Annual Mortality Report

Calendar Year 2018

New Options Waiver and Comprehensive Supports Waiver (NOW/COMP)

Georgia Department of Behavioral Health and Developmental Disabilities

August 15, 2019

This is the fifth annual report on mortality, mortality trends, and related information pertaining to the health and care received by individuals with intellectual and developmental disabilities served by the Georgia Department of Behavioral Health and Developmental Disabilities. The report focuses on an analysis of mortality data and findings from DBHDD's mortality review process. Reports are scheduled for publication in August of each year and cover the prior calendar year of January 1 through December 31.

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Executive Summary

An analysis of individual deaths and trends in mortality is a component of health and safety oversight and is part of the Georgia Department of Behavioral Health and Developmental Disabilities' ("DBHDD" or "the department") quality management and improvement system. This is the fifth annual mortality report released by DBHDD. The purpose of this report is to provide information about what DBHDD has learned about deaths, to identify trends or patterns in mortality, and to identify indicators that may assist DBHDD in the prevention and treatment of certain illnesses/conditions that may lead to deaths or other disorders/diseases in the future. This report does not issue recommendations, as these will emanate from later processes when DBHDD has had the opportunity to consider findings and observations reported within this document.

This report includes data and information concerning adults who died during calendar year 2018 while receiving intellectual and developmental disability (IDD) Medicaid waiver services from DBHDD and its contracted providers.

Major Findings

In calendar year 2018, DBHDD served 12,891 adults with intellectual and developmental disabilities in waiver services. A total of 172 deaths occurred in 2018, resulting in a crude mortality rate of 13.3 deaths per 1,000 individuals.[1, 2] The respective mortality rates for 2016 and 2017 were 14.0 and 16.4 deaths per 1,000 individuals. The mortality rates do not differ significantly across any years.

Heart diseases were the leading cause of death in the general populations of the United States (U.S.; 2016) Georgia (2017), as well as DBHDD NOW/COMP waiver populations (2018). Six of the leading causes of death among DBHDD's intellectual and developmental disabilities population were common to leading causes of death in the U.S. and Georgia: heart diseases, cancer (malignant neoplasm), respiratory diseases, renal disease, pneumonia, and Alzheimer's disease. Five of the leading causes of death for DBHDD's intellectual and developmental disability population were not common to the top causes of death in the U.S. and Georgia: disability, sepsis, aspiration pneumonia, epilepsy / seizures, and gastrointestinal diseases. Results are similar for previous years of study.

Several variables were analyzed to determine their association with mortality in 2018. These included age, gender, health risk, residential setting, and region. Major analytical findings from 2016 through 2017 were that increasing health risk and increasing age were most strongly associated with mortality, while gender, residential setting, region, and other variables were not related to mortality. In 2018, increasing health risk and increasing age were once again significantly related to mortality.

Most providers had no or very few deficient practices that were identified as posing risk to individuals based on Community Mortality Review Committee (CMRC) findings. The most common provider deficiencies that required corrective action were linked to individual care and prevention (89.3% of all critical/high deficiencies). These deficiency areas included assessment and treatment plans, coordination

[1] The mortality rate used in this report is a crude mortality rate, which is an unadjusted mortality rate. The mortality rate is a measure of how many people out of every thousand served by DBHDD died within the calendar year. It is determined by multiplying the number of people who died during the year by 1,000, then dividing by the total number of individuals served in the NOW/COMP waiver program during the same year. The crude mortality rate can be useful when comparing deaths across populations of varying sizes. For the purposes of the remainder of this report, crude mortality rate will be referred to as "mortality rate."

[2] Standard recommended by the U.S. Centers for Disease Control and Prevention, National Vital Statistics Report, *Age Standardization of Death Rates: Implementation of the Year 2000 Standard*, Vol. 47, No. 3, 1998.

of care, medical care needs, medication management, and response to emergency or change in condition. The overlap among the areas above account for 25 of the 28 identified critical- or high-risk deficient practices. Though corrective action plans are intended to remediate deficient provider practices and mitigate further risk, the prevalence of the abovementioned common deficient practices may indicate additional areas for systemic improvement.

Scope of this Report

The focus of the mortality review for this report includes adults with a primary intellectual or developmental disability diagnosis who received services funded by NOW/COMP waivers during the 2018 calendar year. During 2018, data systems for individuals receiving waiver services were maintained separately from state-funded services, and data between these systems vary. This report used the NOW/COMP waiver data because it demonstrated the highest verifiable accuracy and reliability. A description of the chosen method and the analysis conducted in the report can be found in Appendix A. This report also includes data from the Community Mortality Review Committee (CMRC) process from a subset of the deaths that occurred within this population during 2018.

Several considerations are provided for reading and interpreting the findings from this report. Although DBHDD looked closely at other states' reports, given the differences in waiver programs, obligations of the various state agencies, and other state-specific issues, it is difficult to compare mortality rates or conclusions between states. DBHDD has also used caution when comparing mortality rates across unlike methods and populations. In writing this report, the department strongly cautions the reader to resist the inclination to draw conclusions that cannot be supported due to the limits of information available and the differences in eligibility and populations served in other studies.

> Care should be taken when comparing these findings with other mortality reviews and reports that analyzed data from different populations or used different methods. Differences in population definitions, waiver programs, and obligations of other state agencies limit the utility of comparing mortality rates or generalizing findings. DBHDD has used caution when comparing mortality rates across unlike methods and populations.

About DBHDD

The Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) provides treatment and support services for people with mental health challenges and substance use disorders and assists individuals who live with intellectual and developmental disabilities.

Vision

Easy access to high-quality care that leads to a life of recovery and independence for the people we serve.

Mission

Leading an accountable and effective continuum of care to support Georgians with behavioral health challenges, and intellectual and developmental disabilities in a dynamic health care environment.

About DBHDD Intellectual and Developmental Disability Services

DBHDD is committed to supporting opportunities for individuals with intellectual and developmental disabilities to live in the most integrated and independent settings possible. A developmental disability is a chronic condition that develops before a person reaches age 22 and limits his or her ability to function mentally or physically. DBHDD provides services to people with intellectual and other disabilities, such as severe cerebral palsy and autism, who require services similar to those needed by people with an intellectual or developmental disability. State-supported services help families continue to care for a relative at home or independently in the community when possible. DBHDD also contracts with providers to provide home settings and care to individuals who do not live with their families or on their own. DBHDD hospital services are available for some individuals needing the highest level of care.

Services are designed to encourage and build on existing social networks and natural sources of support, and to promote inclusion in the community and safety in the home environment. Contracted providers are required to have the capacity to support individuals with complex behavioral or medical needs. The services a person receives depend on a professional determination of level of need.

DBHDD serves as the operating agency for two 1915c Medicaid Waiver Programs, initially approved in 2007 when the two programs transitioned and expanded into their current form. The Medicaid waiver programs operate under the names New Options Waiver (NOW) and Comprehensive Supports Waiver (COMP). Both waiver programs provide home- and community-based services to individuals who, without these services, would require a level of care comparable to that provided in intermediate care facilities for people with intellectual and developmental disabilities, the costs of which would be reimbursed under the Medicaid State Plan. The Centers for Medicare and Medicaid Services offers the waiver option to states through application, which may be renewed every five years. As in all Medicaid programs, the services and administrative costs are funded through a federal/state match agreement. A complete description of waiver services can be found at www.dbhdd.ga.gov.

DBHDD Sampling Procedure

DBHDD carefully considers information and data to analyze to answer analytical questions. High quality, valid information and data are the basis of useful, practical, and valid research findings and conclusions. Ideally, analysis occurs from data on an entire population, and DBHDD strives to accomplish this when feasible; this produces maximum validity. However, when data on the entire population are not available or feasible, then DBHDD carefully considers how the analytic data sample is built, as the sampling procedure has great impact on the quality, validity, and generalizability of research findings.

DBHDD's sampling procedure proceeds in the following manner:

- First, when available, DBHDD utilizes data on the full population under study (e.g., all individuals who received services within a given period such as calendar or fiscal year).
- Second, if some individuals within the full population have missing data for variables being used for analysis, DBHDD considers widely-accepted procedures to address missing data. For example, individuals with missing data typically are excluded from analysis using listwise deletion,[3] resulting in a subset of the full population. DBHDD may consider other theoretically-sound methods and procedures to understand or address missing data.[4]
- Third, in some cases, DBHDD utilizes some form of random sampling[5] (e.g., a random subset of providers or events that occurred). For this approach to be valid, one must be able to define the entire population from which it is being drawn, and each unit (e.g., individual, situation, etc.) must have an equal chance of being included in the sample. This method is unbiased, and the resulting sample is representative of the full population under study.
- Fourth, DBHDD also occasionally makes use of purposive sampling, a non-probability sampling method. This method is typically reserved for specific instances (e.g., identifying when a situation occurred, selecting specific cases, identifying specific errors, etc.). Purposive sampling is a selective, non-probabilistic method, and purposive sampling is not representative of the full population under study; therefore, findings or results based on purposive sampling are not generalizable to the full population, rather only to the cases from which data were sampled.
- Fifth, a goal of inferential statistics is to make inferences about the population based on a sample smaller than the population. DBHDD considers sample sizes carefully and analytically to create empirical samples large enough to have sufficient statistical power to detect associations or differences and allow valid inferences to be drawn from and generalized about the population being studied.

[3] Listwise deletion is a method for handling missing data, whereby an entire record is excluded from analysis if any single value is missing.

[4] Sensitivity analyses are conducted to evaluate the pattern of missing data, wherein missing data are determined to be either missing completely at random (MCAR) or missing at random (MAR). Data are determined to be MCAR when the probability of missing data on a variable is unrelated to any other measured variable and is unrelated to the variable with missing values itself. Data are determined to be MAR when the missingness can be explained by variables that do not contain missing values.

[5] The leading component of simple random sampling is that every case (e.g., individuals or providers) has the same probability of being selected for inclusion in analysis.

Causes of Death Among the Intellectual and Developmental Disability Waiver Population

The State of Georgia has a mixed coroner/medical examiner system, making the gathering of information concerning causes and manners of death more difficult than if there were a single statewide system. The state has no uniform method for death reporting (i.e., categorizing the causes of death), and information provided on death certificates varies. Due to this lack of uniformity, it is difficult to aggregate causes of death, and the reliability is somewhat questionable since many death certificates are not completed by medical professionals. Currently, the causes of death are identified by DBHDD through one of the following means: the autopsy report, if an autopsy was conducted; the death certificate issued by the Georgia Department of Public Health's Division of Vital Statistics (if available); the medical examiner or coroner's report (if available); or as reported by law enforcement, the physician, or the family.

Prior to the 2016 annual mortality report, DBHDD classified and determined primary cause of death based upon physician review and categorization of causes of death. In 2016, DBHDD began presenting an aggregate of all underlying causes of death listed on the death certificate following the methods outlined by the Centers for Disease Control and Prevention (CDC).[6]

Using CDC direction to create a comprehensive examination of the issues and concerns leading to death in the intellectual and developmental disability population, all underlying causes of death listed on the available death certificates were combined and weighted equally. Modes of death were excluded if present. As stated in the CDC's "Instructions for Classifying the Underlying Cause of Death, 2017" (2017, p. 2):

> *A death often results from the combined effect of two or more conditions. These conditions may be completely unrelated, arising independently of each other or they may be causally related to each other, that is, one cause may lead to another which in turn leads to a third cause, etc.*

This method helps to encompass comorbid conditions that could be missed when assigning a singular cause of death.

A summary of the causes of death as recorded in DBHDD's Reporting of Critical Incidents database follows (**Table 1**). The leading causes of death reported on death certificates among the intellectual and developmental disability waiver population for 2018 are heart diseases, respiratory diseases, disability, sepsis, and aspiration pneumonia. These causes of death also appeared as leading causes of death in 2017.

The leading causes of death reported on death certificates among the intellectual and developmental disability waiver population for 2018 are heart diseases, respiratory diseases, disability, sepsis, and aspiration pneumonia.

[6] (2017). Retrieved from https://www.cdc.gov/nchs/data/dvs/2a_2017.pdf. Accessed March 21, 2019.

Table 1: Leading Causes of Death[7]

	2016	2017	2016	2017	2018
	U.S.	Georgia	Intellectual and Developmental Disability Population		
	All Ages		*Adult Only*		
1	Heart Diseases (23.1%)	Heart Diseases (29.6%)	Heart Diseases (21.2%)	Heart Diseases (22.9%)	Heart Diseases (20.8%)
2	Malignant Neoplasm (21.8%)	Malignant Neoplasm (20.6%)	Disability (12.4%)	Sepsis (17.1%)	Respiratory Diseases (15.8%)
3	Unintentional Injuries (5.9%)	Chronic Lower Respiratory Diseases (10.3%)	Aspiration Pneumonia (11.2%)	Disability (11.8%)	Disability (12.0%)
4	Chronic Lower Respiratory Diseases (5.6%)	Alzheimer's Disease (8.8%)	Sepsis (11.2%)	Aspiration Pneumonia (11.2%)	Sepsis (7.6%)
5	Cerebrovascular Disease (5.2%)	External Causes (8.5%)	Hypertension (8.2%)	Respiratory Diseases (10.0%)	Aspiration Pneumonia (5.7%)
6	Alzheimer's Disease (4.2%)	Endocrine, Nutritional and Metabolic Diseases (4.5%)	Cancer (7.6%)	Cancer (8.8%)	Renal (5.0%)
7	Diabetes Mellitus (2.9%)	Digestive System Diseases (3.6%)	Pneumonia (6.5%)	Pneumonia (7.1%)	Pneumonia (4.1%)
8	Influenza and Pneumonia (1.9%)	Mental and Behavioral Disorders (3.6%)	Respiratory Diseases (6.5%)	Epilepsy / Seizures (5.9%)	Epilepsy / Seizures (3.8%)
9	Renal (1.8%)	Infectious and Parasitic Diseases (3.0%)	Epilepsy / Seizures (6.5%)	Gastrointestinal Disease (2.9%)	Cancer (3.5%)
10	Suicide (1.6%)	Reproductive and Urinary System Diseases (3.0%)	Unintentional Injuries (5.9%)	Renal (2.4%)	Alzheimer's Disease / Gastrointestinal Disease (1.9%)

[7] Percent is given for the overall cause of death, not subcategories within the cause of death. The information presented above is provided for descriptive purposes only. Due to the lack of consistency in categorizing the causes of death and expertise of those completing the death certificates, readers are strongly cautioned against drawing conclusions based on this information. In order to use this information to make conclusions or recommendations regarding system or practice changes, it is necessary to conduct further exploration into available information about individual cases or groups of cases. It is important to understand and consider information, such as the underlying causes of death, the circumstances of the death, the medical care provided prior to the death, co-morbid conditions, and potentially important early detection, screening, and preventive care practices.

That disability is listed as a leading cause of death is peculiar, as disability typically is not considered to be a fatal condition or cause of death, though it often is included as a cause of death on death certificates. It is important to note the prevalence of disability being listed as a cause of death on death certificates. This likely is an artifact of using causes of death from death certificates, complicated by the limitations of Georgia's mixed coroner/medical examiner system.

At the time of writing this report, updated causes of death were not available for the U.S. and Georgia for 2018. Comparing the intellectual and developmental disability population to U.S. mortality data (2016) and Georgia mortality data (2017), heart diseases were the leading cause of death in the general populations of U.S. and Georgia, and heart diseases were also the leading cause of death in 2018 for the intellectual and developmental disability population. Chronic lower respiratory diseases were leading causes of death in U.S. and in Georgia. Respiratory diseases and pneumonia (including aspiration pneumonia) also were in the top leading causes of death in the intellectual and developmental disability population in 2018. Therefore, as in past years, at least half of the top 10 leading causes of death in the U.S. and Georgia and the most prevalent causes of death in the intellectual and developmental disability population in 2018 were similar.

> Heart diseases remain prevalent as the leading cause of death in the United States, Georgia, and among DBHDD's intellectual and developmental disability population.

Five of the leading causes of death among the intellectual and developmental disability population in 2018 were not common to the top causes of death in the U.S. and Georgia during 2016 and 2017:

- Disability
- Sepsis
- Aspiration pneumonia
- Epilepsy / seizures
- Gastrointestinal disease

Interpreting Statistical Tests

The following sections report statistical analyses. Statistical analyses are useful to identify associations and trends among variables that may be associated with mortality. Statistics commonly refers to "statistical significance." Sometimes associations or patterns occur due to random chance. A statistically significant difference for a result or relationship has a likelihood that it is caused by something other than mere random chance. It is a natural tendency to assume when there is a statistically significant difference or association that it must result from something other than a random chance and that the difference must have a specific cause. It is important to exercise caution when interpreting statistical significance in this manner, as sufficient facts may not necessarily be present to conclude a specific idea of what that something is. It is important that statistical significance should be studied further by gathering additional information and by completing a more extensive analysis through additional steps. It also should be noted that statistical significance does not equate to importance or meaningful significance. Meaning and importance of findings can only be determined by more careful examination of additional information.

This annual mortality report does not make conclusions about any differences or statistically significant findings. As such, the statistical findings will be presented to DBHDD to be considered along with other information for further exploration to understand the causes and implications of the statistical findings. Where there are specific information, findings, observations, cases, and issues that warrant additional investigation, analysis, and consideration, work is underway to examine possible strategies to address these concerns within DBHDD.

Mortality During 2018

This section contains information on deaths reported to DBHDD among the intellectual and developmental disability waiver population during calendar year 2018. Calendar years 2016 and 2017 are included for comparison purposes. Appendix A describes the method used to collect and analyze information and data contained in this section.

A search for peer-reviewed research for comparison data yielded data from four states.[8] Compared to research[9] that used data from Connecticut, Louisiana, Ohio, and New York, the combined crude mortality rate for these states was 14.96 deaths per 1,000 individuals in 2009, which is not significantly different from the 2018 intellectual and developmental disability mortality rate for DBHDD, 13.3 deaths per 1,000. The mortality rate for these states combined in 2011 was 9.37, which is significantly lower than the DBHDD 2018 mortality rate ($|z| = 4.347$; $p < 0.001$).

> The respective mortality rates for 2016 and 2017 were 14.0 and 16.4 deaths per 1,000 individuals. The 2018 mortality rate was 13.3 deaths per 1,000 individuals. The mortality rates do not differ significantly across 2016-2018.

[8] As of April 2019, DBHDD searched for additional, more recent intellectual and developmental disability mortality reports and published scientific literature for comparison, to no avail.

[9] Lauer, E & McCallion, P. (2015). Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data. Journal of Applied Research in Developmental Disabilities, 28, 394-405.

DBHDD also compared mortality findings from other states' mortality reports that were available. Tennessee reported mortality rates of 27.4 (fiscal year 2013) and 21.1 (fiscal year 2014) per 1,000,[10] which were significantly higher than the 2018 DBHDD mortality rate ($|z| = 7.307$; $p < 0.001$; $|z| = 4.423$; $p < 0.001$, respectively). Massachusetts reported a mortality rate of 18.0 deaths per 1,000 in 2015,[11] which was significantly higher than the 2018 DBHDD mortality rate ($|z| = 3.393$; $p < 0.001$). The variability in ranges may reflect the differences in population and criteria of the study, as noted above.

As stated earlier: caution should be used in comparing mortality rates across populations that may differ in terms of inclusion criteria for study. States vary in the eligibility and enrollment criteria, yielding unlike populations, which may complicate meaningful comparisons of mortality rates. For example, Massachusetts[12] included all individuals who were eligible for services in the study population, regardless of whether they were receiving services. Ohio, Connecticut, and Louisiana include individuals with an IQ above 70 who have functional support needs; however, some of these individuals were receiving only case coordination.[13] DBHDD's report includes only those individuals who have an IQ below 70 and have the higher functional support needs required to receive more intensive services within the NOW/COMP waivers. Reports that include only individuals with a demonstrated, verified higher level of functional impairment (as does this report) may yield higher mortality rates than reports with a more expanded population that includes individuals with less severe functional or support needs. Because eligibility and enrollment criteria are not consistent across states, generalizations and comparisons may lead to insupportable conclusions.

Age and Mortality

The average ages of death in 2016 and 2017 were 53.54 years (SD = 15.40) and 53.48 (SD = 15.18), respectively. The average age of death in 2018 was 54.35 (SD = 14.97). The average age of death increased by 0.87 years from 2017 to 2018; however, that change was not statistically significant. This means that individuals who died in 2018 lived about the same length of time as those who died in 2017. The reported average age of death falls within the 2009-2011 range for Connecticut, Louisiana, Ohio, and New York (combined), which was 50.4 to 58.7 years.

> Individuals who died in 2018 lived about the same amount of time as those who died in 2017.

[10] Tennessee Department of Intellectual and Developmental Disabilities. Annual Mortality Report, 2013-2014 Fiscal Year.
[11] Commonwealth of Massachusetts, Executive Office of Health & Human Services, Department of Developmental Services. 2015 Preliminary Mortality Report.
[12] Commonwealth of Massachusetts, Executive Office of Health & Human Services, Department of Developmental Services. 2015 Preliminary Mortality Report.
[13] Lauer, E & McCallion, P. (2015). Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data. Journal of Applied Research in Developmental Disabilities, 28, 394-405.

As in 2016 and 2017, mortality rates increased with increasing age (**Table 2**, **Figure 1**). In particular, between 2016 and 2018, the mortality rate for individuals between ages 45 and 54 exceeded the overall mortality rate for the entire population. In 2016, however, the mortality rate increase occurred in the 55-64 population. This would imply that the mortality rate consistently rises above the population mortality group in the 45-64 age range.

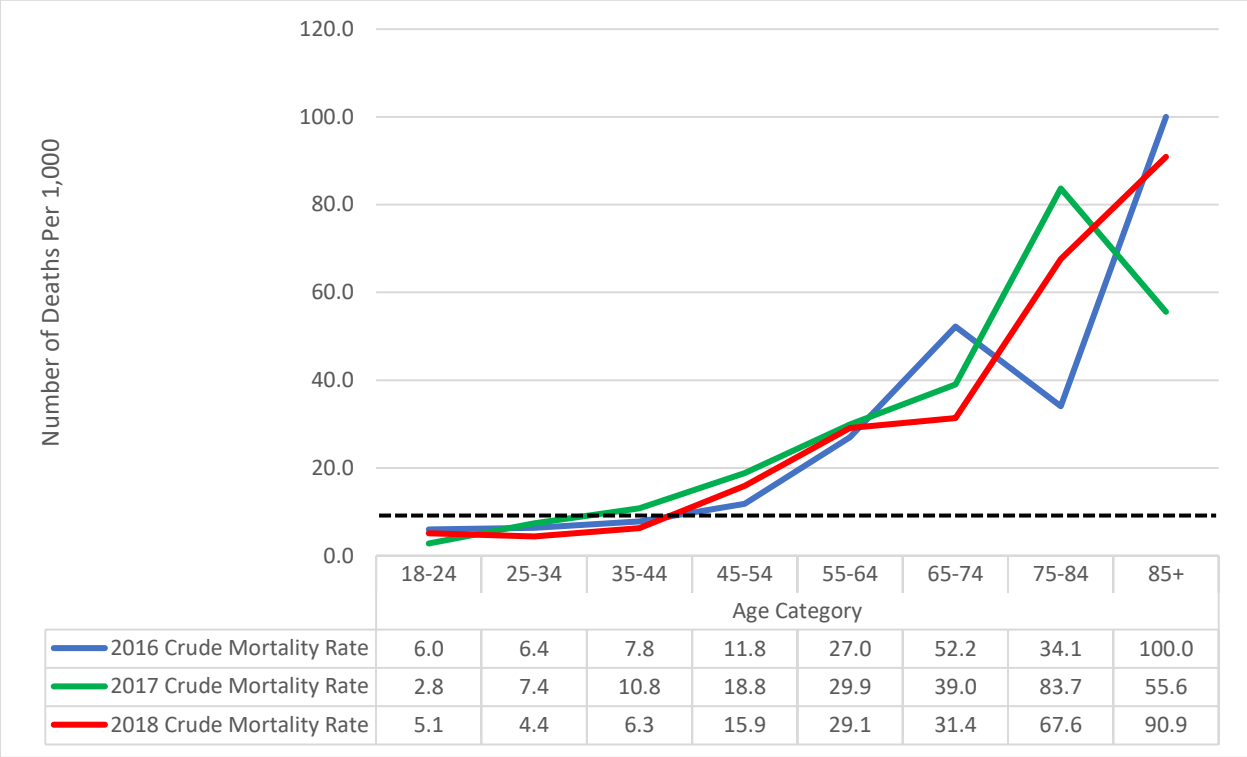
The mortality rate consistently rises with increasing age.

The mortality rate for those within and older than the 45-54 age category exceeds the overall mortality rate for the entire population.

Table 2: Mortality Rates Among the Adult IDD Waiver Population by Age Category, 2016-2018

		Age Category								Total
		18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
2016	Population	1,002	3,450	2,690	2,286	1,818	709	176	20	12,151
	Deaths (#)	6	22	21	27	49	37	6	2	170
	Deaths (%)	3.5%	12.9%	12.4%	15.9%	28.8%	21.8%	3.5%	1.2%	100.0%
	Crude Mortality Rate	6.0	6.4	7.8	11.8	27.0	52.2	34.1	100.0	14.0
2017	Population	1,058	3,508	2,783	2,284	1,838	743	203	18	12,435
	Deaths (#)	3	26	30	43	55	29	17	1	204
	Deaths (%)	1.5%	12.7%	14.7%	21.1%	27.0%	14.2%	8.3%	0.5%	100.0%
	Crude Mortality Rate	2.8	7.4	10.8	18.8	29.9	39.0	83.7	55.6	16.4
2018	Population	1,182	3,663	2,872	2,260	1,889	796	207	22	12,891
	Deaths (#)	6	16	18	36	55	25	14	2	172
	Deaths (%)	3.5%	9.3%	10.5%	20.9%	32.0%	14.5%	8.1%	1.2%	100.0%
	Crude Mortality Rate	5.1	4.4	6.3	15.9	29.1	31.4	67.6	90.9	13.3

Figure 1: Mortality Rates by Age Category, 2016-2018[14]



	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+
	Age Category							
2016 Crude Mortality Rate	6.0	6.4	7.8	11.8	27.0	52.2	34.1	100.0
2017 Crude Mortality Rate	2.8	7.4	10.8	18.8	29.9	39.0	83.7	55.6
2018 Crude Mortality Rate	5.1	4.4	6.3	15.9	29.1	31.4	67.6	90.9

Statistical comparisons of mortality rates between corresponding age categories from 2016-2017 and 2017-2018 were not significantly different. The mortality rate for the age group 45-54 increased above the overall mortality rate for the population. From there, the mortality rate increased with age. This pattern did not occur for the 85+ group in 2017, but such a fluctuation is not abnormal for such a small subgroup.

Other research[15] found that mortality rates tend to increase with increasing age, such that younger groups had lower mortality rates, and significant increases in mortality rates were found to begin at 45-54 and increased dramatically with increasing age. For the U.S. population, mortality rates also increase more rapidly with increasing years after about 55 years of age. The 2017 Georgia mortality rate for individuals aged 55-64 is 10.3 deaths per 1,000, and it increases in subsequent age categories.[16]

These data combined indicate that age-specific mortality rates are similar for intellectual and developmental disability populations across states. The pattern of significantly increasing mortality rates with increasing ages after 55 is similar for the U.S. and Georgia.

The mortality rate for DBHDD's IDD population begins increasing about 10 years earlier relative to general populations.

[14] The horizontal black line indicates the crude mortality rate (13.3 per 1,000) for the overall IDD population.
[15] National Vital Statistics Report, Vol. 67 No. 6, July 26, 2018, p. 8. http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf, accessed March 21, 2019.
[16] https://oasis.state.ga.us/oasis/webquery/qryMortality.aspx, accessed March 21, 2019.

Health Risk and Mortality

The Health Risk Screening Tool (HRST) is a standardized mechanism used to determine an individual's vulnerability to potential health risks and early identification of deteriorating health. The HRST measures health risk using a distinct rating scale related to functional status, behavior, physiological condition, and safety. HRST results are incorporated into the ongoing health care surveillance process. The HRST is completed to inform an individual's approval for community intellectual and developmental disability services. After its initial completion, the HRST is conducted annually and whenever an individual experiences significant health events or changes in health, functional, or behavioral status. The HRST guides providers in determining the individual's need for further assessment and evaluation, services, or modifications to his or her service plan to address identified health risks.

Table 3: HRST Health Care Levels

HCL	Description	Points
1	Low Risk	0-12
2	Low Risk	13-25
3	Moderate Risk	26-38
4	High Moderate Risk	39-53
5	High Risk	54-68
6	Highest Risk	69+

The HRST assigns points to rated items. The resulting numerical total is assigned a health care level (HCL) associated with degrees of health risk. **Table 3** shows the risk level designations and points associated with each of the six health care levels used as a part of the HRST.

The average HCL for 2018 was 2.45 (SD = 1.51). In 2017, the average HCL was 2.35 (SD = 1.48), and, in 2016, the average HCL was 2.26 (SD = 1.45). The average HCLs across 2016-2018 were each statistically different from each other: 2017 to 2018 ($|t| = 5.310$, df = 25,324, $p = < 0.001$) showed an increase and 2016 to 2018 ($|t| = 10.121$, df = 25,040, $p < 0.001$) also showed an increase. This means that, overall, there is a statistically significant increase in the amount of measured health risk in this population over time.

Similar to previous years, there was a statistical association between HCL and mortality rate in 2018. Individuals with lower HCLs (1-3) had a group mortality rate (5.2 deaths per 1,000) that was below the population mortality rate in 2018 (13.3 deaths per 1,000). Individuals with higher HCLs (4-6) had a group mortality rate (43.0 deaths per 1,000) that exceeded the overall population mortality rate (13.3 deaths per 1,000) by a large margin. The mortality rate for higher HCLs (4-6) was significantly higher than the mortality rate for the lower HCLs (1-3) ($|z| = 15.342$; $p < 0.001$).

> There is a statistically significant increase in the amount of measured health risk in this population over time.

Results from previous years have consistently indicated that a two-point increase in HCL is associated with a significant increase in mortality. Analysis of 2018 data indicate that it is also important to consider a one-point change in health risk scores to address increasing mortality risk. For example, attention should be given to HCL 3 (in addition to HCLs 4, 5, and 6). HCL 4 is the health risk level that moves above the overall population mortality rate. An increase of one HCL above HCL 3 would move individuals into a level of risk more significantly associated with mortality (i.e., HCL 4-6).

> It is important to consider a one-point change in health risk scores to address increasing mortality.

Figure 2: Mortality Rates by HCL, 2016-2018[17]

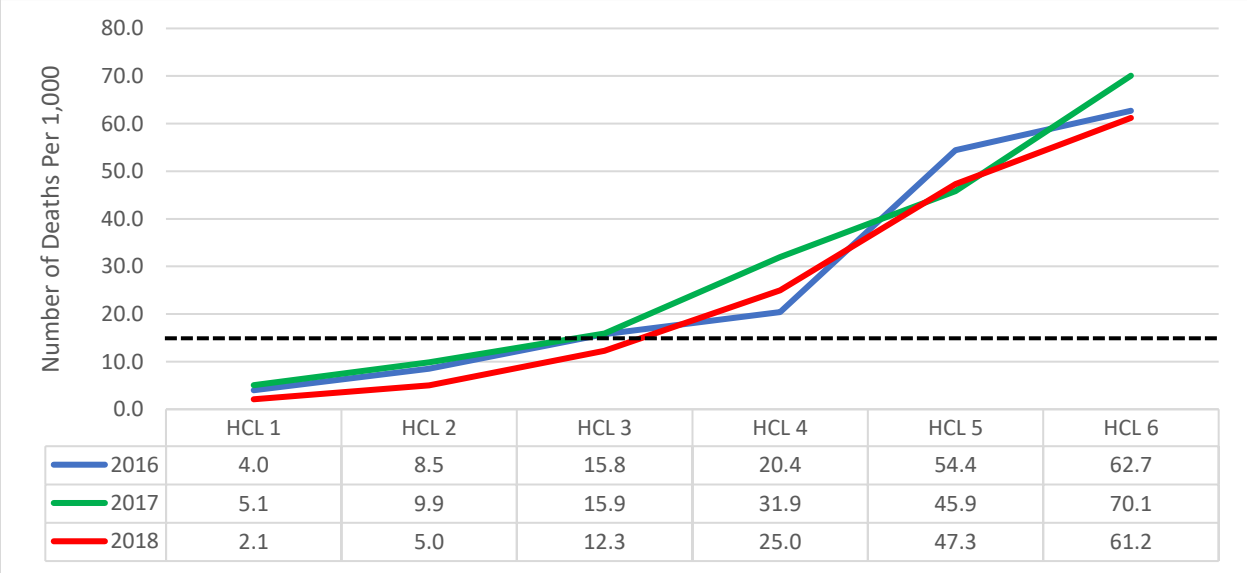


Table 4: Mortality Rates by HCL, 2018[18]

2018					
HCL	**Population**	**Deaths (#)**	**Deaths (%)**	**Crude Mortality Rate**	**Significance**
1	4,320	9	5.23%	2.1	--
2	3,772	19	11.05%	5.0	NS
3	2,031	25	14.53%	12.3	$\|z\| = 3.046$; $p = 0.001$
4	1,118	28	16.28%	25.0	$\|z\| = 2.659$; $p = 0.004$
5	719	34	19.77%	47.3	$\|z\| = 2.577$; $p = 0.005$
6	931	57	33.14%	61.2	NS
Total	**12,891**	**172**	**100%**	**13.3**	**--**

[17] The horizontal black line indicates the crude mortality rate (13.3 per 1,000) for the overall IDD population.
[18] "--" indicates that a statistical test was not conducted. "NS" indicates non-significance.

The Central Importance of Age and Health Risk[19]

Health risk and age are important factors that need to be considered when investigating mortality. Within the intellectual and developmental disability population, high-level risk tends to be present across all age categories, as well as varying degrees of lower-health risks across all age categories. The relationship between health risk and age is not uniform. HCLs are distributed similarly within each age group. Correlations between age (both as continuous and ordinal variables) indicate the association between HCL and age is weak (Pearson's r = 0.08, $p < 0.001$). Though this is statistically significant, the total variance explained in the association between age and health risk is less than one percent, which indicates that for this population, health risk and age are not necessarily meaningfully associated. Therefore, one would also expect that if health risk and age were related to mortality, these variables would have independent (not interactive) effects.

Data analysis to this point has examined variables as they individually relate to mortality. However, it also is important to consider all variables of interest at once to determine the individual effect of each variable on the occurrence of death, while controlling for the influence of other variables. Analyses considered if and how age, gender, region, intensity of residential setting, and health risk (using HCL) were associated with mortality to determine which variables may be of key importance in understanding it. Such associations are examined using logistic regression.[20]

As in previous years, gender, region, and intensity of residential setting were not associated with death in 2018.

Non-significant variables were removed from the final model, leaving only age and HCL (**Table 5**). These logistic regression results align with reported results for 2013-2017.

Table 5: Odds Ratios for Final Logistic Regression Model of Mortality on Age and HCL, 2016-2018

Characteristic	2016	2017	2018
	Odds Ratio	Odds Ratio	Odds Ratio
Age	1.05	1.05	1.05
HCL	1.68	1.65	1.87
Pseudo R^2	**0.13**	**0.13**	**0.17**

[19] Tables 5-7 display odds ratios (ORs). These tables report explained variance using pseudo R^2, a statistical measure of fit that indicates how much variation of a dependent variable (e.g., mortality) is explained by the independent variables in a regression model (e.g., age and HCL). For example, a pseudo R^2 of 1.00 (or 100%) would mean that mortality is completely explained by the independent variables included in each model. Coefficients for Tables 5-7 are available on request.

[20] Several advantages of using logistic regression exist. First, logistic regression allows one to determine the association of a variable without the influence of other variables. For example, logistic regression analysis about age pertains only to the effects of age and mortality without the effect of other variables. In this way, each variable is risk-adjusted so that the effects of other variables do not affect it. Another advantage is that logistic regression can be used to determine the importance of each variable and can be easily interpreted using odds ratios. An odds ratio is a measure of association between a variable and an outcome occurring. The odds ratio represents the odds of death occurring given a particular event or condition compared to the odds of death occurring in the absence of that variable.

As age and HCL increase, the likelihood of dying also increases.

In 2018, each one-year increase in age was associated with a five percent increase in the odds of dying. Similarly, in 2018, each one-unit increase in HCL was associated with an 87 percent increase in the odds of dying.

These results are similar when treating HCL and age in a different manner (i.e., as categorical variables; **Tables 6-7**). For example, in 2018, individuals with HCLs of 3, 4, 5, and 6 had greater odds of mortality, relative to individuals with an HCL of 1 (**Table 6**). Individuals with HCLs of 1 and 2 had statistically equivalent odds of mortality. Results are similar for 2016-2017.

Table 6: Odds Ratios for Logistic Regression Model of Mortality on HCL, 2016-2018

HCL	2016	2017	2018
	Odds Ratio	Odds Ratio	Odds Ratio
1	1 [Reference]	1 [Reference]	1 [Reference]
2	1.93	1.96	2.43
3	3.59	3.18	5.97
4	4.45	6.49	12.31
5	12.57	9.45	23.78
6	14.99	14.81	31.24
Pseudo R^2	**0.09**	**0.08**	**0.12**

In 2018, individuals in the following age categories had greater odds of mortality, relative to individuals aged 25-34: 45-54, 55-64, 65-74, 75-84, and 85+ (**Table 7**). Individuals aged 18-24 and 35-44 (as compared to those aged 25-34) had statistically equivalent odds of mortality. Results are similar for 2016-2017.

Table 7: Odds Ratios for Logistic Regression Model of Mortality on Age, 2016-2018

Age	2016	2017	2018
	Odds Ratio	Odds Ratio	Odds Ratio
18-24	0.94	0.30	1.16
25-34	1 [Reference]	1 [Reference]	1 [Reference]
35-44	1.23	1.53	1.44
45-54	1.86	2.42	3.69
55-64	4.32	3.52	6.84
65-74	8.58	4.21	7.39
75-84	5.50	8.04	16.53
85+	17.31	7.34	22.79
Pseudo R^2	**0.06**	**0.13**	**0.07**

The sections above presented findings and observations based on a statistical analysis of all adults with a primary intellectual or developmental disability diagnosis who received services funded by NOW/COMP waivers during the 2018 calendar year. Statistical analyses are useful for identifying variables and trends that are associated with mortality, which provide information for improvement of service quality. It is worth noting that, among the 2018 IDD population, death was a relatively rare outcome. Large increases in odds (such as with the upper values of HCL and age) do not necessarily mean that individuals with these attributes were in great danger of death; it only means that people in those groups were more likely than others to experience death. It is also worth noting that statistical association does not indicate causation. (Please refer to the discussion about statistical analysis in the section titled "Interpreting Statistical Tests.")

Community Mortality Review Committee and Deficient Practice Analysis

Background

DBHDD's Community Mortality Review Committee (CMRC) uses a standard process to conduct reviews of deaths of individuals receiving services by or through DBHDD community providers. The purpose of the mortality review is to identify opportunities to reduce morbidity or mortality and evaluate and provide information that may improve the quality of services. The overall goals of the mortality review are to provide insight into the way the DBHDD system works; share lessons and learn from an individual's death; discover if the same or similar situations may affect others served; assist in prevention or mitigation of future harm; and improve overall quality of care. The CMRC policy was revised effective July 2018 and can be viewed by clicking on the hypertext.

At a minimum, DBHDD requires providers to correct deficient practices that have the potential for causing minimal harm, which include critical-, high-, and moderate-risk practices. DBHDD requires providers to submit corrective action plans for deficient practices that were identified as either placing the individual or having the potential to place individuals at critical-, high-, and moderate-risk levels.

Deficiencies are tracked in DBHDD's Corrective Action Tracking System (CATS). This database maintains information about deficient practices, entities cited, categorization of the deficiencies (e.g., critical, high, moderate, or low risk), and any corrective actions implemented for those deficiencies. More information about the deficiency determinations and tracking processes can be found in DBHDD policy Internal and External Reviews and Corrective Action Plans, 13-101.

Statewide Analysis of Number and Type of CMRC-Related Deficient Practices

The analysis of CMRC-specific deficient practices and deficiency tracking presented below is based on data entered into CATS. Only deficient practices related to CMRC reviews are included in this report. Not all deaths are reviewed by the CMRC; the CMRC reviews the required deaths per policy.

Due to small sample sizes, statistical analysis is not advisable at this time. The reader is cautioned from generalizing findings and observations from the CMRC analysis below to the DBHDD intellectual and developmental disability population.

In 2018, there were 22 practices entered into CATS that were identified as moderate risk, defined as having the potential to result in no more than minimal physical, mental, or psychosocial discomfort. Providers were required to submit corrective action plans for these. Thirteen practices entered into CATS were identified as low risk. Providers were requested to correct these deficiencies without submitting a formal corrective action plan to DBHDD. Recommendations made as the result of a CMRC review are also sent to the provider. DBHDD requests providers respond to or comment on recommendations identified as the result of CMRC reviews; however, no formal corrective action plan is required for recommendations.

This report focuses on providing analysis of critical- and high-risk deficient practices—the ones with the most potential for adverse outcomes.

Critical Risk: Statewide

Critical-risk deficient practices entered into CATS centered on individual care and prevention, including medical care needs, medication management, and failure to respond to an emergency in a manner that would protect the welfare of the individual (**Table 8**). As mentioned earlier, DBHDD requires providers to submit a corrective action plan to address critical-risk deficient practices.

Table 8: Statewide Critical-Risk Count, 2018

Critical Risk	**9**
Individual Care & Prevention	**9**
Assessments & Treatment Plans	1
Coordination of Care	1
Medical Care Needs	2
Medication Management	2
Response to Emergency/Change in Condition	3

High Risk: Statewide

Deficient practices at the high-risk level have resulted in a negative outcome to an individual. A closer examination of the high-risk deficient practices entered into CATS shows similarities with the critical-risk practices: individual care and prevention is the most common high-risk practice area, specifically, attending to medical care needs and documentation (**Table 9**).

Table 9: Statewide High-Risk Count, 2018

High Risk	**19**
Clients Rights	**1**
Alleged Abuse, Neglect, Exploitation	1
Individual Care & Prevention	**16**
Assessments & Treatment Plans	2
Coordination of Care	1
Documentation	4
Medical Care Needs	5
Medication Management	2
Response to Emergency/Change in Condition	2
Program Planning & Leadership	**2**
Human Resources & Training	1
Policy, Procedure & Protocol Development	1

Regional Analysis of Number and Type of Critical and High Deficient Practices

Regions 1, 2, and 5 had the largest number of identified critical deficient practices and accounted for 88.9 percent of critical-risk deficient practices identified. Regions 1, 2, and 3 had the highest number of deficient practices that were identified as having high risk to individuals, accounting for 89.5 percent of the high-risk deficient practices. It should be noted, however, that there were no statistically significant differences in the number of deficient practices between individual regions and the overall state.

Table 10: Regional Analysis of Number and Type of Deficient Practices, 2018

Region	Population	Critical-Risk Deficiencies (#)	Critical-Risk Deficiencies (%)	High-Risk Deficiencies (#)	High-Risk Deficiencies (%)
1	2,762	2	22.2%	3	15.8%
2	2,192	4	44.4%	11	57.9%
3	3,290	1	11.1%	3	15.8%
4	1,317	0	0.0%	1	5.3%
5	1,550	2	22.2%	1	5.3%
6	1,764	0	0.0%	0	0.0%
Total	**12,875**	**9**	**100.0%**	**19**	**100.0%**

> The number of deficient practices did not vary significantly among regions.

The main points concerning deficient practices identified in the course of CMRC reviews, when considering the 28-combined critical- and high-risk practices conjointly, one notices substantial overlap in one area: individual care and prevention, which constituted 89.3 percent of all critical- and high-risk deficient practices.

The overlap among the areas above account for 25 of the 28 identified critical- or high-risk deficient practices entered into CATS. Though corrective action plans are intended to remediate deficient practices and mitigate further risk, the prevalence (89.3%) of the abovementioned common deficient practices may indicate additional areas for systemic improvement.

Key Findings

Below is a summary of the key findings identified in the 2018 Annual Mortality Report:

The 2018 DBHDD NOW/COMP waiver mortality rate was 13.3 deaths per 1,000 individuals. The 2018 mortality rate did not differ significantly from the DBHDD NOW/COMP waiver mortality rates in 2016 and 2017.

Increasing age was significantly associated with mortality.

Increasing health risk was significantly associated with mortality.

Mortality increased markedly for individuals in the 45-54 age group. Increased risk of mortality due to increasing age is also found in the general U.S. and Georgia populations.

Life expectancy for the 2018 NOW/COMP waiver population (54.4 years) is comparable to the average age of death for intellectual and developmental disability populations as reported in other state mortality reports and in published, peer-reviewed research (50.4 to 58.7 years).

Heart diseases were the leading cause of death in the general populations of U.S. (2016) and Georgia (2017), as well as DBHDD's NOW/COMP waiver population (2018). As in past years, most leading causes of death in the U.S. and Georgia and the most prevalent causes of death in the NOW/COMP waiver population in 2018 were similar: heart diseases, cancer, respiratory diseases, renal, pneumonia, and Alzheimer's disease.

Five of the leading causes of death for DBHDD's intellectual and developmental disability population were not common to the top causes of death in the U.S. and Georgia: disability, sepsis, aspiration pneumonia, epilepsy / seizures, and gastrointestinal diseases.

The most common critical- and high-risk deficient provider practices centered on individual care and prevention, including medical care needs, failure to respond to an apparent change in individuals' health conditions, and failure to respond to an emergency in a manner that would protect the welfare of the individual.

Most providers had none or very few deficient practices (from CMRC reviews) that were identified to pose risk to individuals.

Appendix A: Method for Mortality Review and Analysis

This mortality report analyzes information on individuals and deaths reported to DBHDD that meet the following criteria:

- At least 18 years of age during the calendar year of review
- Primary diagnosis of an intellectual or developmental disability
- Medicaid waiver recipient (NOW or COMP)

This report does not include data for individuals under the age of 18. Deaths for children and adolescents are analyzed on a case-by-case basis and not included in these statistical analyses due to potential differences between children and adults and the small sample size of children.

Other reports (e.g., 2010 & 2011 Mortality Report, Massachusetts) included all individuals that were eligible for services to calculate mortality rates. This report included only those receiving NOW/COMP waivers, who may have a higher level of disability and need for services and supports. Including data from only those individuals receiving services may have produced upwardly biased mortality rates relative to those studies that included all the population eligible for services. Due to data limitations mentioned earlier, it was not possible to investigate this possible bias.

Individuals who moved between the NOW/COMP waiver during 2018 were categorized into the waiver in which they were last enrolled.

The data used to calculate mortality rates per 1,000 people by age group and type of residence were supplied by the Waiver Information System (WIS) and Reporting of Critical Incidents system (ROCI). WIS was the primary source for identifying, demographic, and payer information, as well as residential setting. Health risk information was extracted from the Columbus Information System (CIS). Death and incident information were extracted from ROCI. ROCI and CIS do not track individuals by a common unique identifier stored in WIS. All efforts were made to match individuals using related identifying information, including name, age, address, and region.

For these analyses, the following information was included:

- Region (WIS)
- Medicaid number (WIS)
- Date of birth (WIS)
- Date of death (ROCI)
- Residential setting (WIS)
- Cause of death (if known) (ROCI)
- Whether death was referred for investigation (ROCI)
- Whether a mortality review was completed (CMRC)
- Health risk scores (HCLs from Health Status Risk Screening Tool; CIS)
- Tracking of deficient practices and corrective action plans related to CMRC (CATS)

Due to the large number of statistical comparisons, the statistical significance level was set at $\alpha = 0.01$. Setting $\alpha = 0.01$ as the significance level is to compensate for finding significance due to increased chances afforded by multiple comparisons.

The specific methodology employed by this report to calculate mortality rates per 1,000 people throughout this report appears on the following page.

Crude Mortality Rate

The crude mortality rate is a measure of how many people out of every thousand served by DBHDD died within the calendar year. It is determined by multiplying the number of people who died during the year times one thousand and dividing this by the total number of people served in the NOW/COMP waiver program during the same year. The crude mortality rate can be useful when comparing deaths across populations of varying sizes. Caution should be used when comparing mortality rates across unlike methods and populations.

Deaths were included, regardless of death category, for all population-eligible adults who died in 2018.

Analysis and Measures

Analyses were conducted using Stata version 15,[21] including tests of significance and logistic regression. In order to facilitate the interpretation of coefficients and odds ratios, variables were not transformed. The variables used for the logistic regression follow:

- **Death** (outcome): 0 = No death; 1 = Death
- **Age**: Continuous (ranging from 18 to 94; Table 5); Categorical (18-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+; Table 7)
- **Gender**: 0 = Female; 1 = Male
- **Region**: Categorical (Region 1, Region 2, Region 3, Region 4, Region 5, Region 6)
- **Health Risk (using HRST Health Care Level [HCL])**: Continuous (ranging from 1-6; Table 5); Categorical (HCL 1, HCL 2, HCL 3, HCL 4, HCL 5, HCL 6; Table 6)
- **Intensity of Residential Setting:** 0 = Lower Intensity (independent apartment/home; live with family/relative/caretaker/friend/other)**;** 1 = Higher Intensity (personal care home; community living arrangement; host home; other)

All variables were entered into regression models individually, and the variables were examined for significant association with death. Variables that were indicated as not being significantly associated with death were removed, and the model was recomputed. Those variables that were indicated as significantly associated with death were retained in the model. This process continued until only significantly associated variables with death remained. Finally, the model was examined for meaningful relationships and interpretation.

[21] StataCorp. 2017. *Stata Statistical Software: Release 15*. College Station, TX: StataCorp LLC.

Appendix B: NOW/COMP Population Demographics

Characteristics of the Intellectual and Developmental Disability Waiver Population

Below is a brief demographic description of the 2018 intellectual and developmental disability waiver population:

- The total number of unduplicated intellectual and developmental disability individuals with active NOW/COMP waivers in 2018 was 12,891.
- These individuals were aged 18-94, with a mean age of 42.1.
- Of these, 59.1 percent were male and 40.9 percent were female.
- Region 3 (25.2%) was the most populous region, followed by Region 1 (21.4%), Region 2 (17.2%), Region 6 (13.8%), Region 5 (12.1%), and Region 4 (10.3%).
- Most of the population had COMP waivers (64.8%) as opposed to NOW waivers (35.2%).
- Most of the population resided with family, relatives, or other individuals (54.9%), while the rest of the population resided in community living arrangements (17.8%), lived independently (10.7%), resided in a host home (10.4%), or resided in a personal care home (6.2%).

More information about the characteristics of the population can be found on the following page (**Table 11**).

Table 11: Characteristics of the Adult IDD Waiver Population, 2016-2018[22]

Characteristic	2016		2017		2018	
	n	%	n	%	n	%
Age						
18-24	1,002	8.3	1,058	8.5	1,182	9.2
25-34	3,450	28.4	3,508	28.2	3,663	28.4
35-44	2,690	22.1	2,783	22.4	2,872	22.3
45-54	2,286	18.8	2,284	18.4	2,260	17.5
55-64	1,818	15.0	1,838	14.8	1,889	14.7
65-74	709	5.8	743	6.0	796	6.2
75-84	176	1.5	203	1.6	207	1.6
85+	20	0.2	18	0.1	22	0.2
Gender						
Male	7,107	58.5	7,318	58.9	7,622	59.1
Female	5,044	41.5	5,117	41.2	5,269	40.9
Region						
Region 1	2,501	20.6	2,612	21.0	2,758	21.4
Region 2	2,148	17.7	2,140	17.2	2,221	17.2
Region 3	3,062	25.2	3,148	25.3	3,251	25.2
Region 4	1,285	10.6	1,287	10.4	1,325	10.3
Region 5	1,431	11.8	1,519	12.2	1,562	12.1
Region 6	1,724	14.2	1,729	13.9	1,774	13.8
Waiver Type						
NOW	4,378	36.0	4,339	34.9	4,538	35.2
COMP	7,773	64.0	8,096	65.1	8,353	64.8
Residential Setting						
Community Living Arrangement	1,615	13.3	2,081	16.7	2,297	17.8
Host Home	1,222	10.1	1,305	10.5	1,334	10.4
Independent	1,443	11.9	1,409	11.3	1,382	10.7
Live with Family/Relative/Other	6,534	53.8	6,701	53.9	7,079	54.9
Personal Care Home	1,337	11.0	939	7.6	799	6.2
Total	**12,151**	**100.0**	**12,435**	**100.0**	**12,891**	**100.0**

[22] Shown for each characteristic are totals and percentages. Total percentages may not total to 100.0 because of rounding.