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Results of analyses of deaths in FY17 of service recipients of Virginia Department of Behavioral Health & Developmental Services (DBHDS)

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Executive Summary

The Center of Developmental Disabilities Evaluation and Research (CDDER) at the University of Massachusetts Medical School has prepared this report regarding mortality of service recipients of the Virginia Department of Behavioral Health & Developmental Services (DBHDS), under contract with the Civil Rights Division of the United States Department of Justice. The analyses conducted for this report were performed independently by CDDER on the information provided from DBHDS and other sources as described. This report provides information on people receiving services from DBHDS during the fiscal year 2017 (July 1, 2016 through June 30, 2017), including those who were known to have died during the 2017 fiscal year period.

Monitoring patterns related to deaths of people receiving services is one component of a comprehensive quality assurance and improvement system. Patterns of deaths help inform areas of service strength, as well as areas that may be in need of systemic quality improvement, such as systems focused on maintaining health, managing chronic health conditions, preventing or mitigating adverse medical conditions, accessing appropriate healthcare services in a timely fashion and preventing accidental and intentional injuries.

Over recent years, DBHDS has made positive improvements in its efforts to collect, analyze and act upon mortality-related information regarding to the circumstances and related service experiences of people receiving certain services, such congregate community-based residential services. It is notable that DBHDS has formed a statewide Mortality Review Committee to review these deaths and is working to improve the quality of the mortality reviews conducted as well as data collection and analysis of mortality data. DBHDS has also prepared three annual reports with its own analyses of mortality data and related recommendations. This report covers a broader review of mortality of DBHDS service recipients and will use additional methods beyond those employed by DBHDS to assess and supplement the completeness and quality of the mortality data used as the basis for analyses. Recommendations will be presented in this Executive Summary related to ways DBHDS can continue to improve its processes and use of mortality data.

Methodology and Results

For FY17, 250 deaths were reported through DBHDS's Computerized Human Rights Information System (CHRIS) and supplemental information was reported about deaths occurring in training centers. In an effort to validate that all deaths of DBHDS service recipients were included in information reported through these DBHDS systems, data were compared to the Commonwealth's death certificates and to the federal Social Security Death Index. In addition to the 250 deaths reported by DBHDS for this time period, an additional 18 deaths, or 7.2% of all deaths identified, were identified through the validation methods. [1]

This yielded a total of 268 deaths occurring within FY17 for people receiving services from DBHDS, for a crude mortality rate of 20.4 per thousand people. The average age of death across all DBHDS service recipients was 48.7 years. The rate of death by age group for people living independently, in community-based congregate living settings and state training centers generally increases over ascending age as expected due the increasing risk of mortality as age increases. Males exhibited a lower rate of death

[1] Deaths of individuals who are assigned a waiver slot but who are not receiving DBHDS-licensed services are not currently required to be reported in CHRIS; nonetheless, mortalities of all individuals who are assigned a waiver slot are analyzed in this report in alignment with the state's responsibility to protect the health and welfare of waiver recipients under Section 1915(c) of the Social Security Act.

(19.0 per thousand) than females (22.5 per thousand), as well as a lower average age at death (47.2 years) compared to females (50.7 years). In comparison with other state systems serving people with intellectual and developmental disabilities, the crude mortality rate for DBHDS for both males and females was higher than other comparable states.[2]

The crude mortality rate for DBHDS was lowest for those living in more independent settings (people receiving only crisis services and no waiver services, people living in their own home), and increases as the level of support provided in each setting increases (i.e., training centers and ICF-IIDs provide some of the highest levels of support compared to other settings and have the highest crude mortality rates).

The leading categories of causes of death were heart disease, followed by influenza and pneumonia. Two causes were tied for third: cancer and septicemia. Aspiration pneumonia ranked fifth. The sixth leading cause of death category was unintentional injury (or accidents). A total of 21 deaths (7.8% deaths) were categorized as due to an unknown cause. In comparison to select other state systems serving people with intellectual and developmental disabilities, DBHDS's rate of death to heart disease was in between other state rates. However, mortality rates due to cancer, influenza and pneumonia, aspiration pneumonia and septicemia for DBHDS were all higher than the comparison state disability systems. Compared to patterns observed in the general population of Virginia and the United States, rates of death from cancers and Alzheimer's disease were similar, and rates of chronic lower respiratory disease were lower for DBHDS service recipients.

Recommendations

Process-based recommendations

1. Ensure the full names of decedents are reported within CHRIS (rather than truncated versions) to facilitate comparison to other data source and validation.
2. External validation of deaths reported within DBHDS reporting systems (CHRIS and Training Center deaths) demonstrated an opportunity to improve the accuracy of reporting within these systems. A majority of the unreported deaths for DBHDS service recipients were found by comparing DBHDS reports to Virginia's vital statistics data (death certificates) for DBHDS service recipients. As the Virginia Health and Human Resources Secretariat oversees both DBHDS and collection of the Commonwealth's vital statistics data, the comparison of these dataset is recommended as an efficient method for DBHDS to monitor accuracy of reporting in the future.
3. It is also recommended that DBHDS access the Commonwealth's death certificates to aid the mortality review committee and any preparers of aggregate mortality reports to obtain a more complete perspective on each decedent's cause of death. The addition of this information may be useful in reducing the number of deaths reported as due to unknown causes.
4. To ensure that categories of causes of death are defined in a manner that make them comparable to state and national data, DBHDS should be sure to follow the tabulation guidance of the NCHS/CDC in analyzing and reporting on causes of death. (See references.)
5. DBHDS should consider collecting data about mortalities of service recipients living in congregate settings that are not licensed by DBHDS, including state institutional settings and

[2] CDDER compared the data discussed in this report to data from other public state-run I/DD systems where available. Few states report data about public I/DD systems, and states serve different types of populations. Accordingly, CDDER used the publicly available data from states with the most comparable service populations to Virginia's system.

nursing facilities, to facilitate a more informed perspective about mortality patterns and their corresponding implications for service improvements for the full population of DBHDS service recipients.

Systemic improvement recommendations

1. Both choking and aspiration (as part of unintentional injuries) and aspiration pneumonia were major contributors of mortality in DBHDS service recipients in FY17. While the underlying drivers of risk in these areas can be varied in people with I/DD, and choking/aspiration may not always be preventable, these findings suggest that there may be room for quality improvement in the identification and management of choking and aspiration-related risks.

   It is recommended that DBHDS review the availability of educational materials for service providers (including both licensed and unlicensed settings) as well as family members and guardians on the risk and mitigation strategies for choking and aspiration, and the availability and access to risk screens, swallowing studies, etc. by qualified clinical staff. There may also be benefit in DBHDS using its mechanisms for alerting providers or otherwise raising awareness on the identification and management of risks associated with choking and aspiration, specifically in people with I/DD. For example:
   a. Numerous public web-based resources have been developed by other state I/DD systems to train I/DD service providers on this topic.
   b. Consider strategies tied to each opportunity to intervene in the pathway from identifying risk, to managing risk, to identifying and responding to occurrences of choking or aspiration to monitor for and intervene in the development of infections.
2. Influenza and pneumonia were also major contributors of mortality. It is recommended that DBHDS review with case managers and providers preventive strategies including annual vaccination and infection control procedures during flu seasons, as well as recognition of signs and symptoms of respiratory infections and prompt treatment of respiratory infections.
3. Septicemia was another major contributor to mortality. Because septicemia typically starts as an infection in a specific area before it spreads, there is often an opportunity to recognize the signs and symptoms of the underlying infection and seek timely treatment. As the majority of deaths due to septicemia in FY17 started as aspiration pneumonias or urinary tract infections, it is recommended that DBHDS ensure that it is undertaking efforts to build awareness and skills in service providers in the prompt recognition and action regarding signs and symptom of illness – and particularly these infections.
4. Ensure that DBHDS service recipients and the people who support them receive information on the preventive screenings they may need at their annual physicals, particularly related to cancer screenings.
5. While there were a small number of deaths due to suicide (4 in FY17), the rate of death due to suicide is higher than comparison groups. Because only one year of data is available, it was not possible to determine whether this is reflective of a larger pattern or trend. This is an area that DBHDS should watch in the future, particularly because even small patterns of this cause of intentional self-harm may have important implications for mental-health related service needs in, and service delivery for, the population.

Introduction

The Center of Developmental Disabilities Evaluation and Research (CDDER) at the University of Massachusetts Medical School has prepared this report regarding mortality of service recipients of the Virginia Department of Behavioral Health & Developmental Services (DBHDS), under contract with the Civil Rights Division of the United States Department of Justice. The analyses conducted for this report were performed independently by CDDER utilizing the information provided from DBHDS and other sources as described.

Monitoring patterns related to deaths of people receiving services is one component of a comprehensive quality assurance and improvement system. Patterns of deaths, in comparison with benchmarks, help inform areas of service strength, as well as potential needs for improvement because they represent critical incidents (deaths) and are also likely to reflect underlying patterns in morbidity (illness, accidents, etc.). These patterns typically can be utilized to identify areas for targeted quality improvement efforts in human services such as maintaining health, managing chronic health conditions, preventing and mitigating adverse medical conditions, accessing appropriate healthcare services in a timely fashion and preventing accidental and intentional injuries.

Over recent years, DBHDS has made positive improvements in its efforts to collect, analyze and act upon mortality-related information regarding to the circumstances and related service experiences of people receiving certain services, such congregate community-based residential services. It is notable that DBHDS has formed a statewide Mortality Review Committee to review these deaths and is working to improve the quality of the mortality reviews conducted as well as data collection and analysis of mortality data. DBHDS has also prepared three annual reports with its own analyses of mortality data and related recommendations. As discussed in more detail below, this report covers a broader view of mortality of DBHDS service recipients and will use additional methods beyond those employed by DBHDS to assess and supplement the completeness and quality of the mortality data used as the basis for analyses.

Methods

This report provides information on people receiving services from DBHDS during the fiscal year 2017 (July 1, 2016 through June 30, 2017), who were known to have died during the 2017 fiscal year period.

Deaths were included in this report for people who were recipients of a Home and Community-based Services waiver and/or of any one or more services from DBHDS at the time of their death. The report also includes one person,[3] who was known to be on the waiting list for DBHDS services at the time of death.[4] Services include but are not limited to developmental disability (DD) waivers, DBHDS-licensed services, crisis services, DBHDS-operated facilities and training centers. To be included in this report, deaths also needed to be reported to DBHDS through DBHDS's Computerized Human Rights Information System (CHRIS) system or through Training Center death tracking systems or found during external validation activities conducted by CDDER (described below).

Any information regarding the size of the populations or subpopulations of people served was provided by DBHDS and was not independently verified by CDDER.

[3] It is unclear why this person's death was provided by DBHDS since only deaths of those receiving services were requested.

[4] One reported death was excluded from the report because the person and family had refused all services from DBHDS over multiple attempts.

External Validation

Multiple efforts were used to attempt to validate that all deaths of DBHDS service recipients were included in information reported through DBHDS's Computerized Human Rights Information System (CHRIS) and supplemental information about deaths occurring in training centers. Data was requested from DBHDS on any person who was discharged from services during the year of FY17 to validate that the CHRIS reports of deaths contained information on any person who left services due to a death. The Commonwealth provided a list of people who received services on a DD waiver and were discharged during FY17 from waiver or crisis services, as well as a list of people actively receiving crisis services not provided through the DD waivers or discharged from these services during the year. This analysis includes all deaths of service recipients that CDDER was able to identify regardless of whether they were reported through CHRIS.

It was only possible for CDDER to conduct a partial external validation through the methods described below. Because complete data was not available for a full validation, it is important to note that deaths could not be fully validated for the following groups:

- DBHDS service recipients who stopped receiving DBHDS services during FY17, but for whom a valid social security number was not collected by DBHDS,
- People with developmental disabilities residing in State institutional settings other than Training Centers such as State Psychiatric Hospitals, or residing in non-DBHDS institutional settings such as inpatient care, nursing home/physical rehabilitation, residential treatment/alcohol and drug rehabilitation, and other institutional settings that are not specifically for people with developmental disabilities.

Therefore, deaths of people with developmental disabilities that occurred in these scenarios may not be included in this report if they were not reported through CHRIS and were not captured among DBHDS tracking systems for deaths in Training Centers. This validation also does not include any people who were on the waiting list for services but were not actively receiving services during this fiscal year.[5] Because only a partial validation could be conducted, the information provided in this report should be viewed with caution and considered to reflect the minimum mortality rates.

Social Security Death Index (SSDI)

DBHDS provided information regarding discharges from waiver services during FY17 that included social security numbers. Because a social security number is not a required field in the crisis data set, only a portion of people discharged from crisis services had this information available. The list with social security numbers was matched to the Social Security Death Index (SSDI), a database of people with social security numbers who are known to the Social Security Administration to have died, and any resulting verified reports of deaths within SSDI were cross-checked for reporting within CHRIS.

Virginia Department of Health Vital Statistics

Electronic data from the Commonwealth's death certificates was requested pertaining to all deaths that occurred for DBHDS service recipients with I/DD during FY17. Decedents were matched to CHRIS reporting.

[5] A relatively large number of people are on the waiting list for DBHDS services (approx. 11,000 people in fiscal year 2017 (DBHDS Mortality report)

Validation Results

In addition to the 250 deaths reported by DBHDS for this time period, an additional 18 deaths, or 7.2% of all deaths identified, were identified through the validation methods described above. The comparison between the DBHDS reported deaths and the Commonwealth's vital statistics data, also housed within Health and Human Resources Secretariat, did contribute information on a majority of the deaths of people not reported through CHRIS and may yield a relatively efficient method of validation for DBHDS in its mortality reporting going forward.

Some data quality issues were observed in the information reported within CHRIS that may limit the ability to conduct future matches between the Commonwealth's systems.[6]

Mortality Results

In FY17, DBHDS served approximately 13,137 people in the middle of this fiscal year across settings.[7] The population served within each service setting is shown in Table 1. See the section on deaths by service setting for a definition of each setting.

Table 1: Population served by service type

Setting	Population Served
DD Waivers	11,957
State Training Center (including HDMC)	353
ICF- IID	538
Crisis services	289[8]
TOTAL	13,137

A total of 268 deaths were identified as occurring within the time period of FY17 for people receiving services from DBHDS, for a crude mortality rate of 20.6 per thousand people.

Table 2: Mortality profile

DBHDS	FY17: July 1, 2016 to June 30, 2017
Population Served	13,137
Deaths	268
Crude Mortality Rate (per thousand)	**20.4**

Deaths by Age

Table 3 presents mortality information by age group. The average age of death across all DBHDS service recipients was 48.7 years, with a standard deviation of 19.9. The median age of death was 54 years, showing a skewness in the distribution of age among deaths toward the older age groups.

Information about the ages of the full population of people included in this report was not available, therefore age-specific mortality rates could not be calculated for the entire group. Instead, age-specific mortality rates are presented for a subset of people, including only those living independently, in

[6] For example, the names of some decedents within CHRIS were truncated to the first 4 letters of their first and last name.

[7] A mid-year population is used to estimate the service population, as the service population changes over time.

[8] Population is approximated based on the number of admissions and discharges to this service over the course of the year that was provided by DBHDS. This data should be interpreted with caution because of the high rate of turnover and short length of stay in this service.

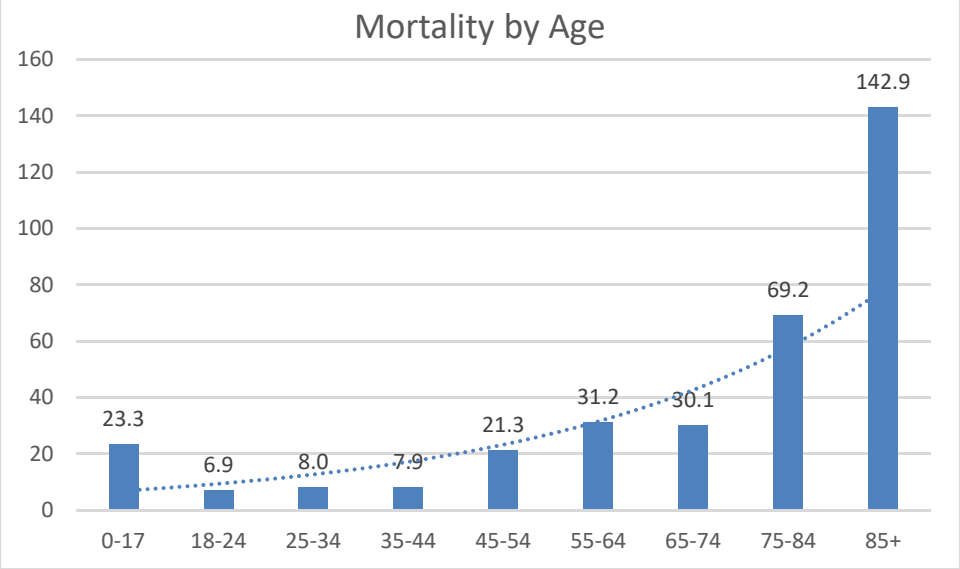
community-based congregate living settings and in state training centers (see service location section, including Table 5, for more detailed descriptions of these settings).

Table 3: Mortality by Age

	All Deaths		Deaths of people living independently, in community-based congregate living settings and state training centers		
Age (years)	Deaths		Deaths	Population	Crude Mortality Rate (per thousand)
0-17	24		21	902	23.3
18-24	17		12	1,741	6.9
25-34	27		24	2,989	8.0
35-44	20		17	2,015	8.4
45-54	52		43	2,022	21.3
55-64	78		54	1,729	31.2
65-74	32		22	732	30.1
75-84	15		11	159	69.2
85+	3		3	21	142.9
Total	268		207	12,310	16.8

As shown in Figure 1, the rate of death by age group for people living independently, in community-based congregate living settings and state training centers generally increases over ascending age as expected due the increasing risk of mortality as age increases. The trendline shows more substantial increases in mortality rate between age groups of advanced age. There is an increased risk of mortality observed for children; CDDER does not have sufficient information to discern how much of this increased risk is due to the etiology of the children's disabilities and/or related factors, and how much is due to other factors.

Figure 1



The above figure only includes deaths of people living independently, in community-based congregate living settings and state training centers.

Deaths by Gender

Table 4 presents mortality patterns by gender. Males exhibited a lower rate of death (19.0 per thousand) than females (22.5 per thousand), as well as a lower average age at death (47.2 years) compared to females (50.7 years).

Table 4: Mortality by gender

Gender[9]	Deaths	Population[10]	Crude Mortality Rate (per thousand)	Average Age at Death (years)
Male	150	7,882	19.0	47.2
Female	118	5,255	22.5	50.7
Total	**268**	**13,137**	**20.4**	**48.7**

Deaths by Service Location

The locations of where people included in this report receive services have been categorized. Each category is described below. Some of these categories and their descriptions are presented in a modified version from those used in DBHDS's own mortality report for this period of time (see references).

- **Own Home** 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.
- **Community-based congregate support** 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.
- **State Training Center** includes training centers, including Hiram Davis Medical Center.
- **State Institutional Setting – Other** include all other types of state-run institutional settings such as state hospitals and mental health facilities where an individual had a I/DD diagnosis at the time of death based on ICD-10 codes.
- **ICF-IID** is a residential Intermediate Care Facility that specializes in providing services to people with intellectual disabilities.
- **Non-DBHDS Institutional Setting**[11] is a non-state operated setting, excluding ICF-IIDs, that provides comprehensive and individualized health care and rehabilitation services to individuals. These settings are not specifically designed for people with intellectual and developmental disabilities. Institutional settings include inpatient care, nursing home/physical rehabilitation, residential treatment/alcohol and drug rehabilitation, and other institutional settings.

[9] In some cases, gender was imputed based on name due to missing data. Quality issues were observed with the coding of gender on the Commonwealth's vital statistics death certificates.

[10] Gender breakouts were not available for the populations served in every setting. These population figures are approximated based on the total number of people served across settings using gender splits that were observed to be nearly identical across service location-specific data provided.

[11] If it was clear from the documentation related to the death that person had resided in the Non-DBHDS Institutional Settings less than 30 days prior to their death, they were categorized under their prior living situation. Because CDDER was not able to fully validate deaths in this setting, the information presented may be an incomplete representation of mortality.

- **Crisis Service Recipients** are recipients of crisis services who were not also receiving DD waiver services. These individuals frequently come from the waiting list for DBHDS supports.
- **Unknown** means the residence type was unknown, based on information provided by DBHDS. In some cases, the residency type was unknown by DBHDS at the time of death and MRC review. In other cases, the residence type may have been known by DBHDS (e.g., for a number of waiver recipients) but was not able to be categorized based on information provided to CDDER by DBHDS.

Table 5 presents mortality patterns by service setting. Of the settings for which mortality rates could be calculated, the crude mortality rate is lowest for those living in more independent settings (crisis services, own home), and increases as the level of support provided in each setting increases (i.e. training centers and ICF-IID provide some of the highest levels of support compared to other settings). This pattern is generally reflective of the increased care needs of people living in settings with higher support. The crude mortality rate for individuals receiving DD waiver services, which includes the own home setting and the community-based congregate supports as well as the waiver recipients living an unknown setting, is at least 16.4 deaths per thousand people.[12]

Table 5: Mortality by service setting

	No. Deaths	**Population**	**Crude Mortality Rate** (per thousand)	**Avg. Age of Death**
Own Home	99[13]	7,389	13.4	39.6
Community-based congregate supports	92[14]	4,568	20.1	54.0
State Training Center	15	353	42.5	61.8
State Institutional Settings - Other	1	Unknown	Unknown	*
ICF-IID	15	538	27.9	57.7
Non-DBHDS Institutional Settings	13	Unknown	Unknown	55.5
Crisis Service Recipients	1	289[15]	3.5	*
Unknown	32	Unknown	Unknown	50.0
Unknown – Known Waiver Recipient	7	Unknown	Unknown	40.7
Unknown – Service Receipt Unknown	25	Unknown	Unknown	52.6
Total[16]	**268**	**13,137**	**20.4**	**48.7**

*Data hidden to prevent ability to identify underlying individuals

[12] Actual crude mortality rate may be higher if any of the people living in unknown settings were DD waiver recipients. This rate could be as high as 18.9 per thousand if all of the people in this unknown setting category were DD waiver recipients.

[13] Actual number of deaths for this category may be higher due to Community Living (CL) waiver recipients with insufficient information provided to classify residential setting. Number of deaths may be as high as 105 and rate of deaths may be as high as 14.6 per thousand.

[14] Actual number of deaths for this category may be higher due to CL waiver recipients with insufficient information provided to classify residential setting. Number of deaths may be as high as 99 and rate of deaths may be as high as 20.7 per thousand.

[15] Population is estimated based on the number of admissions and discharges to this service over the course of the year that were provided by DBHDS. This data should be interpreted with caution because of the high rate of turnover and short length of stay in this service.

[16] Due to missing information about small subpopulations residing in certain settings, the total population likely underestimates the total number of people with I/DD across these settings by a small amount.

Causes of Death

The causes of death[17] were categorized based on the World Health Organization's International Classification of Disease 10th edition (ICD-10)[18] and were tabulated in accordance with guidance from the U.S. Centers for Disease Control and Prevention (National Center for Health Statistics/CDC). Where possible, a single underlying cause of death was selected for the purpose of this classification. See Appendix 1 for more information about how causes of death, based on ICD-10 codes, were categorized. Information used to determine the causes of death was obtained from DBHDS's CHRIS reporting system, state training center incident reporting system, notes from DBHDS's mortality review committee which reviews a range of support-related documents pertaining to the person, and Death Certificates which includes causes categorized by ICD-10 and will have considered results of autopsies and toxicology screenings when conducted. The amount of information available for each death varied, and CDDER reviewed all information provided across these sources to determine the best category for the death according to the ICD-10 system and CDC's tabulation specifications.

Table 6 presents the leading causes of death for people included in this report. The leading cause of death was heart disease, followed by influenza and pneumonia. Two causes were tied for third: cancer and septicemia. Aspiration pneumonia ranked fifth. The sixth leading cause of death was unintentional injury (or accidents). For further context about how the frequency of these causes and their cause-specific mortality rates compare to other populations, see the Benchmarking section below.

Table 6: Mortality by cause

Ranking	Cause of Death	No. of Deaths	Percent of deaths	Rate of Deaths (per 1,000 people served)
1	Heart Disease	35	12.9%	2.7
2	Influenza and pneumonia	21	7.7%	1.6
3	Cancer, Septicemia	20 each	7.4% each	1.5 each
5	Aspiration Pneumonia	19	7.0%	1.4
6	Unintentional injury (Accidents)	18	6.6%	1.4
7	Congenital malformation, Cardiopulmonary Arrest/Seizure	11 each	4.1% each	0.8 each
9	Cerebral Palsy	9	3.3%	0.7
10	Gastrointestinal, Stroke	8 each	3.0%	0.6
12	Renal	7	2.6% each	0.5 each
13	Diabetes	6	2.2%	0.5
14	Dementia, Chronic Respiratory Failure	5 each	1.8% each	0.4 each
	Unknown	21	7.8%	

[17] "A cause of death is the morbid condition or disease process, abnormality, injury, or poisoning leading directly or indirectly to death. The underlying cause of death is the disease or injury which initiated the train of morbid events leading directly or indirectly to death or the circumstances of the accident or violence which produced the fatal injury." (NCHS instruction Manual)

[18] This is the same classification system used by state vital statistics departments and the U.S. Centers for Disease Control and Prevention National Center for Health Statistics (NCHS) which prepare state and U.S. mortality reports, respectively.

A total of 21 deaths (7.8% of deaths) were categorized as due to an unknown cause. In some cases, the death certificate listed the death as due to unknown causes. In other cases, insufficient information was available to determine the cause. In other situations, there was insufficient information to categorize the cause with certainty. Because of the number of deaths that had an unknown cause, the rankings in Table 5 must be viewed with caution because if any of the deaths with unknown causes are due to the causes listed in Table 6, the rankings could shift. Similarly, the percentage and rates of death for these causes should be considered as minimums, but could be higher in reality due to the deaths of unknown causes.

Pneumonia

Deaths with an underlying cause of pneumonia (of any type) accounted for at least 40 deaths, or about 15% of all FY17 deaths. Based on the ICD-10-related categories commonly used in public mortality reports, deaths to pneumonia are distinguished as either (a) pneumonia due to acute infection (Influenza and Pneumonia) or unknown etiology or (b) pneumonia due to aspiration of liquids and solids (Aspiration Pneumonia). However, because pneumonias of undetermined type are categorized under the 'influenza and pneumonia' category it is possible that some of these pneumonias were aspiration pneumonia that could not be categorized as such due to insufficient information or lack of a specific diagnosis. It is strongly suspected from the information provided that numerous of the pneumonias of unknown type did involve aspiration because the decedents had a history of aspiration and/or known swallowing disorders; therefore, the rate of death from aspiration pneumonia is likely higher than listed here. It is also important to note that an additional 14 deaths from septicemia involved pneumonia, frequently aspiration pneumonia, further emphasizing the contribution of this cause to mortality in the population served by DBHDS. Table 7 provides more information about pneumonia-related deaths.

Table 7: Pneumonia-related deaths

	No. of deaths	Rate of death (per 1000)
Pneumonia, type known	4	0.3
Pneumonia, type unknown	17	1.3
Pneumonia, aspiration	19	1.4

Cancer

Of the deaths due to cancer, the most frequent cause of cancer was colorectal cancer (4 deaths), which is notable because early detection screenings exist for this type of cancer. The remaining deaths from cancer were spread across different primary sites of the cancer. Numerous deaths from cancer involved metastatic cancers with secondary or greater locations. It is not fully known whether people with intellectual and developmental disabilities are at greater risk for certain types of cancers, or whether those cancers may occur at younger ages or present with greater severity because the literature that studies this population of people is limited. Of the research that does exist, studies suggest that people with intellectual disabilities of certain etiologies, particularly genetic-based disabilities, may be at increased risk of colorectal cancer and that it may develop at younger ages than in people without these disabilities (Willis et al. 2018, Lucci-Cordisco et al. 2005, Smith et al. 2006, Patja et al. 2001, Hill et al. 2003). Additionally, conditions with increased association to intellectual disabilities, such as chronic gastrointestinal problems, including infection with certain bacteria commonly found in group settings, may also be at increased risk for stomach and colorectal cancer (Wallace et al. 2002, Duff et al. 2001). Screening for early detections of cancers can be particularly important for people with intellectual and

developmental disabilities because the clinical presentation is frequently masked, resulting in late diagnoses and lower success rates in treatment (Willis et al. 2018).

Septicemia

Septicemia is a serious, life-threatening infection in a person's bloodstream that can cause very serious effects. Septicemia typically starts as an infection in a specific area that spreads across the body's systems through the bloodstream. The majority of deaths due to infections that became septic started as aspiration pneumonias or urinary tract infections (at least 14 deaths) for the people served by DBHDS who died during the fiscal year.

Injuries

Table 8 presents greater details on the deaths due to injuries, which are classically categorized first based on intent (intentional, unintentional, undetermined) and then by type. Of deaths due to unintentional intent (accidents), the most common cause was choking and aspiration with 13 deaths. Of the deaths due to falls, it is important to note that more deaths involved falls; however, the fall was not the underlying cause of the death (for example, someone fell while choking). Four deaths were due to suicide. There were zero deaths due to homicide, firearms or drug overdoses.

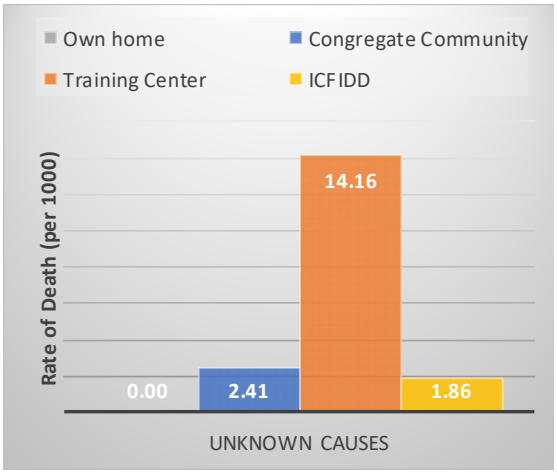
Table 8: Injury-related deaths

Intent	Subcategory	No. of deaths	Rate of death
Unintentional Injuries		18	1.4
	Choking and Aspiration	13	1.0
	Fall	1	0.1
	Poisoning	2	0.2
	Unknown	2	N/A
Homicide		0	0
Suicide		4	0.3

Alzheimer's disease and dementia

In total there were 3 deaths categorized as being due to Alzheimer's disease, and 5 deaths due to dementia. There was insufficient information provided about these dementia deaths to know if they were related to Alzheimer's disease. It is likely that some of the dementia deaths may be due to Alzheimer's disease, as multiple were in people with Down Syndrome which is related to a pre-disposition to Alzheimer's disease. Therefore, more complete information may change the total number and associated ranking of Alzheimer's disease as a cause of death.

Figure 2: Rate of deaths due to unknown causes by service setting



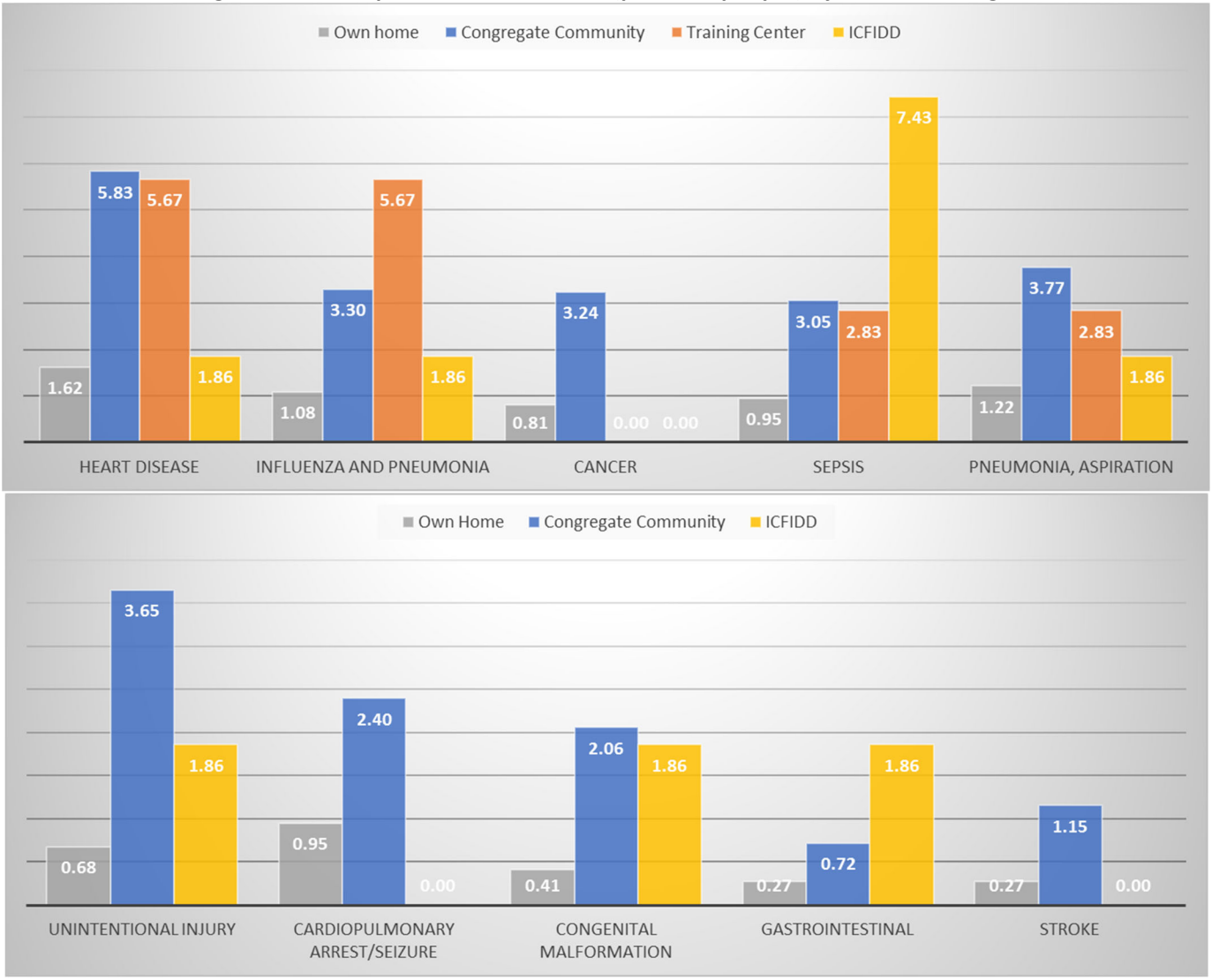
Causes of Death by Service Setting

In comparing causes of death across service settings, a few areas of caution should be kept in mind. First, the sizes of the populations served vary substantially across settings, and settings with small populations may have small numbers of people dying from specific causes, patterns which would be expected to vary

greatly across years. Second, the nature of the service needs of the recipients can vary as well and may influence the setting in which the people are served; in other words, people with greater support needs connected with specific service settings may also have a higher risk of mortality from natural causes connected to their need for services. Third, the information available for this analysis varied across settings. As a result, the rate of deaths that were due to unknown causes varied greatly by service settings which affects the ability to analyze accurate data for cause of death patterns. This limitation is particularly true for deaths from training centers, which had the highest rate of deaths due to unknown causes of any service setting given the available information.

The greatest similarities in causes of death patterns are seen between community-based congregate residential service settings and training centers across the leading causes of death. However, Training Centers had higher rates of death from Influenza and Pneumonia than other service settings. Rates of death from sepsis were highest in ICF-IID settings. Rates of death from unintentional injuries were highest in community-based congregate residential service settings.

Figure 3: Cause-specific Rates of death (per 1000 people) by Service Setting[19]



[19] Deaths in Training Centers are not presented graphically where the numbers of deaths were very small.

Benchmarking

To provide further context to the findings presented in this report, this section compares the DBHDS data to numerous external benchmarks. This section is provided to aid in the understanding of whether DBHDS FY17 findings are similar to or differ from expectations of mortality patterns for people with intellectual and developmental disabilities, as well as for the general populations.

People with intellectual and developmental disabilities may have different risks of dying, for example at earlier ages or from different conditions, than people without these disabilities. Some of this different risk can be related to the etiology of their disability (such as the cancer risks previously described related to genetic conditions); additionally, some people with these disabilities have complex co-morbidities (secondary health and behavioral conditions) that can increase their risk of dying. For this reason, benchmarking data is presented in this section from other populations of people with similar disabilities, as well as other people who live in the United States and who live in Virginia.

When data is compared to other external findings, care has been taken to use similar methodologies across data sources and to set up comparisons that are structured as similarly as possible to ensure valid comparisons are made.

Very little information is publicly available from other state agencies about deaths of people with intellectual and developmental disabilities. The data presented in this section from other state systems providing services to people with intellectual and developmental disabilities was selected from publicly available sources. In addition, the service system and data provided was reviewed to the extent possible with public information to ensure a reasonable degree of comparability. Some state comparisons were excluded because their service population was defined narrowly and was too dissimilar to the I/DD population served by DBHDS, or because the mortality data was not presented or tabulated in ways that facilitated comparison. In some cases, differences may exist between the best sources of comparisons and these differences are noted where found.

It is very important to recognize these limitations when reviewing the comparative benchmark data presented below. Benchmark data should be viewed with caution and should only be used as a very general guide for understanding the DBHDS findings. Patterns within the population served by DBHDS are not expected to exactly mirror any of the findings presented in this section.

It is also important to note that CDDER has very limited methods of risk-adjusting the comparisons made in this section. As described in the methods section, there is a substantial waiting list for services from DBHDS – one that is almost equal to the number of people who are actively receiving services. It is not known to CDDER whether and to what extent the people who receive services from DBHDS differ in terms of mortality-related risk factors from those who are on the waiting list for services. If mortality-related risks differ between the two groups, these differences may affect the comparison of DBHDS to other state I/DD service systems that provide services to a greater proportion of the population eligible for services. For example, if people who are served by DBHDS have greater support needs and/or greater co-morbid health management needs than those on the waiting list, a difference of this nature may cause DBHDS mortality rates to be relatively higher compared to states with smaller waiting lists that serve a broader array of people with I/DD.

Mortality, Gender, and Age Benchmarks

Mortality rates by gender and overall are compared in this section to other state systems that provide services to people with intellectual and developmental disabilities and publicly report on mortality of service recipients in Tables 9 and 10.

Table 9: Rate of death by gender: Comparisons across State I/DD systems

	VA DBHDS FY17 (all ages)	CT DDS FY2016 (all ages)	OH DDD 2014 (all ages)	IN DDRS CY2014 (all ages)		MA DDS CY14 (adults)
Males	19.0	13.2				15.0
Females	22.5	12.7				18.8
Total	20.4	13.0	9.3	18.4		16.6

By comparison, crude mortality rates for DBHDS are higher for males and females compared to patterns for service recipients in Connecticut. Overall crude mortality rates are higher in DBHDS than for Connecticut, Ohio, and Indiana state systems.

Massachusetts DDS at the time of its latest publicly available data (CY14) served only people with intellectual disabilities, therefore its mortality report does not include individuals with other types of developmental disabilities. This differs from DBHDS which reported on deaths of both children and adults and serves people with both developmental and intellectual disabilities. These differences from DBHDS would contribute to an expectation that Massachusetts DDS's crude adult mortality rates would be higher than DBHDS's crude all-age mortality rates because of the increased mortality risk associated with older ages. However, DBHDS's mortality rates were higher for both males and females and in total compared with Massachusetts DDS.

Table 10: Average Age of death by gender: Comparisons across State I/DD systems

	VA DBHDS FY17 (all ages)	CT DDS FY2016 (all ages)		VA DBHDS FY17 (adults)	MA DDS CY14 (adults)	GA DBHDD CY17 (adults)
Males	47.5	59.6		51.7	61.7	
Females	50.7	62.9		54.5	60.1	
Total	48.7	60.9		52.9	60.9	53.5

In comparing average age at death, DBHDS demonstrated lower average ages of death for males and females compared to Connecticut, and a lower overall average age at death.

Cause of Mortality Benchmarks

Table 11 compares leading causes of death across state systems that also serve both children and adults. It should be noted that there appear to be some differences in how Connecticut and Ohio categorize their deaths compared to the ICD-10 system, so caution should be used when comparing patterns of respiratory diseases, for example. Percentages of deaths were in between benchmarks for Connecticut and Ohio for heart disease for DBHDS, and lower than Ohio for influenza and pneumonia. Comparisons show similar percentages of deaths for cancer, though because the overall mortality rate is higher for

DBHDS, Virginia's relative percentage may represent relatively more cancer deaths than other state systems. Both the heart disease and cancer categories contain sub-conditions that have increased risk of onset and contributions to mortality patterns as people get older; because the average age at death for DBHDS is lower than in other state I/DD systems, the increased mortality for younger age groups may contribute to lower proportional mortality for heart disease.

Table 11: Comparison of the Leading Causes of Death As Reported by State I/DD Agencies

Rank	VA DBHDS FY2017 (all ages)	CT DDS FY2016 (all ages)	OH DDD 2010 (all ages)
Causes of Death Method	**Underlying Cause**	**Primary Cause, non ICD-10**	**Unknown Cause**
1	Heart Disease 13.1%	Heart Disease 31.4%	Influenza and pneumonia 12.9%
2	Influenza and pneumonia 7.8%	Respiratory Disease[20] 25.5%	Heart Disease 11.3%
3	Cancer, Septicemia 7.5% each	Cancer 6.8%	Congenital anomalies 10.0%
4		Pneumonia 5.9%	Cancer 9.1%
5	Aspiration Pneumonia 7.1%	Sepsis 5.0%	Brain Related Illness-Disease 8.0%
6	Unintentional Injuries (Accidents) 6.7%	Aspiration Pneumonia 4.5%	

Table 12 compares cause-specific mortality rates across state systems. For heart disease, DBHDS was in between the rates for CT and Ohio. For influenza and pneumonia, DBHDS's percentages of deaths was lower than Ohio, and higher than Connecticut; however, because Virginia had a higher overall mortality rate, the cause-specific rate of death for influenza and pneumonia in Virginia was higher than in Ohio, as shown in Table 12. Mortality rates due to cancer, aspiration pneumonia and septicemia were higher for DBHDS compared to benchmarks. **These findings suggest it may be beneficial for DBHDS to review early detection screening use for cancers with these screenings, and that efforts to manage aspiration pneumonia and recognize and treat infections a timely manner may benefit the health of the population receiving services.** Rates of unintentional injuries were also higher than benchmarks; **because the majority of accidental deaths for DBHDS involved choking and aspiration, efforts around prevention of these accidents and identification and management of swallowing-related risks may be beneficial.**

[20] Note: Connecticut DDS categorizes pulmonary embolisms as respiratory diseases, however in ICD-10 based coding these deaths fall under Heart Disease due to their involvement of the circulatory system. Additionally, Respiratory diseases include influenza for Connecticut DDS, which would be categorized under 'Influenza and Pneumonia' for ICD-10 based coding.

Table 12: Comparison of the Cause-specific mortality rates As Reported by State I/DD Agencies

		Rate of Deaths (per 1,000 people served) All Ages		
DBHDS Ranking	**Cause of Death**	**VA DBHDS FY17**	**CT DDS FY16**	**OH DODD CY14**
1	Heart Disease	2.7	4.1	1.1
2	Influenza and pneumonia	1.6	*	1.2
3	Cancer	1.5	0.9	0.8
	Septicemia	1.5	0.7	
5	Aspiration Pneumonia	1.4	0.6	
6	Unintentional injury (Accidents)	1.4	<0.2	0.5
7	Congenital malformation	0.8	<0.2	0.9
	Cardiopulmonary Arrest/Seizure	0.8	<0.2	
9	Cerebral Palsy	0.7	<0.2	
10	Gastrointestinal	0.6	<0.2	
	Stroke	0.6	0.2	

**Due to different categorization methods used by Connecticut DDS for Influenza and Pneumonia, a direct comparison of rates is not feasible*

Table 13 compares cause-specific mortality rates between DBHDS and the general populations of Virginia and the United States. Rates of death from cancers, stroke, chronic lower respiratory disease and Alzheimer's disease were similar to the general population patterns. Of these causes, cancer, stroke and Alzheimer's disease are known to have age-associated risks; because the average age of death for people with intellectual and developmental disabilities is substantially lower than the general population, their risk of dying from these conditions may be lower because of their shorter lifespan.

Table 13: Benchmarking to the General Population

		Mortality Rates				
VA Gen Pop Rank	Causes of death	VA Rate 2016 (age adjusted)	US Rate 2016	VA DBHDS FY17 (minimum)[21]	Rate Ratio[22]	
1	Cancer	1.561	1.558	1.5	1.0	↔
2	Heart Disease	1.507	1.655	2.7	1.8	↑
3	Unintentional Injuries (Accidents)	0.424	0.474	1.4	3.3	↑
4	Stroke	0.382	0.373	0.6	1.6	↑
5	Chronic Lower Respiratory Disease	0.346	0.406	0.2	0.6	↓

[21] See note related to the number of deaths due to unknown causes, and how this can affect cause-specific mortality rates.

[22] Comparing the crude cause-specific mortality rate for DBHDS to the age-adjusted Virginia general population mortality rate. Rate Ratios of 1 indicate the rates were equal between the two populations. Rate Ratios exceeding 1 indicate the cause-specific mortality rate for DBHDS was higher than the Virginia general population rate. For example, the rate of death from unintentional injuries was 3.3 times higher for DBHDS than for the Virginia general population.

6	Alzheimer's disease	0.268	0.303	0.2	0.7	↔
7	Diabetes	0.217	0.210	0.5	2.3	↑
8	Renal Disease	0.166	0.131	0.5	3.0	↑
9	Septicemia	0.132	0.107	1.5	11.4	↑
10	Influenza and Pneumonia	0.127	0.135	1.6	12.6	↑

Key: ↔ = rates are similar; ↑ = DBHDS rate is higher than the Virginia general population; ↓= DBHDS rate is lower than the Virginia general population

Rates of death due to heart disease, diabetes, renal disease, septicemia and influenza/pneumonia were all higher than state and national patterns. **Related to influenza and pneumonia, it may be beneficial for DBHDS to review preventive strategies including annual vaccination and infection control procedures during flu seasons, as well as recognition of signs and symptoms of respiratory infections and prompt treatment of respiratory infections. Related to aspiration pneumonia, these findings suggest it may be beneficial for DBHDS to review strategies of proactive risk assessment to identify people who are at increased risk for aspiration, strategies to develop and implement plans to minimize this risk, strategies to identify when someone aspirates and strategies to seek prompt care to treat any related respiratory infections to try to prevent septicemia and related complications.**

There does not appear to be evidence that the mortality rate should be expected to be higher from diabetes for people with intellectual and developmental disabilities due to a differential underlying risk that is not modifiable for people with these disabilities, and yet the risk of mortality from diabetes was 2.3 times higher for DBHDS. **Therefore, diabetes, as well as others such as heart disease, represent targets for potential improvements in the way people served by DBHDS are supported to live healthy lifestyles, get screening for chronic conditions and work with health care providers and support staff to manage these conditions.**

The rate of deaths due to septicemia, which was 11.4 times the Virginia general population rate, strongly suggests an area for improvement in recognition and timely treatment of infections.

Similar to the comparison to the state I/DD systems, rates of death for unintentional injuries (accidents) were higher for the DBHDS system than for the state or nation. While the underlying patterns of accidental deaths for people with intellectual and developmental disabilities tend to differ from the general population (i.e. more choking/aspiration and falls), **the higher rate of deaths from injuries (three times the rate for the Commonwealth of Virginia) suggests a potential area for service improvement.**

While not shown in Table 13, the rate of deaths due to suicide for DBHDS in FY17 exceeded patterns seen in the Commonwealth of Virginia for the general population, and patterns in other state service agencies. In 2014-2016, the rate of suicide deaths in Virginia for the general population was 0.15 per thousand (MMWR 2018). By comparison, both Connecticut DDS and Ohio DODD reported zero deaths from suicide in their latest years of reporting, FY16 and CY14 respectively. In contrast, the rate of deaths for DBHDS due to suicide was 0.3 per thousand due to 4 deaths from this cause in FY17. While some variation may be expected in the mortality rate from this cause year-to-year because it generally involves small numbers of people, the pattern for DBHDS may demonstrate an elevated contribution to mortality from suicides compared with these other benchmarks in FY17. Because only one year of data was available for DBHDS, it is not possible to determine whether this is reflective of a larger issue or trend. This is an area of potential further consideration to identify mental health conditions and people

who may be at risk of committing suicide, and to ensure the delivery of timely and appropriate services to this group.

Other causes that were highly ranked contributors to mortality for DBHDS did not appear in the top causes for the general population – including aspiration pneumonia (ranked 5th for DBHDS), congenital anomalies and cardiopulmonary arrest/seizures (both tied for 7th), cerebral palsy (ranked 9th) and gastrointestinal disorders (ranked 10th). These causes largely have increased risk of occurring in people with intellectual and developmental disabilities in connection to either the etiology of developmental and intellectual disabilities, or co-morbid conditions found with increased prevalence (such as epilepsy) and likely also have an increased risk of contributing to mortality patterns.

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Appendix 1
ICD-10 Codes Used in this Publication

(Sorted by ICD-10 Codes)

Cause of Death	ICD-10 Code
Infectious and parasitic diseases	A00-B99
Septicemia	A40-A41
Human Immunodeficiency Virus (HIV) disease	B20-B24
Cancer (Malignant Neoplasms)	C00-C97
of esophagus	C15
of stomach	C16
of colon, rectum, rectum and anus	C18-C21
of pancreas	C25
of trachea, bronchus and lung	C33-C34
of female breast	C50
of cervix uteri	C53
of corpus uteri and uterus, part unspecified	C54-C55
of ovary	C56
of prostate	C61
of kidney and renal pelvis	C64-C65
of bladder	C67
of meninges, brain & other parts of central nervous system	C70-C72
Hodgkin's Disease	C81
Non-Hodgkin's lymphoma	C82-C85
Leukemia	C91-C95
Multiple myeloma and immunoproliferative neoplasms	C88, C90
Diabetes Mellitus	E10-E14
Alzheimer's Disease	G30
Heart Disease	I00-I09, I11, I13, I20-I51
Stroke (Cerebrovascular Disease)	I60-I69
Influenza and Pneumonia	J10-J18
Chronic Lower Respiratory Diseases	J40-J47
Chronic Liver Disease and Cirrhosis	K70, K73-K74
Nephritis and other renal diseases	N00-N07, N17-N19, N25-N27
Congenital malformations, deformations, and Chromosomal abnormalities	Q00-Q99
External causes of injuries and poisonings (intentional, unintentional and of undetermined intent)	V01-Y89
Accidents (Unintentional Injuries)	V01-X59, Y85-Y86
Suicide	X60-X84, Y87.0
Homicide	X85-Y09, Y87.1
Injuries of undetermined intent	Y10-Y34, Y87.2, Y89.9

ICD-10 Codes Used in this Publication

(Sorted by Category)

Cause of Death	ICD-10 Code
Accidents (Unintentional Injuries)	**V01-X59, Y85-Y86**
Alzheimer's Disease	G30
Aspiration Pneumonia	J69
Cancer (Malignant Neoplasms)	C00-C97
Cardiopulmonary Arrest/ Seizure	G40, R09.2, J96.0
Chronic liver disease and cirrhosis	K70, K73-K74
Chronic Lower Respiratory Diseases	J40-J47
Congenital malformations, deformations, and Chromosomal abnormalities	Q00-Q99
Diabetes Mellitus	E10-E14
Heart Disease	I00-I09, I11, I13, I20-I51
Influenza and Pneumonia	J10-J18
Nephritis and other renal diseases	N00-N07, N17-N19, N25-N27
Septicemia	A40-A41
Stroke (Cerebrovascular disease)	I60-I69
Unknown	R96-R99