Virginia Department of
Behavioral Health &
Developmental Services

Annual Mortality Report
SFY2017

Mortality Among Individuals With A Developmental Disability

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I. DBHDS Mortality Review

Introduction

This is the third annual mortality report released by the Virginia Department of Behavioral Health and Developmental Services (DBHDS). DBHDS monitors trends in mortality among individuals receiving developmental disability (DD) services in a state operated facility or in the community through a DBHDS-licensed provider. This report provides aggregate data from the DBHDS Mortality Review Committee (MRC) deliberations. The MRC will use this report to develop conclusions and recommendations for future processes which will be included as an appendix upon completion.

Purpose of the Mortality Review

The purpose of a mortality review is to learn from an individual's death, to discover if the same or similar situation may affect others in the future, and to improve overall quality of care at the individual and system levels. A mortality review is an approach to:

- Identify immediate safety issues that require remedial action in order to prevent deaths, poor health outcomes, injury, or disability in other individuals served;
- Identify early warning signs in the change or deterioration of an individual's medical condition that may help to prevent other negative outcomes;
- Identify the conditions contributing to an individual's death to determine if changes are needed to prevent negative outcomes in other individuals;
- Identify system trends or patterns that will serve as the basis for initiatives to improve the quality of care; and
- Direct training needs to programs and services that serve individuals who are at high risk of injury, illness, or death.

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.

The Mortality Review Committee (MRC)

The MRC membership includes the DBHDS Medical Director, Assistant Commissioner for Quality Management and Development, and directors of the following offices listed alphabetically:

- Community Integration
- Community Quality and Risk Management
- Data Quality and Visualization

- Facility Quality and Risk Management
- Office of Integrated Health
- Licensing

Other members include a practitioner who is otherwise independent of the state, the DBHDS Director of Pharmacy Services and additional members as designated by the DBHDS Commissioner.

The MRC:

- Strives to review each death within 90 days to identify safety issues that require action to reduce the risk of future adverse events;
- Reviews, or documents the unavailability of, medical records and all incident reports for the three months preceding an individual's death;
- Recommends quality improvement initiatives to reduce mortality rates to the fullest extent practicable; and
- Reports its findings and makes recommendations to the DBHDS Quality Improvement Committee (QIC) and to the commissioner.

The DBHDS Mortality Review Process

The DBHDS Medical Director or designated clinical reviewer collects and reviews all information available about the death and presents a factual summary of each death and the initial findings to the MRC. The MRC reviews the summary and other information about the events leading up to a death and the treatment provided to the individual, to the extent that such information is available from hospitals and medical providers. Based on this information, the MRC makes a determination of cause of death and whether the death was expected or unexpected. Following a review of a death, the committee may take one or more of the following actions:

- Request additional information relevant to the death from the provider or others;
- Communicate to the provider issues identified as part of the mortality review;
- Issue a Safety and Quality Alert to all providers regarding risks identified as part of a single mortality review or a pattern of findings;
- Establish a subcommittee to study or take action to address an identified pattern of risks;
- Make recommendations to the QIC to reduce the risk of death, based on a single finding or a pattern of findings;
- Take other actions deemed necessary to reduce the risk to individuals served in community and facility programs.

Classifications of Death

After the review and deliberation, the MRC classifies the death as one of the following:

- Expected Death is defined as 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 means a death that occurred as a result of an acute medical event, accident, or other event that was not expected in advance or based on a person's known medical conditions.
- Unknown is, in a limited number of cases, when there is insufficient information to classify a death as either expected or unexpected. When this occurs, the death is classified as 'Unknown.'

Determining Cause of Death

The MRC makes a determination as to the cause of death. This may be based on a death certificate or the circumstances surrounding the death. For the purpose of data trending, the committee enters the cause of death into the Mortality Review Tracking Tool under one of several predefined categories. In some cases, it is not possible to assign a death to one of the predefined categories. When this occurs, one of the following classifications is used:

- Other is used to classify a death when the cause is not attributable to one of the major causes of death used by the MRC for data trending. These are often unusual conditions or illnesses such as Lewy body dementia, complications of Crohn's disease or stiff person syndrome. In other instances, the cause of death is classified as "Other" because the individual suffered from multiple chronic conditions, any of which may have resulted in the death.
- Unknown is used to classify a death as "Unknown" when there is insufficient information to make a determination as to the cause of death.

Data Quality

The Office of Data Quality & Visualization (DQV) supports the MRC through ongoing data quality and monitoring efforts. The data used for committee deliberations originates from the serious incident report submitted by the provider. Community providers are required to submit serious incident and death reports within 24 hours; DBHDS-operated facilities must report within 12 hours. Details entered by providers on these reports, such as residential setting and waiver status, are verified during mortality reviews. DQV also conducts quarterly and annual quality reviews to ensure any late reports are identified for review by the committee.

The MRC elected to change the reporting period from the calendar year to state fiscal year (July 1st through June 30th) after the 2014 report, resulting in an 18 month report that combined SFYs 2015-2016. This current report is the first state fiscal year annual report, beginning July 1, 2016, and ending

June 30, 2017. Much of the data was re-analyzed to accommodate the presentation of comparative data from previous fiscal years.

During September and October 2016, DBHDS transitioned the pre-authorization and waiver management system from IDOLS to WaMS; at the same time, individuals receiving services on the intellectual disability (ID) or the developmental disability (DD) waiver were combined under the new waiver amendments. Therefore, references to DD throughout this report is inclusive of individuals with ID. With the successful implementation of WaMS for pre-authorization, mortality rates for individuals on a DD waiver will continue to be calculated so that future comparisons can be made over time. DQV recommends that the MRC consider exploring the possibility of collecting additional factors such as underlying causes of death, contributing co-morbid conditions, life expectancy, and preventative care. The collection of such data elements as part of a systematic and defined process would provide a more holistic approach to mortality review and enable more comprehensive statistical analyses.

For individuals discharged from training centers under the settlement agreement, both quarterly and annual checks against the Training Center Discharge Tracker ensures that deaths among these individuals are identified and reviewed, regardless of whether their death occurred while under the supervision of a DBHDS-licensed provider. This information is maintained by the Community Integration Project Team and data is analyzed with their collaboration.

Process refinements, integration of newly available demographic information, and data cleaning/validity checks are all DQV data quality monitoring efforts conducted for the MRC. Such efforts would not change the two MRC determinations (the cause of death and whether it was expected or unexpected) once a death review has been closed. DQV does not manage information or data related to MRC operating procedures, action items, recommendations, documents reviewed for each death, or the unavailability of such documents.

II. Virginia Mortalities

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). On December 31, 2016, there were 11,957 individuals on a DD waiver with approximately 11,000 more on the waiting list. There were an additional 318 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. For SFY 2018, the MRC will continue to seek available population denominators.

The MRC reviewed 247 deaths among individuals receiving DD services reported to DBHDS in SFY 2017. Of these 247 deaths, there were 20 reported for individuals served in state facilities. The remaining 227 were reported for individuals in community residential settings, which include nursing homes and ICFs. Of these 227 individuals, 169 were receiving services on the DD waivers. The DD waiver crude mortality rate was 14.13 deaths per 1,000 individuals. 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.

Since its inception, the MRC has made two determinations during reviews: the cause of death and whether a death was expected or unexpected. In SFY 2017, the MRC developed a process to collect two additional data elements during mortality reviews: hospice care information and a narrative description for causes of death deemed as "Other."

Causes of Death

Cardiovascular death was the leading cause of death in SFY 2017 (Table 1). Cardiovascular death includes sudden cardiac death and cardiovascular/heart disease. The second leading cause was "Unknown" (31, 13%). The third leading cause was pneumonia (26, 11%).

Heart disease and cancer were the first and second leading causes of death in the general populations of the U.S. in 2015 (Centers for Disease Control and Prevention, 2016), while cancer outranked heart disease for the same year in Virginia (Centers for Disease Control and Prevention, 2015). Aggregate data shows that cardiovascular death and cancer were the first and third leading causes of death for all deaths reviewed by the MRC since 2015 (Table 1). Compared to U.S. general population, the causes of death that were unique to the DD population were sepsis, aspiration, gastrointestinal/bowel obstruction, slow decline/failure to thrive, seizure, and post-operative complications. With the exception of sepsis, these causes of death were also unique when compared to the Virginia general population.

A 2015 review in Hawaii found similarly high ranking for deaths attributable to pneumonia and sepsis among those with DD compared to the general population. The report stated that individuals with DD may have co-morbid conditions such as cerebral palsy, which can increase dysphagia, putting individuals at increased risk for aspiration. Other issues, such as being non-ambulatory or non-communicative, may increase risk for death related to septic shock (Okamoto, 2016).

Table 1. MRC Causes of Death | Count (Annual Ranking)

Cause of Death	2015	2016	2017	2017 Percent	Grand Total
Cardiovascular*	31 (3)	62 (1)	57 (1)	23%	150
Sudden Cardiac Death	22	39	35	*14%*	
Cardiovascular/Heart Disease	9	23	22	*9%*	
Unknown	59 (1)	47(2)	31 (2)	13%	137
Pneumonia	29 (4)	27 (5)	26 (3)	11%	82
Respiratory	6	17	22 (4)	9%	45
Other	18	21	18 (5)	7%	57
Sepsis	16	30 (4)	14	6%	60
Cancer	34 (2)	41 (3)	14	6%	89
Aspiration	21 (5)	14	13	5%	48
Seizure	-	-	9	4%	9
Renal	5	10	9	4%	24
Multiple medical problems	-	-	7	3%	7
Slow decline/Failure to thrive	8	6	7	3%	21
Genetic condition complications	-	-	6	2%	6
Post-operative complications	7	15	4	2%	26
GI/Bowel obstruction	8	8	4	2%	20
Alzheimer's	4	3	3	1%	10
Stroke/Cerebrovascular Accident	6	10	3	1%	19
Total	252	311	247	100%	810

-Not a cause of death category in this year.

Overall, there were more deaths reviewed by the MRC in SFY 2016 compared to both 2015 and 2017. The cause for this difference is unknown; however, the MRC will continue to monitor these trends. Statistical analysis related to cause of death is limited by the absence of data related to health risk factors, such as co-morbid conditions. Beginning with SFY 2018 deaths reviews, the MRC has implemented a new process for the identification of potentially preventable deaths, as well as the collection of information related to contributing factors in these deaths.

The "Other" category includes causes not attributed to a category. The most common categories of deaths determined to be "Other" were unintentional trauma and probable suicide (Table 2).

Table 2. Number and Percent of "Other" Causes of Death, SFY 2017

"Other" Causes of Death	Deaths	Percent of all Deaths
Unintentional trauma	**4**	**22%**
Probable suicide	**4**	**22%**
Related to seizure	2	11%
Complications from a chronic disease	2	11%
Complications from surgery	2	11%
Blood dyscrasia	1	6%
Diabetes	1	6%
Brain hemorrhage	1	6%
Related to infection	1	6%
Grand Total	18	100%

Expected and Unexpected Deaths

The decision of whether a death was expected or unexpected is made immediately following the cause of death determination. The distribution of expected versus unexpected has been consistent between SFY 2015-2017 with the majority of deaths deemed as unexpected (Table 3). In SFY 2017, the leading cause of unexpected deaths was **cardiovascular** (48) and the leading cause of expected deaths was **cancer** (14). Cardiovascular includes sudden cardiac and cardiovascular/heart disease.

Table 3. Number and Percent of Expected vs Unexpected Deaths

	SFY 2015		SFY 2016		SFY 2017	
Determination	Deaths	Percent	Deaths	Percent	Deaths	Percent
Unexpected	178	71%	202	65%	164	66%
Expected	74	29%	106	34%	83	34%
Unknown	0	0%	3	1%	0	0%
Total	252		311		247	

Hospice Care

Hospice care was described in the provider reports or death review timeline for 53 individuals (Table 4). Of the individuals that died in hospice care, 87% of the deaths were expected. **Cancer** was the leading cause of expected deaths (10, 19%) among individuals receiving hospice care. The leading cause of unexpected deaths for individuals receiving hospice care is **pneumonia** (2, 29%).

Table 4. Number and Percent of Individuals Receiving Hospice Care at Death, SFY 2017

Hospice Period	Individuals	Percent
<=7 days	13	25%
8 - 89 days	26	49%
>=90 days	10	19%
Unknown	4	8%
Total	53	

Residential Setting

Due to the low number of individuals in certain residential settings, the MRC analyzed these results according to the following groupings for residence types: independent living, congregate living, institutional community living, state facility, and unknown (Table 5).

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.
- Institutional Community 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 5. Deaths by Residential Setting

	SFY 2015		SFY 2016		SFY 2017	
Residential Living Group	Deaths	Percent	Deaths	Percent	Deaths	Percent
Independent Living	114	45%	118	38%	99	40%
Congregate Living	71	28%	107	34%	82	33%
Institutional Community Living	30	12%	39	13%	40	16%
State Facility	30	12%	26	8%	20	8%
Unknown	7	3%	21	7%	6	2%
Total	252		311		247	

In SFY 2017, the leading cause of death among individuals in the Independent Living group was "Unknown" (18, 18.2%) followed by "Other" (14, 14.1%). If the individual is living in a private home, living independently, or residing in a nursing facility it is far less likely that information is available to the Mortality Review Committee. The MRC may request information from these settings or from the family but it has no authority to require documentation from any non-licensed setting.

Sudden cardiac death was the leading cause in the Congregate Living group (17, 20.7%), followed by cardiovascular/heart disease (12, 14.6%). **Sudden cardiac** and "Unknown" were the leading causes of death in the Institutional Community Living group (both 5, 12.5%), followed by sepsis and aspiration

(both 4, 10%). **Pneumonia** was the leading cause of death for individuals in the state facility group (5, 25%), followed by respiratory causes (4, 20%).

The residential setting for individuals receiving services on the DD waivers was determined for SFY 2017, based on a fiscal year mid-point of December 31, 2016. Most individuals whose deaths were reviewed by the MRC lived in an Independent Living setting, followed by a Congregate Living setting (Table 6). The SFY 2017 DD waivers Congregate Living mortality rate was 16.64 per 1,000 individuals. These rates are crude and do not take into account demographic variables such as age and gender.

Table 6. Mortality Rate by Residential Group per 1,000 population, SFY 2017

Residential Group	Deaths	DD Waiver Population	Crude Mortality Rate
Independent Living	71	6,865	10.34
Congregate Living	76	4,568	16.64

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 all but one training center. Deaths among individuals discharged from training centers receive an additional mortality review by the Community Integration Project Team.

In SFY 2017, there were 23 deaths among individuals discharged from a training center into the community (Table 7). **Cardiovascular/heart disease** was the leading cause of death among individuals discharged from training centers (7, 30%), followed by sepsis (4, 17%) and aspiration (3, 13%).

Community tenure has increased since SFY 2015 (Table 7). 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.

Table 7. 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	31	60	24
2017	23	62	31

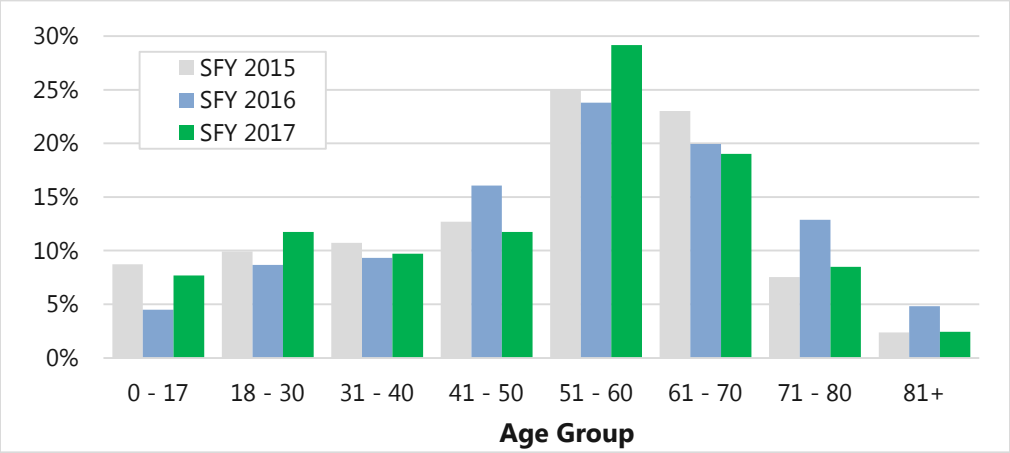
III. Population Demographics

This section includes three-year demographic trends for all individuals reviewed by the MRC. For SFY 2017, a separate comparison shows mortality rates for individuals receiving DD waiver services.

Age

Since 2015, most deaths have occurred in the 51 to 60 year age group (Figure 1). In SFY 2017, 72 of the 247 deaths were in this age group.

Fig 1. Percentage of Deaths by Age Distribution, SFYs 2015 – 2017



The median and mean age at death is compared for individuals aged 18 years and older, based on residence group (Table 8). Both the mean and median ages of death remained relatively stable over the three year period for all residence groups. These medians and means are consistent with research showing that for state intellectual and developmental disabilities systems, the average age at death for adults (aged 18 years and older) is 50.4-58.7 years (Lauer & McCallion, 2015).

Table 8. Adult (18+) Age at Death by Residence Group per 1,000 population

	SFY 2015		SFY 2016		SFY 2017	
Residence Group	Median	Mean	Median	Mean	Median	Mean
Congregate Living	60	57	59	58	57	54
Independent Living	50	49	51	51	52	48
Institutional Community Living	57	56	57	57	58	58
State Facility	58	58	62	61	60	60

In SFY 2017, the leading cause of death among individuals aged 0-17 years old was "**Unknown**" (4, 21%), followed by respiratory causes (3, 16%). For individuals aged 18-70, the leading cause of death was **sudden cardiac** (33, 16.4%), followed by "Unknown" (23, 11.4%). Among individuals aged 71 years and older, the leading causes of death were **cancer, pneumonia, and "Unknown"** (each 4, 14.8%).

The crude mortality rate was calculated for each age group among individuals receiving DD waiver services (Table 9).

Table 9. Mortality Rates by Age per 1,000 population, SFY 2017

Age Group	Deaths	DD Waiver Population	Crude Mortality Rate
0 – 17	8	901	8.9
18 – 30	23	3,618	6.4
31 – 40	17	2,390	7.1
41 - 50	25	1,744	14.3
51 - 60	46	1,970	23.4
61 - 70	30	1,025	29.3
71 - 80	15	266	56.4
81 +	5	43	116.3
Total	169	11,957	-

Gender

Males have consistently had a higher mortality rate since SFY 2015 (Table 10). This trend is consistent with the literature for other DD service systems (Lauer & McCallion, 2015). A 2011 meta-analysis of international studies shows that intellectual disability is generally more common in males than females (Maulik PM, 2011). Reasons may include a higher rate of autism spectrum disorders and traumatic brain injuries, as well as more severe impacts from X-chromosomal disorders in males (Arvio M, 2016).

Table 10. Percentage of Deaths by Gender

	SFY 2015		SFY 2016		SFY 2017	
Gender	Individuals	Percent	Individuals	Percent	Individuals	Percent
Female	101	40%	127	41%	108	44%
Male	151	60%	184	59%	139	56%
Total	252		311		247	

In SFY 2017, the leading cause of death among males was **sudden cardiac** (22, 16%). The leading cause of death among females was **pneumonia** (15, 14%). Although a higher numbers of males died, the crude mortality rate was higher for females among individuals receiving DD waiver services (Table 11).

Table 11. Mortality Rates by Gender per 1,000 population, SFY 2017

Gender	Deaths	DD Waiver Population	Crude Mortality Rate
Male	93	7,161	12.99
Female	76	4,794	15.85
Total	169	11,957	-

Race

Race trends are steady from SFY 2015-2017 with little variation from the SFY 2017 distribution of 64% white, 30% black, 4% other, and 2% unknown for those that died. The "other" race category includes individuals who recorded their race as "other" and those who identify with two or more races.

In SFY 2017, the leading cause of death among white individuals was **sudden cardiac** (21, 13%). The leading cause of death for black individuals was "**Unknown**" (12, 16%). Crude mortality rates were calculated for each race among individuals receiving DD waiver services (Table 12) with mortality rates of 15% for both white and black.

Table 12. Mortality Rates by Race per 1,000 population, SFY 2017

Race	Deaths	DD Waiver Population	Crude Mortality Rate
White	108	7,364	14.67
Black	52	3,505	14.84
Other	8	725	11.03
Unknown	1	363	-
Total	169	11,957	-

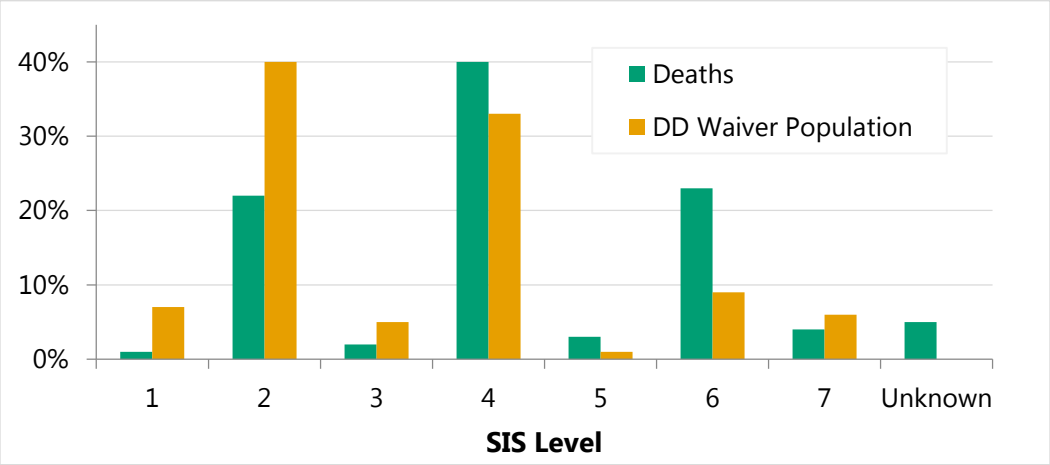
Supports Intensity Scale (SIS) Level

The adult Supports Intensity Scale (SIS) is a reliable tool for measuring the support intensity needs of individuals with I/DD and has been in use since 2004 (American Association of Intellectual and Developmental Disabilities).

DBHDS uses the SIS results 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 and are not associated with AAIDD or the SIS developers. Level 1 represents those with the lowest support needs while Levels 6 and 7 represent individuals with the highest need for support (Va Dept. of Behavioral Health and Developmental Services). See Definitions section for the seven level assessment framework.

The largest negative discrepancy between the distribution of deaths of individuals on the waiver and the total waiver population surrounds those in Level 6; 9% of individuals on the waiver are in Level 6 whereas 23% of the deaths were in Level 6 (Figure 2). The largest positive discrepancy between SIS levels and death is in Level 2 (Figure 2). 40% of individuals that had a SIS score were in Level 2 but only 22% of those individuals that died were in Level 2.

Figure 2. Proportions of Deaths and Waiver Population by SIS Level, SFY 2017



The crude mortality rate was calculated for each SIS Level among individuals receiving DD waiver services (Table 13).

Table 13. Mortality Rates by SIS Level per 1,000 population, SFY 2017

SIS Level Group	Deaths	DD Waiver Population	Crude Mortality Rate
Level 1	2	854	2.34
Level 2	37	4,771	7.76
Level 3	3	542	5.54
Level 4	68	3,905	17.41
Level 5	5	166	30.12
Level 6	39	1,044	37.36
Level 7	7	672	10.42
Unknown	8	3	-
Total	169	11,957	-

In SFY 2017, among individuals with a SIS Level 1, 2, 5, or 7, the leading cause of death was **sudden cardiac** death. The leading cause of death among individuals with a SIS Level 3 or 4 was **pneumonia**. For SFY 2018, the MRC will continue to collect and analyze SIS level information to compare with this first year baseline data.

IV. SFY2016 Report Follow-up

Review of SFY16 Recommendations

The SFY 2016 Mortality Review report included a number of recommendations intended to reduce the risk of death to individuals with a developmental disability in community and facility programs, to improve information capture, and to improve the quality of data on which the annual MRC reports are based. The recommendations were as follows:

Examine training center discharges and deaths by residential category.

> **Outcome**: As of July 1, 2017, 669 individuals were discharged from training centers into the community, or transferred to other institutional settings or state facilities. Most individuals transitioned into a group home, with 477 (71%) of the 669 individuals transitioned to this setting. Of these 477 individuals, 66 died (14%). The most common cause of death for these individuals was aspiration, sepsis, and cardiovascular/heart disease (each 9, 14%). The MRC will continue to look for trends by residential setting to identify potential opportunities for improvement.

Examine post-operative complications in greater detail. For example, track whether post-operative complications were first noted in the hospital or post-discharge.

> **Outcome**: In SFY 2017, there were four deaths attributed to post-operative complications. One of these deaths contained narrative information related to bowel obstruction. Further examination of post-operative complications in greater detail will not become possible until this data begins to be tracked in a systematic way, with an outlined process and thorough definitions, and using an analytical tool (i.e. Microsoft Excel).

Further analyze deaths by age for children, adults, and the elderly populations.

> **Outcome**: These described age groups are not currently defined by MRC for trending purposes. In SFY 2017, the leading cause of death among individuals aged 0-17 years old was "Unknown" (4, 21%), followed by respiratory causes (3, 16%). For individuals aged 18-70, the leading cause of death was sudden cardiac death (33, 16%), followed by "Unknown" (23, 11%). Among individuals aged 71 years and older, the leading causes of death were cancer, pneumonia, and "Unknown" (each 4, 15%).

Explore ways to improve information capture and data collection to better document and trend important aspects of care such as time between identification of a problem and medical treatment, adequacy of the treatment plan, complicating conditions such as dental care, and whether the ISP identified and included a treatment plan for identified medical issues.

Outcome: The MRC has entered into an agreement with the Virginia Department of Health (VDH) to share information on the death certificate. The VDH data is captured in the DBHDS OneSource Data Warehouse, which automatically populates the Mortality Review Tracking Tool, to make the information available to reviewers and the MRC.

The DBHDS does not have legal authority to access the records of private hospitals and nursing homes without proper authorization. Such access would require legislative approval.

The MRC has implemented a new information capture process to ensure that all available information is submitted in a timely fashion; and it is now tracking adherence to these timeframes.

Utilize as part of the mortality review process the risk reduction tool that the DBHDS Office of Integrated Health Services is developing, as a retrospective test of the tool.

Outcome: This recommendation was not implemented. The risk reduction tool was a joint project between Community Quality Improvement/Risk Management and the Office of Integrated Health. The tool was being tested in community services boards when it was circumvented by the Managed Care Organization contract, which requires each organization to conduct a risk assessment of individuals served and recommendations for improvements must be made available to support coordinators. However, there is as yet, no single tool that is being used by all providers nor is there a requirement that providers use a standard risk assessment tool. The DBHDS will continue to work with the Department of Medical Assistance Services to examine this process and explore options for a universal individual risk assessment.

Consider updating the Mortality Review Tracking Tool's categories of death to include "DD related deaths" and "Unknown due to multiple medical conditions."

Outcome: "Multiple medical problems" was added as a cause of death category in the SFY 2017 mortality tracker, per MRC request. Upon further review "DD related deaths" was not added as a cause of death option to the mortality tracker in SFY 17 as data for SFY 2017 do not include any deaths captured as "Other" that would have been considered "DD related deaths." As the MRC begins SFY 2019 reviews, the cause of death category should be examined to eliminate unnecessary options and add new ones, based on committee approval.

Continue to monitor trends to determine their stability over time.

Outcome: In addition to annual reporting efforts, the MRC was presented with a report on the data quality and monitoring efforts conducted by DQV for SFY 2017.

Beginning with SFY2018 deaths, the MRC requested a new quarterly reporting schedule, including visualizations and data quality efforts. For this process to be successful, MRC should consider what would be important to investigate and communicate this request to DQV.

Study the professional literature and the initiatives taken by other states to identify interventions that may reduce the risk of death by sepsis.

Outcome: The MRC collected and reviewed the professional literature and initiatives by other state DD agencies to reduce the risk of sepsis. The findings show that the literature's predominant focus is on treating sepsis in acute care hospitals. Only a few studies addressed the prevention of sepsis and most had hospitals as their focus. A review of several state health department websites showed that sepsis was typically mentioned as one of the leading causes of death but there was little additional information made available on these sites. The MRC will continue to scan the literature for information on reducing the risk of sepsis, and this information will be shared with providers. The Office of Integrated Health has already prepared a Safety Alert and additional detailed information to educate providers on the risk of sepsis and will continue to provide new educational materials to providers through meetings with community nurses.

Expand the information requested for the mortality review to include medical protocols in place at the time of death and whether they were being followed as written.

Outcome: This recommendation relates specifically to documentation required by the MRC clinical reviewers for a thorough mortality review. In SFY2017, the MRC introduced a written format for the presentation of the preliminary review information – the Mortality Review Presentation Form (MRPF). The MRPF has undergone multiple revisions as the need and value of information for a comprehensive and clinically sound mortality review is tested. Whether a medical protocol was in place at the time of death is included in the current MRPF.

Accomplishments

- At the recommendation of the Mortality Review Committee, the Office of Integrated Health issued nine Safety Alerts and more detailed educational Alerts for four of these nine topics during SFY 17. These Alerts were issued in response to the findings of the MRC. They are as follows:
  - Breast Cancer Screening
  - Type I Diabetes – Summary Alert and Detailed Alert
  - Type II Diabetes – Summary Alert and Detailed Alert
  - Sepsis Awareness – Summary Alert and Detailed Alert
  - Fall Prevention – Summary Alert and Detailed Alert
  - Drug Recall Alert
  - Flu Season Reminder
  - Adult Immunization Schedule
  - Stroke – Updated

- The Office of Integrated Health holds monthly educational meetings with nurses working in community DD settings. Office of Integrated Health conducted skin integrity trainings in all regions of the state
  - November 9-11, 2017: HPR5
  - December 7-9, 2017: HPR2
  - October 13, 2017:(HPR2)
  - February 8-10, 2018: HPR1
  - March 22-24, 2018: ;HPR4
  - April 12-14, 2018: HPR3

- During SFY 2017, the MRC made considerable progress in improving the capture of information surrounding each death and doing so in a more timely fashion. Processes were put in place for the identification of offices that have information about an individual scheduled for review; deadlines were established for posting information; and a process to track compliance with the new requirements was developed and is currently in the testing stages. The MRC additionally adopted the use of a written report format for the presentation of each death. These combined efforts have resulted in more robust deliberations by the MRC and more informed decisions as to cause of death, whether the death was expected or unexpected and how to address issues surrounding the death.

- During SFY 2017, a new format for recording minutes was put in place, which allows for a more detailed description of deliberations, decisions, and actions taken by the MRC. The MRC established new processes for tracking the actions taken in response to the recommendations and established procedures to follow-up with offices that have not taken recommended actions.

- The MRC developed procedures for collecting and tracking additional information about a death. The information capture process was implemented in SFY2017 and tracking began at the beginning of SFY2018. Additional information tracked includes Issues (Safety; Delay in Action; No Medical Plan/Protocol; Equipment Missing/Failure; Communications Breakdown; Licensing Regulations Cited; Lack of Follow-up; and Failure to Provide Care) and Documents Received and Used. The MRC tested the capture of additional information about the eight medical conditions most frequently related to the death (Sepsis; Constipation/Bowel Obstruction; Falls and Fractures; Aspiration Pneumonia; Urinary Tract Infections; Dehydration; and Seizures) but this was discontinued because there were questions about the reliability of the information. The MRC is now considering how to reliably capture this additional information.

- The MRC made a recommendation to the OneSource Data Warehouse to work with the Virginia Department of Health (VDH) to capture cause of death information from the death certificate. The Data Warehouse team entered into an agreement with the VDH for the electronic transfer of this information and initiated work on the data transfer process. The transfer of data is to be tested and operationalized in SFY 2018. This data will include not only the primary cause of

death but up to four contributing causes of death, which will enable the MRC to capture more reliable information on medical conditions associated with a death.

- In SFY 2017, the MRC continued its recruitment efforts to locate an independent nurse practitioner to serve on the committee. The MRC was able to recruit a clinician who is in independent practice. The individual began her participation on the MRC on April 12, 2018. In addition, the MRC confirmed the Assistant Director of Human Rights and the DBHDS Chief Psychopharmacologist as new members.

V. Closing

Key Findings

- There was an overall decrease in the number of deaths in SFY 2017.
- Cardiovascular Disease, which includes Sudden Cardiac Death and Cardiovascular/Heart Disease, and Pneumonia were the top two leading causes of known death (hereafter referred to as death unless otherwise specified) for individuals with DD in Virginia.
- Cardiovascular disease was the leading cause of death and the leading cause of unexpected death for 2015 through 2017. This is consistent with findings in the general U.S. general population, where heart disease was the leading causes of death in 2015 (Centers for Disease Control and Prevention, 2016).
- Sudden cardiac death was the leading cause of death for individuals in congregate and institutional living arrangements in the community; among adults with DD between the ages of 18 and 70; for males; and it was the leading cause of unexpected deaths.
- Pneumonia and respiratory disorders were the leading causes of death in state facilities for SFY 2015-2017. Pneumonia was one of the three leading causes of death among individuals 81 years and older in all settings; it was the leading cause of death for women; and it was the leading cause of unexpected death among individuals in hospice care.
- The cause of death classified as Unknown remained high in 2017. When the category of Unknown is included in the calculation of causes of all death, it ranks first for individuals who died in independent living situations, for black males and for individuals under the age of 18. It ranked as the second leading cause of death for all individuals receiving services.
- During SFY17, there were four deaths attributed to probable suicide in the study population. A closer examination of the deaths by probable suicide found that three were male and one was female. All were between the ages of 15 and 26 and all died of asphyxiation by hanging. Each of the individuals had been diagnosed with either a bipolar disorder or depression and three of the four had a diagnosed seizure disorder. One individual was in an out-of-state residential placement, another was receiving services in an in-state group home and two were living in private homes. All four individuals were receiving some level of behavioral health services at the time of their deaths.
- Four deaths were attributed to post-operative complications. Three of the deaths were the result of complications of bowel surgery and one was a death following surgery on the lungs. Three deaths occurred in the hospital and one death occurred following discharge. This death was due to a surgical complication that led to a steady decline.

Discussion

During SFY 2017, the MRC took steps to reduce risk for the leading causes of death by recommending education and training to help reduce the risk of mortality. The Office of Integrated Health had taken the lead in preparing training resources for nurses and non-nursing providers through Health and Safety Alerts and by offering on-site training to community nurses and other provider staff. Although it is not possible to evaluate the impact of such training on changes in mortality, these training programs nevertheless are valuable resources for community providers and state training centers because they provide critical information that can help to reduce the risk of death.
http://www.dbhds.virginia.gov/office-of-integrated-health#

The MRC continued to develop, test and refine processes and protocols. These enhancements to the basic MRC process resulted in more robust and clinically meaningful evaluations of each death, improved data capture, and ongoing monitoring to ensure that MRC recommendations are acted upon. At the same time, the MRC raised questions about how to best capture information for mortality reviews for individuals who are living independently. The number of individuals living independently is increasing each year as the community services system is developed but there is often little documented information available to the Case Manager (CM) and the MRC about the medical and other services these individuals receive from independent practitioners. Some individuals do not authorize the CM access to this information and the CM must rely on the individual to provide information about changes in health status, medication changes, and other changes in health or living situation. Even when there is documentation by the CM, it is not the daily or weekly documentation available from other residential settings. The MRC has and will continue to explore potential options for more detailed information in a manner that respects the individual's privacy and self-determination.

The MRC's ongoing improvements to the Mortality Review Tracking Tool (MRTT), which is the repository of information about each death, has provided more detailed and more meaningful data that is critical for the identification of patterns and issues as they relate to mortality. Despite its value to the MRC, the MRTT is an Excel program with limited capabilities. The DBHDS must consider the value of investing in a more robust system that is easier to navigate and to use for reporting purposes.

The SFY2017 data results indicate that overall the number of deaths decreased this year. There was no identified reason for this shift and it could not be attributed to changes in the reporting of deaths, which has improved over the last three years. The SFY2017 data additionally noted changes in the leading causes of deaths in the last three years. While the reasons for these shifts are not clear, it is highly likely that these are the byproducts of improved information, which allowed the MRC to conduct more clinically meaningful reviews of the deaths.

The leading cause of death among individuals with DD in Virginia, cardiovascular disease, is consistent with findings in the general U.S. general population, where heart disease was the leading causes of death in 2015 (Centers for Disease Control and Prevention, 2016). While pneumonia, the second leading

cause of known death, was not among the top ten causes of death nationally, a 2015 review in Hawaii found similarly high ranking for deaths attributable to pneumonia among those with DD compared to the general population. The report stated that individuals with DD may have co-morbid conditions such as cerebral palsy, which can increase dysphagia, putting individuals at increased risk for aspiration. (Okamoto, 2016). These findings suggest the need for both short-term interventions to address deaths by pneumonia as well as long-term strategies for lifestyle changes that reduce the risk of cardiovascular disease among individuals with a developmental disability.

The findings showed that during SFY2017 there were four potential suicides among individuals with a DD in the Virginia services system. Historically, death by suicide was not considered a risk for individuals with a developmental disability. However, there is a growing body of research to show that children and adolescents with DD are at risk of developing psychiatric conditions, including depression, bi-polar disorder and psychosis, and at a rate that is 2.89-4.5 times that of children in the general population (Ludi, 2012). While suicide rates among individuals with DD may be lower than in the general population, the rates of suicide risk factors are higher (Giannini, 2010). Most researchers agree that, while the risk of suicide among individuals with a developmental disability is a highly nuanced area of research it is nonetheless a pressing public concern.

Three specific data reviews were requested by the MRC following its review of the previous mortality report. These were: training center discharges by residential category, post-operative complications, and mortality by age, children, adults and the elderly. None of the data evaluations showed any clear patterns nor did they raise questions for further study. The MRC will continue to collect and evaluate these data to identify possible long-term trends.

Next Steps

- Explore the relationship between DBHDS and Adult Protective Services to identify areas for information sharing and intervention when there is suspected abuse or neglect.
- Develop operating procedures to document the growing number of processes and protocols used by the MRC.
- Develop data definitions for cause of death categories and for key terms in the Mortality Review Presentation Form prior to beginning SFY 2019 reviews. This is intended to increase the reliability of the data by ensuring more consistent use of the "cause of death" categories.
- Review the SFY2017 deaths to identify how frequently the issue of provider competence is identified and the context in which it is raised.
- Beginning with SFY2019, review the causes of death from death certificates against the MRC's determination of cause of death.

- Conduct a review to determine how DD systems are addressing the risk of suicide among individuals with DD, especially among children, adolescents and young adults.
- Add to the MRTT a separate cause of death category for choking.
- Reach out to providers at round-tables and other, similar meetings to recommend that mortality prevention projects be addressed at their meetings.
- Further examine the decrease in the number of deaths by cancer in SFY 17.

VI. References

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Definitions

The following definitions for Residential settings for individuals on the DD waivers were established for the purposes of this report.

- **Congregate/Group Home** means an individual is on the community living (CL) waiver AND receiving congregate/group home residential services.
- **Sponsored Residential** means an individual is on the CL waiver AND receiving sponsored residential services.
- **Living Independently** means an individual is on either the CL or family and individual support (FIS) waiver AND either lives alone, lives in their own house/apartment (whether leased or not), or lives independently.
- **Supported Living** means an individual is on either the CL or FIS waiver AND receiving supported living services.
- **Building Independence** means an individual is on the BI waiver AND/OR receiving shared living or independent living services.
- **Living with Family** Individuals that are not determined to be in any other category.
- **Unknown** Residential setting is unknown.

Supports Intensity Scale (SIS) seven level assessment framework:

- **Level 1**: Adults in this level have some but largely mild need for support, including little to no support need for medical and behavioral challenges. They can manage many aspects of their lives independently or with little assistance. This includes activities like eating or dressing, as well as daily living activities such as shopping or going out into the community.
- **Level 2**: Adults in this level have modest or moderate support needs and little to no support needs for medical and behavioral challenges. Although they need more support than those in Level 1, their support needs are minimal in a number of life areas.
- **Level 3**: Adults in this level have little to moderate support needs as in Levels 1 and 2. They also have an increased, but not significant, support needs due to behavioral challenges.
- **Level 4**: Adults in this level have moderate to high need for support. They may have behavioral support needs that are not significant but range from none to above average.
- **Level 5**: Adults in this level have high to maximum support needs. They may have behavioral support needs that are not significant but range from none to above average.
- **Level 6**: Adults in this level have significant need for medical support but also may have similar support needs to individuals in Level 5. Individuals in this level may have some need for support due to behavior that is not significant but may range from none to above average.

- **Level 7**: Adults in this level have significant behavioral challenges, regardless of their support need to complete daily activities or for medical conditions. These adults typically need significantly enhanced supports due to their behavioral challenges.