaths by Residential Setting, SFY 2016-2019

Residential Living Group	2016		2017		2018		2019	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Congregate Setting	107	34.4%	82	33.1%	109	41.8%	147	47.1%
Facility	26	8.4%	20	8.1%	15	5.8%	16	5.1%
Independent Living	118	37.9%	100	40.3%	106	40.6%	127	40.7%
Institutional Setting	39	12.5%	40	16.1%	31	11.9%	20	6.4%
Unknown	21	6.8%	6	2.4%	0	0	2	0.6%
Total	**311**	**-**	**248**	**-**	**261**	**-**	**312**	**-**

The increase in crude mortality rates for congregate settings is attributed to the record number (312) of cases reviewed in SFY 2019, which is higher than in any previous year.

As in SFY 2018, the MRC reviewed fewer deaths among those living independently in SFY 2019 than among those living in congregate settings. In SFY 2019, the leading cause of death among those living independently was "unknown" (24, 19%), followed by cancer (15, 12%) and respiratory failure (11, 9%). If the decedent lived in a private home, lived independently, or resided in a nursing facility, the MRC is far less likely to have access to sufficient information to conduct a review. The MRC may request information from these settings or from a family, but the committee has no authority to require documentation from non-licensed settings.

Among those individuals who lived in congregate settings, the leading cause of death in SFY 2018 was "other" (16, 14.7%), followed by sudden cardiac death (15, 13.8%). "Unknown" (5, 16.7%), followed by pneumonia (4, 13.3%), were the leading causes of death among individuals who resided in institutional settings. Pneumonia (3, 20%) was the leading cause of death among those who resided in facilities.

Among those individuals who lived in congregate settings, the leading cause of death in SFY 2019 was "other" (19, 12.9%), followed by "unknown" (16, 10.9%). Kidney disease and respiratory failure (each 3, 15%), were the leading causes of death among individuals who resided in institutional settings. Heart disease (3, 18.8%) was the leading cause of death among those who resided in facilities.

As in fiscal years 2017 and 2018, the majority of deaths reviewed by the MRC in SFY 2019 were of individuals who lived in congregate settings. While fewer than 35 percent of individuals on the DD waiver

or receiving a licensed service, reside in congregate settings, this population accounted for more than 56 percent of all deaths reviewed by the MRC.

Table 9a Crude Mortality Rates by Residential Setting per 1,000 population, SFY 2019

Residential Living Group	Deaths	DD Waiver Population	Crude Mortality Rate
Congregate Living	134	4,624	29
Independent Living	102	8,779	11.6
Total	**236**	**13,403**	-

Table 9b Crude Mortality Rates by Residential Setting per 1,000 population, SFY 2019

Residential Living Group	Deaths	Population Estimate	Crude Mortality Rate
Facility	16	347	46
Institutional	20	8,633	2.3

Table 9a presents the crude mortality rates of individuals on a DD Waiver or receiving a licensed service in SFY 2019. There are 13 individuals that died in a congregate setting and 25 in an independent setting that were not on a waiver (not receiving a licensed service) and were not included in these rates. Their exclusion from the calculation of these rates is due to the total population (denominator) of individuals living in these settings not being known or able to be estimated by DBHDS.

Table 9b presents the crude mortality rates of individuals in non-waiver settings. Estimates of the population are based on the midpoint of the SFY. The "Institutional" group includes several settings where the total population is unknown to DBHDS resulting in the crude mortality rate to be a conservative estimate.

Between SFY 2017 and 2019, the crude mortality rate for individuals living in congregate settings increased faster than the rate for those living independently. In SFY 2019, the crude mortality rate among those living in congregate settings was 29 deaths per 1,000 population, an increase from 23.7 deaths per 1,000 population in SF18 and SFY 2017's rate of 16.6 deaths per 1,000 population. In contrast, the crude mortality rate among those living independently increased from 9.6 deaths per 1,000 population in SFY 2017 to 9.9 deaths per 1,000 population in SFY 2018 and 11.6 deaths per 1,000 population in SFY 2019. Data from the past three years is indicative of a trend, and further analysis is needed to determine the contributing factors to this increase rate in both congregate and independent living settings.

Less than 1 percent of all deaths reviewed by the MRC among those who lived independently were potentially preventable (3 deaths), while approximately 2.6 percent of deaths among those in congregate settings were potentially preventable (8 deaths).

Individuals Discharged from Training Centers

For decades, DBHDS has worked to transition individuals residing in state-funded training centers 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 receive an additional review by the Community Integration Project Team.

In SFY 2019, the MRC reviewed 36 deaths among individuals discharged from a training center into the community (community tenure). Aspiration pneumonia was the leading cause of death among individuals discharged from training centers (7, 19.4%), followed by septicemia (5, 13.9%). One death that occurred among those discharged from training centers was potentially preventable.

Community tenure continued to increase in SFY 2019, and the average age at death among individuals discharged from training centers increased from 62 years in SFY 2017 and 60 years in SFY 2018 to 64 years in SFY 2019. 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 considered discharges to the community and do not have community tenure. Due to the shifting population out of training centers, mortality rates for individuals that died in a training center are subject to large fluctuations. Such a rate would be considered unstable, and is therefore not included in this report.

Table 10 Age at Death and Community Tenure for Individuals Discharged from Training Centers

SFY	Deaths	Average Age at Death	Average Community Tenure (months)
2015	16	60	17
2016	28	59	22
2017	23	62	31
2018	31	60	39
2019	36	64	45

Conclusion

As a commitment to the Commonwealth of Virginia, DBHDS and the Mortality Review Committee continue to improve the system of care through integration of clinical evidence, data-driven determinations and evidence-based quality improvement recommendations. The Commonwealth continues to make significant improvements in the delivery of state system care to meet the health and wellness needs of individuals with intellectual and developmental disabilities. Identification of risk factors and development of specific systemic interventions are essential to making a positive impact on the reduction of preventable deaths. Promoting the health, safety, and well-being of these individuals and their families, in order to promote overall quality of life and life-expectancy, continues to be the primary goal for service providers in the Commonwealth.