Virginia Department of Behavioral Health & Developmental Services

Annual Mortality Report: SFY 2018

A report on deaths reviewed by the Mortality Review Committee during State Fiscal Year 2018

Annual Mortality Report

SFY 2018

Executive Summary

This is the fourth 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, 2017 through June 30, 2018 as reported to the DBHDS via its incident reporting systems. The information presented compares mortality results in SFY 2018 to data collected in previous years.

There are an estimated 8.4 million residents in Virginia (UVA Weldon Cooper Center, 2016) and an estimated 123,080 have an intellectual or developmental disability (Larson, 2013). Since the inception of the Mortality Review Committee in 2012, the system of care has significantly shifted from institutional and congregate care settings to community integration and a robust system of community support. On January 5, 2018, there were 12,719 individuals on a Developmental Disability (DD) waiver and an additional 12,319 on the waiting list. There were an additional 242 individuals in state-funded training centers. Exact counts for the number of individuals residing in community intermediate care facilities (ICFs) are not readily available; however, this population is estimated to be approximately 500 individuals.

The successes could not occur without the collaborative support and partnership of the individuals and families who receive care, the dedicated service providers, the Department's state sister agencies, and the Virginia General Assembly. It is important that the system continues to evolve as the body of evidence on effective medical and psychosocial interventions grows. Specifically, understanding the factors and causes contributing to preventable deaths have led to significant positive advances in public health to improve the life expectancy and the quality of life of individuals. This report contributes to the continuous quality improvement of the Virginia system of care.

Key Findings

- The Mortality Review Committee (MRC) reviewed 260 deaths among individuals receiving DD services reported to DBHDS in SFY 2018. Of these 260 deaths, there were 15 reported for individuals served in state facilities. The remaining 245 were individuals in community residential settings, which include nursing homes and ICFs. Of these 245 individuals, 201 were receiving services on the DD Home and Community-Based Services (HCBS) waivers.
- The top leading known cause of death in SFY 2018 was aspiration (25, 10%). The MRC classified more deaths as "other" in SFY 2018 than in any previous fiscal year (26, 10%), suggesting an increased degree of clinical discernment of causes of death.

- 22 percent of deaths reviewed by the MRC in SFY 2018 were determined to be potentially preventable (56 deaths). More than half of all potentially preventable deaths in SFY 2018 involved a failure of assessment or supervision (31 deaths); more than half involved a failure to adhere to established protocol (29 deaths), either as an additional factor in the death or a standalone classification. The MRC determined that:
  - 48% of deaths by aspiration in SFY 2018 (12 deaths) were potentially preventable
  - 50% of deaths from sepsis in SFY 2018 (7 deaths) were potentially preventable
  - Approximately 71% of deaths caused by GI/bowel obstructions in SFY 2018 (5 deaths) were potentially preventable
- The DD HCBS waiver crude mortality rate increased from 14.13 deaths per 1,000 population in SFY 2017 to 15.8 deaths per 1,000 population in SFY 2018.
  - The crude mortality rate among those living in congregate settings was 23.7 deaths per 1,000 population, an increase from SFY 2017's rate of 16.6 deaths per 1,000 population. In contrast, the crude mortality rate among those living independently remained stable, increasing from 9.6 deaths per 1,000 population in SFY 2017 to 9.9 deaths per 1,000 population in SFY 2018.

Recommendations

Recommendation 1: DBHDS should establish a target of less than 10% of deaths reviewed to be classified as 'Unknown' and develop a process improvement plan to better identify causes of death through the mortality review process.

Recommendation 2: DBHDS should establish a target that potentially preventable deaths make up less than 15% of the total DD deaths per year, and develop quality improvement interventions targeted at addressing the contributory factors specifically related to the top two identified reasons: failure of assessment or supervision and failure to adhere to established protocol.

Recommendation 3: DBHDS should establish specific quality improvement initiatives specifically targeted at decreasing the rate of potentially preventable deaths related to aspiration.

Recommendation 4: DBHDS should establish specific quality improvement initiatives specifically targeted at decreasing the rate of potentially preventable deaths related to bowel obstruction.

Recommendation 5: DBHDS should establish specific quality improvement initiatives specifically targeted at decreasing the rate of potentially preventable deaths related to sepsis.

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 (ID/DD) diagnosis who received services in a state-operated facility or in the community through a DBHDS-licensed provider, provide ongoing monitoring and data analysis to identify trends/patterns, and make recommendations to promote the health, safety and well-being of said individuals and reduce the incidence of potentially preventable deaths.

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 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 is charged with review and discussion of unexplained and/or unexpected deaths, cause of death, and determination of preventability. 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* 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.
- *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

Causes of Death

"Unknown" was the leading cause of death in SFY 2018 (34, 13%). The second leading cause of death was "other" (26, 10%). The third leading cause of death was aspiration (25, 10%).

Table 1 Number of Annual Deaths by Cause of Death (SFY 2015-2018) (sorted by 2018 Deaths)

Cause of Death	2015	2016	2017	2018	Total
Unknown	59	47	31	34	171
Other	18	21	18	26	83
Aspiration	21	14	13	25	73
Cancer	34	41	14	22	111
Sudden Cardiac Death	22	39	35	22	118
Pneumonia	29	27	26	21	103
Cardiovascular/Heart Disease	9	23	22	19	73
Respiratory	6	17	22	18	63
Sepsis	16	30	14	14	74
Complications of a Genetic Condition	0	0	6	12	18
Multiple medical problems	0	0	7	10	17
Renal	5	10	9	9	33
GI/Bowel Obstruction	8	8	4	7	27
Seizure	0	0	9	6	15
Post-operative complications	7	15	4	5	31
Slow Decline/FTT	8	6	7	4	25
Alzheimer's	4	3	3	3	13
Stroke/Cerebrovascular accident	6	10	3	3	22
Total	**252**	**311**	**247**	**260**	**1,070**

The MRC classified more deaths as "other" in SFY 2018 than in any previous fiscal year. Unlike deaths in which the cause is specific "unknown", deaths classified as "other" causes have known etiologies that exist outside of the MRC's primary categories for statistical trending. In SFY 2018, the leading causes of "other"

deaths were decubitus ulcers, multiple system organ failure, and pulmonary emboli, each accounting for two deaths. Each of the following "other" causes of death was responsible for a single death in SFY 2018: cerebral palsy, clostridium difficile colitis, complications of dementia, complications of hiatal hernia, complications of hip fracture, fall, hernia idiopathic thrombocytopenic purpura, influenza, liver, malnutrition, motor vehicle accident, neurodegenerative disease, pica, pulmonary edema, hemorrhagic shock, smoke inhalation, and suspected drug overdose.

Expected and Unexpected Deaths

Immediately following the cause of death determination, the MRC identifies whether a death was expected or unexpected. The distribution of expected to unexpected deaths has remained similar from SFY 2015 to 2018, although SFY 2018 had the greatest percentage of expected deaths to date. The leading causes of unexpected deaths in SFY 2018 were "unknown" (30) and sudden cardiac death (22). The leading cause of expected deaths was cancer (20).

Table 2 Expected and Unexpected Deaths, SFY 2015-2018

Determination	2015		2016		2017		2018	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Expected	74	29.4	106	34.1	83	33.6	94	36.1
Unexpected	178	70.6	202	65.0	164	66.4	165	63.5
Unknown	0	0	3	1.0	0	0	1	0.4

Potentially Preventable Deaths

In SFY 2018, the MRC implemented a new process to identify potentially preventable deaths and collect information related to contributing factors in these deaths. 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 of, or absence of, (at least) one of the following factors:

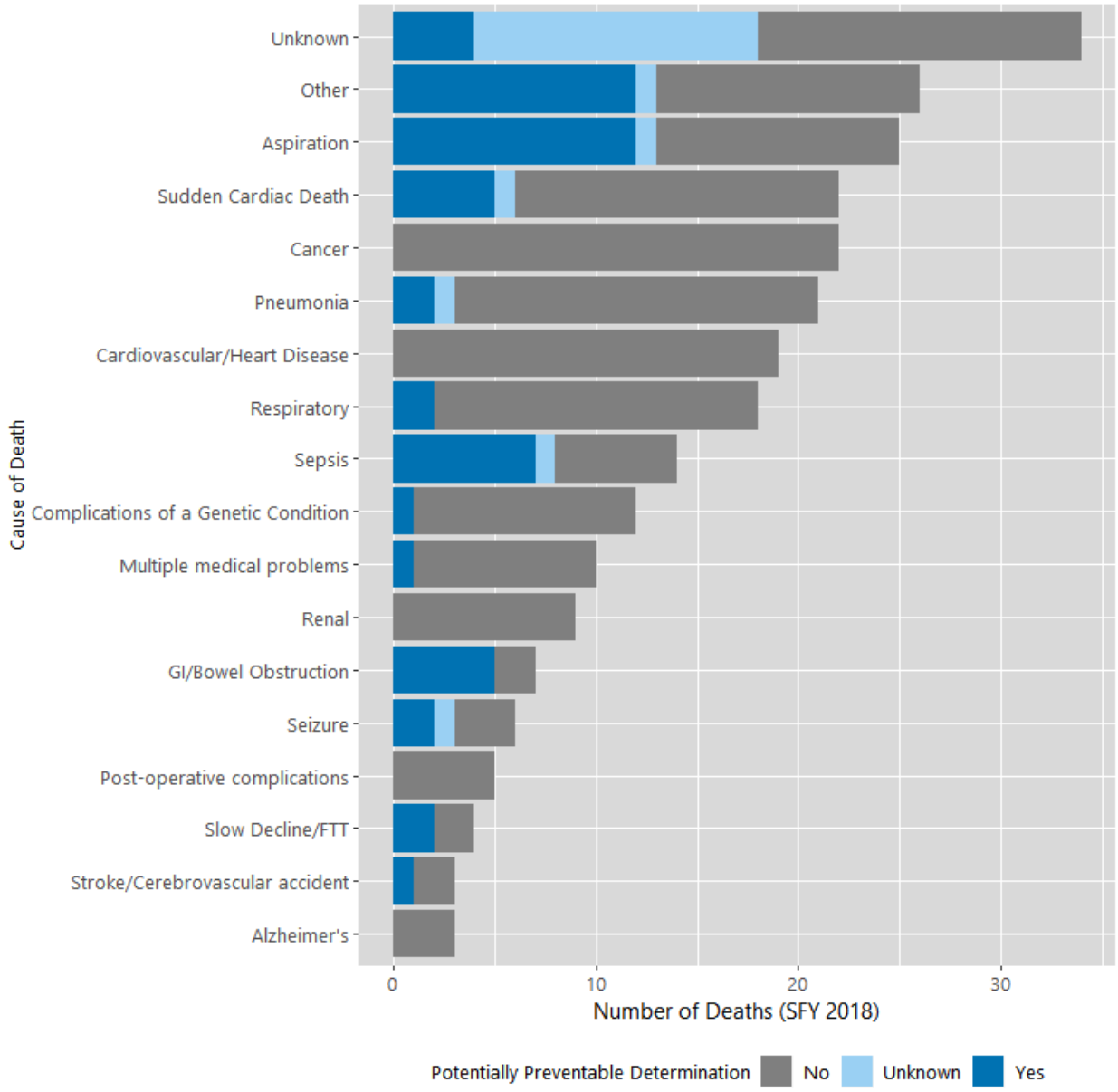
1. Coordination of care (including medication management)
2. Access to care, including delay in seeking treatment
3. Execution of established protocols
4. Assessment of the individual's needs or changes in status

Most deaths reviewed by the MRC in SFY 2018 were determined to *not* be potentially preventable; however, 56 deaths (21%) reviewed were classified as potentially preventable.

When the MRC determines a death is potentially preventable, the committee categorizes factors that might have prevented the death. Approximately 55 percent of potentially preventable deaths in SFY 2018

involved a failure of assessment or supervision (31 deaths), and nearly 52 percent of potentially preventable deaths included a failure to adhere to established protocols (29 deaths).[1]

Fig. 1 Potentially Preventable Deaths by Cause of Death, SFY 2018



The MRC determined that 48 percent of deaths by aspiration in SFY 2018 (12 deaths) were potentially preventable, 46 percent of "other" deaths in SFY 2018 (12 deaths) were potentially preventable, and half of

[1] A single potentially preventable death may have multiple contributing factors. Consequently, the percentages of these factors will add to more than 100.

deaths from sepsis in SFY 2018 (7 deaths) were potentially preventable. Approximately 71 percent of deaths caused by GI/bowel obstructions in SFY 2018 (5 deaths) were potentially preventable.

Population Demographics

This section includes demographic trends for individuals reviewed by the MRC. For SFY 2018, a separate comparison shows mortality rates for individuals receiving DD waiver services.

Age

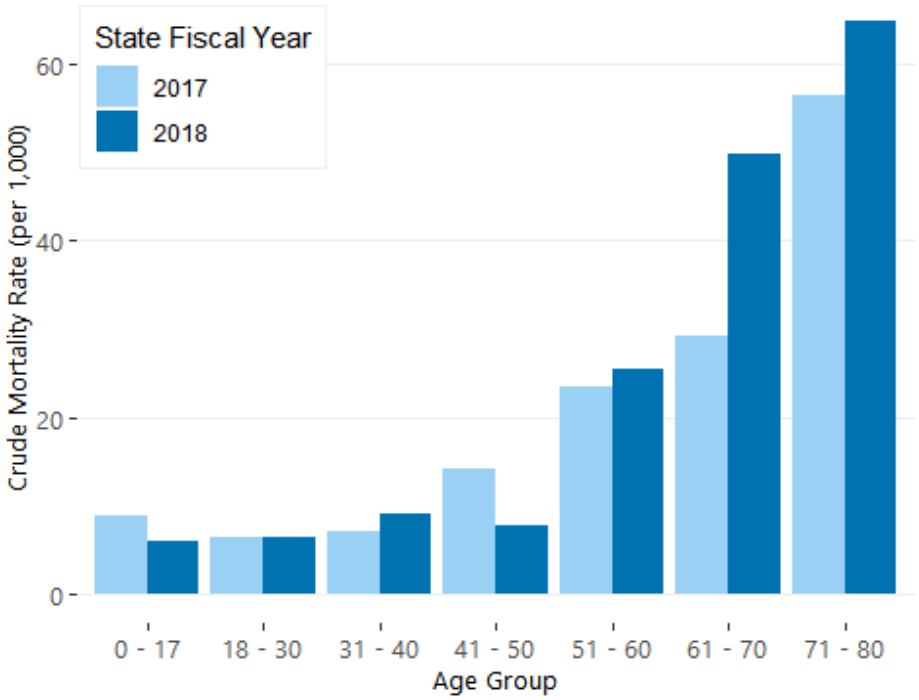
Prior to SFY 2018, the plurality of deaths reviewed by the MRC occurred among individuals 51 to 60 years old. However, in SFY 2018, 70 of the 260 deaths occurred among individuals aged 61 to 70. While the percentage of deaths among individuals aged 41 to 50 decreased in SFY 2017 and 2018, the percentage of deaths among those aged 18 to 40 increased in both SFY 2017 and 2018.

Table 4 Crude Mortality Rates by Age per 1,000 population, SFY 2018

Age Group	Deaths	DD Waiver Population	Crude Mortality Rate
0 - 17	6	990	6.1
18 - 30	25	3,895	6.4
31 - 40	23	2,529	9.1
41 - 50	14	1,822	7.7
51 - 60	51	2,000	25.5
61 - 70	56	1,124	49.8
71 - 80	20	308	64.9
81 or Greater	0	50	0
Unknown	0	1	0
Total	**195**	**12,719**	-

Between SFY 2017 and 2018, the crude mortality rate increased for all age groups between 51 and 80 years of age. For individuals on DD HCBS waivers aged 61 to 70, the crude mortality rate increased from 29.3 deaths per 1,000 population in SFY 2017 to 49.8 deaths per 1,000 population in SFY 2018.

Fig. 2 Crude Mortality Rates by Age per 1,000 population, SFY 2017-2018



Conversely, the crude mortality rate decreased for individuals aged 41 to 50 from 14.3 deaths per 1,000 population in SFY 2017 to 7.7 deaths per 1,000 population in SFY 2018.

Gender

Males comprised the majority of individuals whose deaths were reviewed by the MRC in SFY 2018, consistent with trends from previous fiscal years.

Table 5 Crude Mortality Rates by Gender per 1,000 population, SFY 2018

Gender	Deaths	DD Waiver Population	Crude Mortality Rate
Female	87	5,077	17.1
Male	114	7,640	14.9
Unknown	0	2	0
Total	**201**	**12,719**	-

Between SFY 2017 and 2018, 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 to 17.1 deaths per 1,000 population. Among males on the DD waiver, the crude mortality rate increased from 13 to 14.9 deaths per 1,000 population.

The leading cause of death among males in SFY 2018 was unknown (18, 12%), followed by aspiration, pneumonia, and sudden cardiac death (each accounting for 15 deaths). Among females, the leading causes of death in SFY 2018 were other and unknown, each accounting for 16 deaths (14% each), followed by aspiration and cancer (10 deaths each).

Race

Consistent with data from previous years, the majority of deaths reviewed by the MRC were of individuals identified as Caucasian (188 deaths, 72%). Individuals identified as Black/African American accounted for approximately 27 percent of deaths reviewed by the committee.

The crude mortality rate among individuals identified as Caucasian on the DD waiver was 17.8 deaths per 1,000 population in SFY 2018 – an increase from 14.7 deaths per 1,000 population in SFY 2017. By contrast, the crude mortality rate among individuals identified as Black/African American on the DD waiver decreased from 14.8 deaths per 1,000 population in SFY 2017 to 14.6 deaths per 1,000 population in SFY 2018.

Table 6 Crude Mortality Rates by Race per 1,000 population, SFY 2018

Race	Deaths	DD Waiver Population	Crude Mortality Rate
Caucasian	145	8,139	17.8
Black/African American	55	3,780	14.6
Other	1	759	1.3
Unknown	0	41	0
Total	**201**	**12,719**	-

SIS Level

DBHDS uses the Supports Intensity Scale (SIS) to assign individuals 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 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 2018

SIS Level Group	Deaths	DD Waiver Population	Crude Mortality Rate
1	2	893	2.2
2	39	5,402	7.2
3	3	577	5.2
4	90	3,909	23
5	10	177	56.5
6	48	1,041	46.1
7	6	719	8.3
Total	**198**	**12,718**	-

From SFY 2017 to 2018, the crude mortality rate increased for individuals on the DD waiver with SIS Levels of 4 or 6, while decreasing for those with a SIS Level of 2. Between SFY 2017 and 2018, the crude mortality rate among those on SIS Level 4 increased from 17.4 deaths per 1,000 population to 23 deaths per 1,000 population. Similarly, the crude mortality rate among those on SIS Level 6 increased from 37.4 deaths per 1,000 population in SFY 2017 to 46.1 deaths per 1,000 population in SFY 2018. Conversely, during the same timeframe, the crude mortality rate among those on the DD waiver with a SIS Level of 2 decreased from 7.8 to 7.2 deaths per 1,000 population.

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 2015-2018

Residential Living Group	2015		2016		2017		2018	
	Deaths	Percent	Deaths	Percent	Deaths	Percent	Deaths	Percent
Congregate Setting	71	28.2	107	34.4	82	33.2	109	41.9
Facility	30	11.9	26	8.4	20	8.1	15	5.8
Independent Living	114	45.2	118	37.9	99	40.1	100	38.5
Institutional Setting	30	11.9	39	12.5	40	16.2	30	11.5
Unknown	7	2.8	21	6.8	6	2.4	6	2.3
Total	**252**		**311**		**247**		**260**	

In contrast to previous fiscal years, the MRC reviewed fewer deaths among those living independently in SFY 2018 than among those living in congregate settings. In SFY 2018, the leading cause of death among those living independently was unknown (19, 19%), followed by complications of a genetic condition (10, 10%). If the individual lived in a private home, lived independently, or resided in a nursing facility, the MRC is 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.

As in SFY 2017, the majority of deaths reviewed by the MRC in SFY 2018 were of individuals who lived in congregate settings.

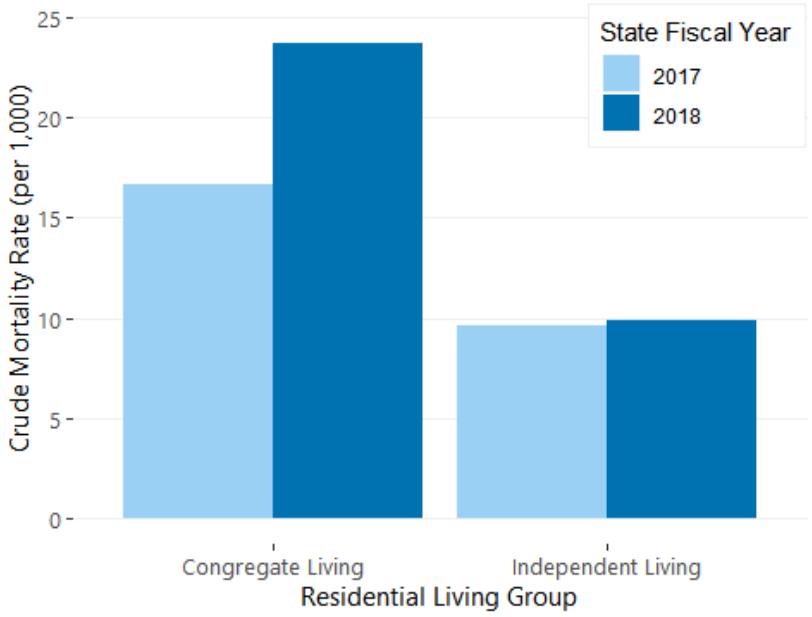
Table 9 Crude Mortality Rates by Residential Setting per 1,000 population, SFY 2018

Residential Living Group	Deaths	DD Waiver Population	Crude Mortality Rate
Congregate Living	107	4,506	23.7
Independent Living	81	8,213	9.9
Total	**188**	**12,719**	-

Between SFY 2017 and 2018, the crude mortality rate for individuals living in congregate settings increased while the rate for those living independently remained stable. In SFY 2018, the crude mortality rate among those living in congregate settings was 23.7 deaths per 1,000 population, an increase from 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. The MRC will continue to monitor crude mortality rate to determine the presence of a trend.

Fig. 2 Crude Mortality Rates by Residential Living Group per 1,000 population, SFY 2017-2018



Approximately 18 percent of all deaths among those who lived independently were potentially preventable (18 deaths), while more than 28 percent of deaths among those in congregate settings were potentially preventable (31 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 mortality review by the Community Integration Project Team.

In SFY 2018, the MRC reviewed 31 deaths among individuals discharged from a training center into the community. Aspiration was the leading cause of death among individuals discharged from training centers (6, 19.4%), followed by "other" (5, 16.1%). Approximately 29 percent of all deaths that occurred among those discharged from training centers were potentially preventable (9 deaths).

Community tenure continued to increase in SFY 2018, however the average age at death among individuals discharged from training centers decreased from 62 years in SFY 2017 to 60 years in SFY 2018. 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 SA) 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

Summary

Virginia has continued to make significant improvements in their system of care to meet the health and wellness needs of individuals with developmental disabilities. Identification of risk factors and development of targeted systemic interventions are essential to making a positive impact on the reduction of preventable deaths. While the rates of common causes of death reported in the general population such as cardiovascular disease and cancer are similar for this population, there is an opportunity to better understand disease surveillance and collaborate with other partners to encompass population health interventions that may be unique for individuals with developmental disorders and intellectual disability. Promoting health, safety, and well-being is a primary goal for service providers in the Commonwealth that impacts overall quality of life and life-expectancy of the population. 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 and data driven decisions.