

2016 Annual Mortality Report

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



DBHDD

Georgia Department of Behavioral Health and Developmental Disabilities

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This is the third 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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2016 DBHDD Mortality Review Report

Waiver Services

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 third 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, 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 2016 while receiving intellectual and developmental disability Medicaid waiver services from DBHDD and its contracted providers.

Major Findings

In calendar year 2016, DBHDD served 12,151 adults (at least 18 years of age) with intellectual and developmental disabilities in waiver services. A total of 170 deaths occurred in 2016; the 2016 mortality rate was 14.0 deaths per 1,000 individuals.^{1, 2} The respective mortality rates for 2014 and 2015 were 11.1 and 12.5 deaths per 1,000 individuals. The mortality rates do not differ significantly across any years.

Heart disease was the leading cause of death in the general populations of the U.S. (2014), Georgia (2015), and DBHDD 2016 waiver populations. Six of the top 10 leading causes of death in the U.S. and Georgia, and the most prevalent causes of death among people with intellectual and developmental disabilities served by DBHDD in 2016 were similar to past years' findings. Four of the leading causes of death for the 2016 intellectual and developmental disability population that were not common to the top causes of death in the U.S. and Georgia during 2014 and 2015 included disability, aspiration pneumonia, sepsis, and epilepsy/seizures.

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 times one thousand and dividing this by the total number of people served in the NOW and 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.

Several variables were analyzed to determine their effect on mortality in 2016. These included age, intensity of residential setting, gender, region, and health risk. Major analytical findings from 2013 through 2015 were that increasing health risk and increasing age were most strongly associated with mortality, while gender, intensity of residential setting, region, and other variables were not related to mortality. In 2016, health risk was significantly related to mortality along with increasing age once again.

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. DBHDD required providers to submit corrective action plans for 138 deficient practices that were identified as either placing individuals or having the potential to place individuals at critical, high, and moderate risk. As of the date this report was written, most of the reviews identifying deficient practices were closed. The most common provider practices that required corrective action follow:

Health and Wellness Medical (40, 28.9% of all critical/high/moderate deficiencies)

- Deficient response to change in condition
- Deficient response to an emergency
- Deficient response to medical care needs

Neglect (15, 10.9% of all critical/high/moderate deficiencies)

Documentation of Care (23, 16.7% of all critical/high/moderate deficiencies)

- Deficient progress/clinical notes
- Deficient medication documentation

The overlap among the areas above account for 78 of the 138 identified deficient practices that required a corrective action plan. Though corrective action plans are intended to remediate deficient practices and mitigate further risk, the prevalence (57%) of the abovementioned common deficient practices may indicate additional areas for improvement.

Utilization of Mortality Report Findings

The observations and findings in this report will be presented to leadership of DBHDD, the department's Division of Developmental Disabilities, and the Department of Community Health (the Medicaid Authority of Georgia) for consideration in identifying issues that need additional analysis, investigation, and interpretation to improve quality of care in specific areas vital to maintaining health.

The responsibility for the use of the information within this report is that of the director of the Division of Developmental Disabilities. The director will consider these and other mortality data, publicly available national mortality data, and recommendations from the CMRC to develop and implement quality improvement initiatives, including those to reduce mortality rates for individuals with intellectual and developmental disabilities in the community. DBHDD's organizational alignment provides a platform for clarified roles and responsibilities in addressing mortality in the intellectual and developmental disability population in Georgia, including analysis, implementation of targeted action steps, and determination of the impact of selected initiatives. Both expertise and responsibility exist in other areas within the department to help the Division of Developmental Disabilities accomplish improvement strategies; the Division of Developmental Disabilities has the responsibility to use these resources. The Division of Developmental Disabilities has at its disposal department resources to accomplish improvement initiatives with the assistance of support functions provided by the divisions of Accountability and Compliance and Performance Management and Quality Improvement.

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 for 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. For individuals needing the highest level of care, DBHDD operates five state hospitals across Georgia.

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.

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 and COMP waivers during the 2016 calendar year. During 2016, 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 and 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 2016.

This report does not include data for children under the age of 18. Five deaths of children were reported to DBHDD in 2016. Deaths for children 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.

Several considerations are provided for reading and interpreting the findings from this report. The reader should take care when comparing this report's findings with those from mortality reviews in other states, especially when said reviews included all eligible individuals or analyzed data from different populations. 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.

Causes of Death among the Intellectual and Developmental Disability Waiver Population

The State of Georgia is 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.

In prior years, DBHDD classified and determined primary cause of death based upon physician review and categorization of causes of death. Beginning this year, DBHDD presents 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).³

³ (2017). Retrieved from https://www.cdc.gov/nchs/data/dvs/2a_2017.pdf. Accessed June 8, 2017.

Using CDC direction to create a comprehensive look into 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. The leading causes of death reported on death certificates among the intellectual and developmental disability waiver population for 2016 are heart disease, disability, aspiration pneumonia, sepsis, and hypertension. Aspiration pneumonia appeared as a leading cause of death in 2015 and remains a leading cause of death in 2016.

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. Disability, though often included as a cause of death on the death certificates, has not been captured for the purposes of this report prior to this year. 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 U.S. and Georgia causes of death were not available. Comparing the intellectual and developmental disability population to U.S. mortality data (2014) and Georgia mortality data (aggregate 2010-2014), heart disease was the leading cause of death in the general populations of U.S. and Georgia, and heart disease was also the leading cause of death in 2016 for the intellectual and developmental disability population. Chronic lower respiratory disease was the third leading cause 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 2016. 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 2016 were similar.

Four of the leading causes of death in 2016 were not common to the top causes of death in the U.S. and Georgia during 2014 and 2015:

- Disability
- Aspiration pneumonia
- Sepsis
- Epilepsy/seizures

Table 1: Leading Causes of Death

Rank	2014	2015	2013	2014	2015	2016
	U.S.	Georgia	Intellectual and Developmental Disability Population			
	All Ages		Adult Only			
1	Heart Diseases 23.4%	Heart Diseases 28.9%	Respiratory Disease 18.2%	Heart Diseases 21.9%	Respiratory Disease 23.1%	Heart Diseases 21.2%
2	Malignant Neoplasms 22.5%	Malignant neoplasms 20.6%	Heart Diseases 16.4%	Respiratory Disease 17.4%	Heart Diseases 15.8%	Disability 12.4%
3	Chronic Lower Respiratory Diseases 5.6%	Chronic Lower Respiratory Diseases 9.8%	Sepsis 12.1%	Epilepsy/seizures 7.1%	Sepsis 8.5%	Aspiration Pneumonia 11.20%
4	Unintentional Injuries 5.2%	Alzheimer's (Nervous System Diseases) 7.4%	Pneumonia 7.9%	Sepsis 8.5%		Pneumonia 8.5%
5	Cerebrovascular Diseases 5.1%	Unintentional Injuries 6.2%	Cancer 7.3%	Cancer 6.5%	Aspiration Pneumonia 8.5%	Hypertension 8.2%
6	Alzheimer's Disease 3.6%	Mental and Behavioral Disorders 4.3%	Gastrointestinal Disease 6.7%	Gastrointestinal Disease 6.5%	Epilepsy/seizures 3.6%	Cancer 7.6%
7	Diabetes mellitus 2.9%	Endocrine, nutritional & metabolic diseases 4.0%	Epilepsy/seizures 4.2%	Pneumonia 5.8%	Complications of Cerebral Palsy 3.6%	Pneumonia 6.5%
8	Influenza and Pneumonia 2.1%	Digestive system disease 3.5%	Renal 4.2%	Renal 3.9%		Alzheimer's Disease 3.6%
9	Renal 1.8%	Reproductive & urinary system diseases 3.1%	Aspiration Pneumonia 3.6%	Peripheral Vascular Disease 3.9%	Cancer 2.4%	Epilepsy/seizures 6.5%
10	Suicide 1.6%	Infectious & parasitic diseases 3.0%	Peripheral Vascular Disease 3.6%	Aspiration Pneumonia 2.6%	Peripheral Vascular Disease 2.0%	Unintentional Injuries 5.9%

NOTE: 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.

The following sections report statistical analyses. Statistical analyses are useful to identify associations and trends among variables that may be associated to 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 the *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.

Analysis of Intellectual and Developmental Disability Waiver Data Related to Mortality

This section presents analyses of intellectual and developmental disability waiver data related to mortality. First, the intellectual and developmental disability waiver population is described by presenting analysis of key variables that are associated with mortality. Tables and charts include data from 2014 and 2015 for comparison purposes.

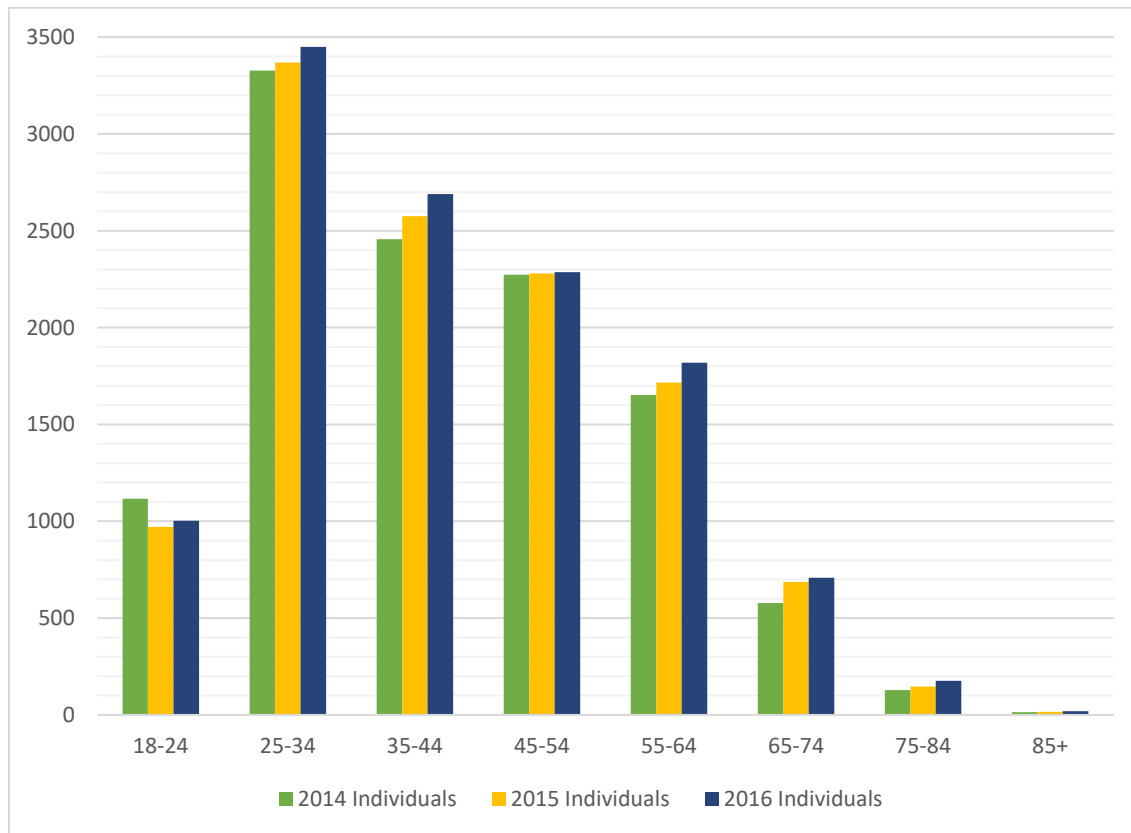
Age

Table 2 and Figure 1 present the distribution of the intellectual and developmental disability population by age groups. Age was calculated as the duration between the individual’s birth date and the end of calendar year 2016; when applicable, the age was calculated as the duration between the individual’s birth date and their date of death. The average age of the adult intellectual and developmental disability waiver population in 2016 was 42.3 years (SD = 14.3), which was slightly higher than (but not statistically different from) the average age of 42.2 years (SD = 14.1) in 2015 ($|t| = .521$, $df = 23901.09$, $p = .301$). The largest age group in each year was 25-34. More than half (55.91%) of the population is between 35 and 64 years. Approximately one and a half percent of the population is 75 or older.

Table 2: Age Distribution of the Adult Intellectual and Developmental Disability Waiver Population, 2014-2016

Age	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
18-24	1,116	9.67%	971	8.26%	1,002	8.25%
25-34	3,327	28.83%	3,368	28.64%	3,450	28.39%
35-44	2,456	21.28%	2,576	21.90%	2,690	22.14%
45-54	2,273	19.69%	2,280	19.39%	2,286	18.81%
55-64	1,651	14.30%	1,716	14.59%	1,818	14.96%
65-74	577	5.00%	686	5.83%	709	5.83%
75-84	128	1.11%	147	1.25%	176	1.45%
85+	14	0.12%	16	0.14%	20	0.16%
Totals	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 1: Age Distribution of the Adult Intellectual and Developmental Disability Waiver Population, 2014-2016



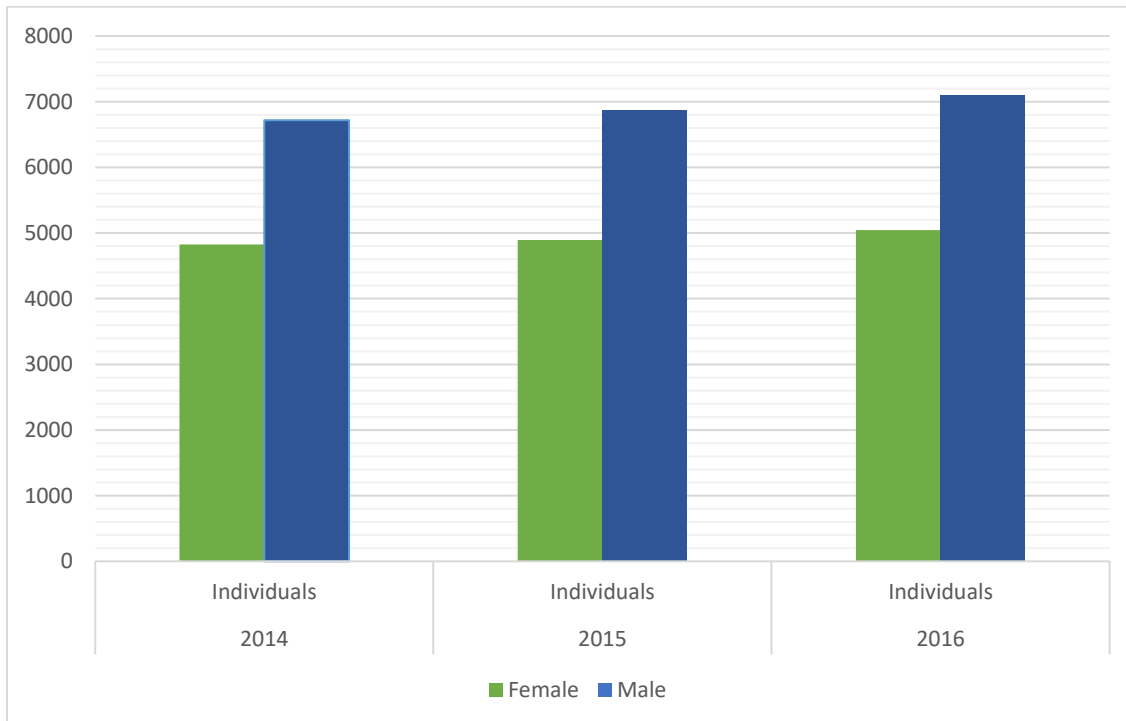
Gender

Table 3 and Figure 2 show that the distributions of gender were equal across the years 2014 to 2016. This null relationship was reinforced by statistical testing.

Table 3: Gender Distribution of the Adult Intellectual and Developmental Disability Waiver Population, 2014-2016

Gender	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Female	4,824	41.80%	4,892	41.59%	5,044	41.51%
Male	6,718	58.20%	6,868	58.41%	7,107	58.49%
Total	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 2: Gender Distribution of the Adult Intellectual and Developmental Disability Waiver Population, 2014-2016



Region

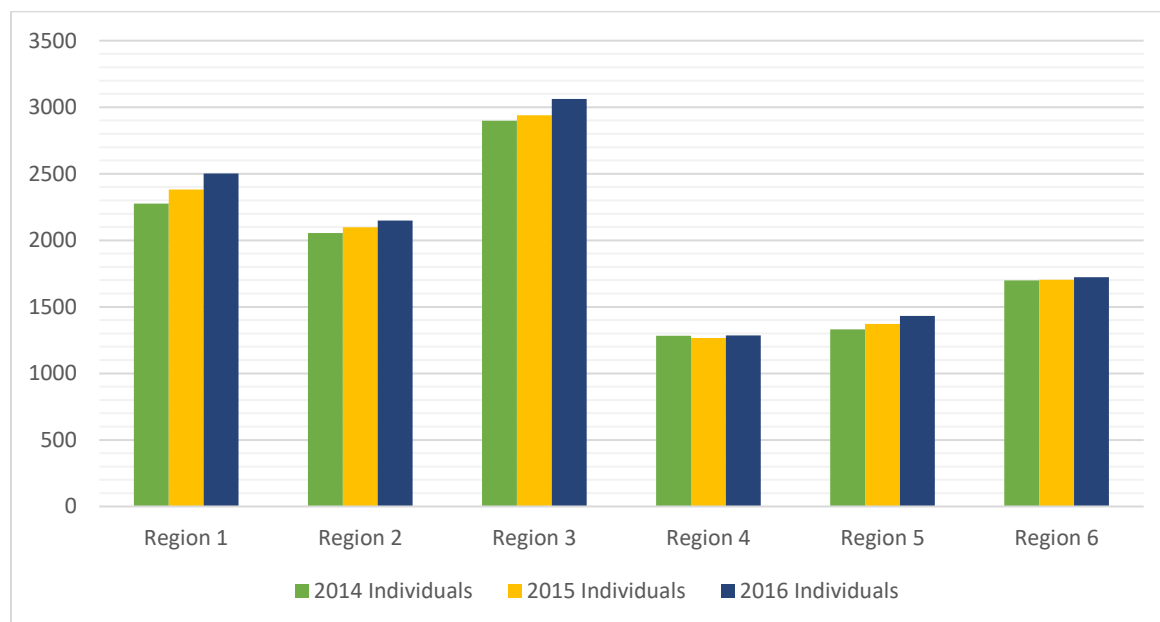
DBHDD serves individuals throughout the state in six geographic regions through a network of contracted providers. See Appendix B for a description of the regions.

Table 4 and Figure 3 show the regional distribution of waiver participants. The percent of individuals being served in each respective region remained uniform between 2014 and 2016. (No statistical differences between proportions were found.) Region 3, the most densely-populated region, had the largest population of individuals served (3,062, 25.20%); regions 4 and 5 are less-populated areas and had the smallest population of individuals served (1,285, 10.58%; 1,431, 11.78%, respectively).

Table 4: Distribution of Adults Receiving Intellectual and Developmental Disability Waiver, 2014-2016

Region	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Region 1	2,275	19.71%	2,381	20.25%	2,501	20.58%
Region 2	2,055	17.80%	2,098	17.84%	2,148	17.68%
Region 3	2,899	25.12%	2,940	25.00%	3,062	25.20%
Region 4	1,284	11.12%	1,265	10.76%	1,285	10.58%
Region 5	1,331	11.53%	1,372	11.67%	1,431	11.78%
Region 6	1,698	14.71%	1,704	14.49%	1,724	14.19%
Total	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 3: Adult Intellectual and Developmental Disability Waiver Population by Region, 2014-2016



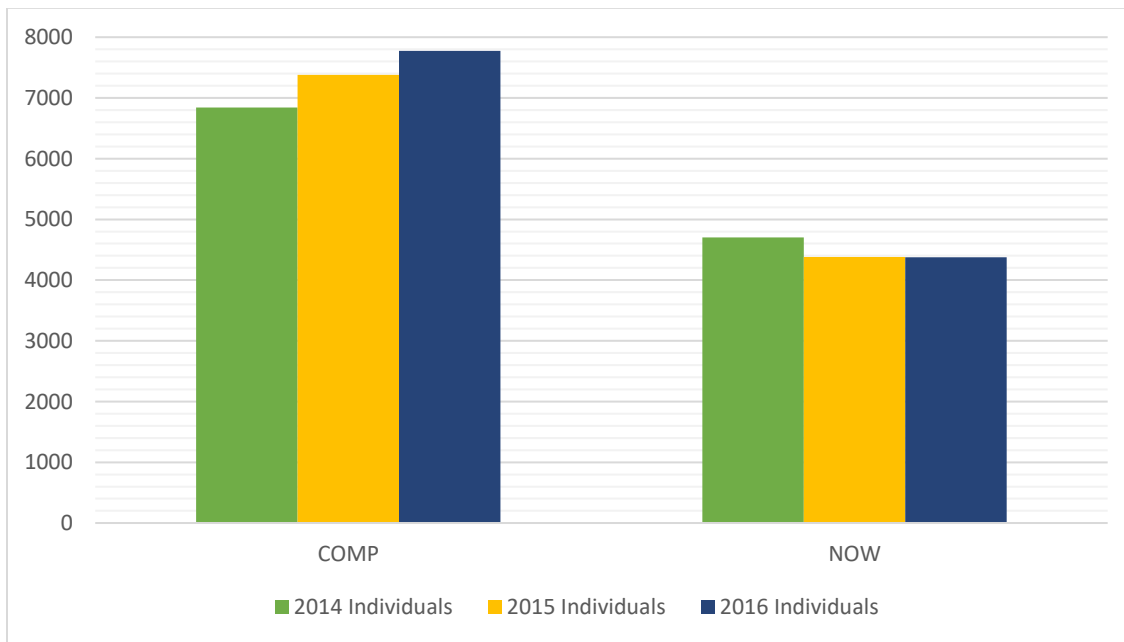
Type of Medicaid Waiver

The number (and percent) of individuals receiving COMP waivers increased by 392 (5.3%) in 2016. The number of individuals receiving NOW waivers decreased by one (0.02%). The only statistically significant difference in proportions was between calendar years 2014 and 2016 ($|z| = 7.437$, $p < .0001$).

Table 5: Distribution of Adult Intellectual and Developmental Disability Waiver Population, 2014-2016

Waiver	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
COMP	6,841	59.27%	7,381	62.76%	7,773	63.97%
NOW	4,701	40.73%	4,379	37.24%	4,378	36.03%
Total	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 4: Distribution of Adult Intellectual and Developmental Disability Waiver Population, 2014-2016



Residential Setting

Individuals who receive intellectual and developmental disability services from DBHDD live in a variety of settings. Many live independently or with family members, friends, or caretakers/caregivers.

Individuals may also receive services in small group settings in any of the following arrangements:

- **Host Home (life-sharing):** The individual resides and receives services in an owner-occupied home, where the owner includes the individual in household routines and provides training, support, and supervision.
- **Community Living Arrangement:** “Community Living Arrangement” means any residence, whether operated for profit or not, that undertakes through its ownership or management to provide or arrange for the provision of daily personal services, supports, care, or treatment exclusively for two or more adults who are not related to the owner or administrator by blood or marriage and whose residential services are financially supported, in whole or in part, by funds designated through DBHDD. Provider agencies must hold a Community Living Arrangement License from the Georgia Department of Community Health’s Healthcare Facilities Regulation Division.
- **Personal Care Home:** “Personal Care Home,” “home,” or “facility” means any dwelling, whether operated for profit or not, which undertakes through its ownership or management to provide or arrange for the provision of housing, food service, and one or more personal services for two or more adults who are not related to the owner or administrator by blood or marriage. Agencies providing this service must hold a Georgia Personal Care Home Permit/License from the Georgia Department of Community Health’s Healthcare Facilities Regulation Division.
- **Independent:** The individual resides and receives services in a residence which he or she owns, leases, or rents.
- **Live with Family/Relative/Other:** The category combines several residential setting categories that do not live independently or in higher-intensity residential settings. Specifically, the individual lives and receives services in a residence owned, leased, or rented by a family member or relative. “Other” refers to individuals who reside with a caretaker/caregiver who is not a relative, friend, or immediate family member. This category also includes 12 individuals whose residence in the Waiver Information System (WIS) is designated as “foster care.” Finally, 44 individuals’ residential setting was designated in WIS as “other.”

Host homes, community living arrangements, and personal care homes are residential settings that can provide more intensive services and supports. Generally, individuals with greater support needs tend to reside in host homes, community living arrangements, and personal care homes, though individuals and families may choose these settings to allow individuals the opportunity for increased independence and socialization. It is important to note that “higher intensity” and “lower intensity” are used in this report to categorize for analytical purposes. It also is important to understand that individuals living in “lower intensity” residential settings may also receive higher-intensity services, such as 24/7 nursing, for example. The level of intensity of the services are based on individual needs, not the residential setting.

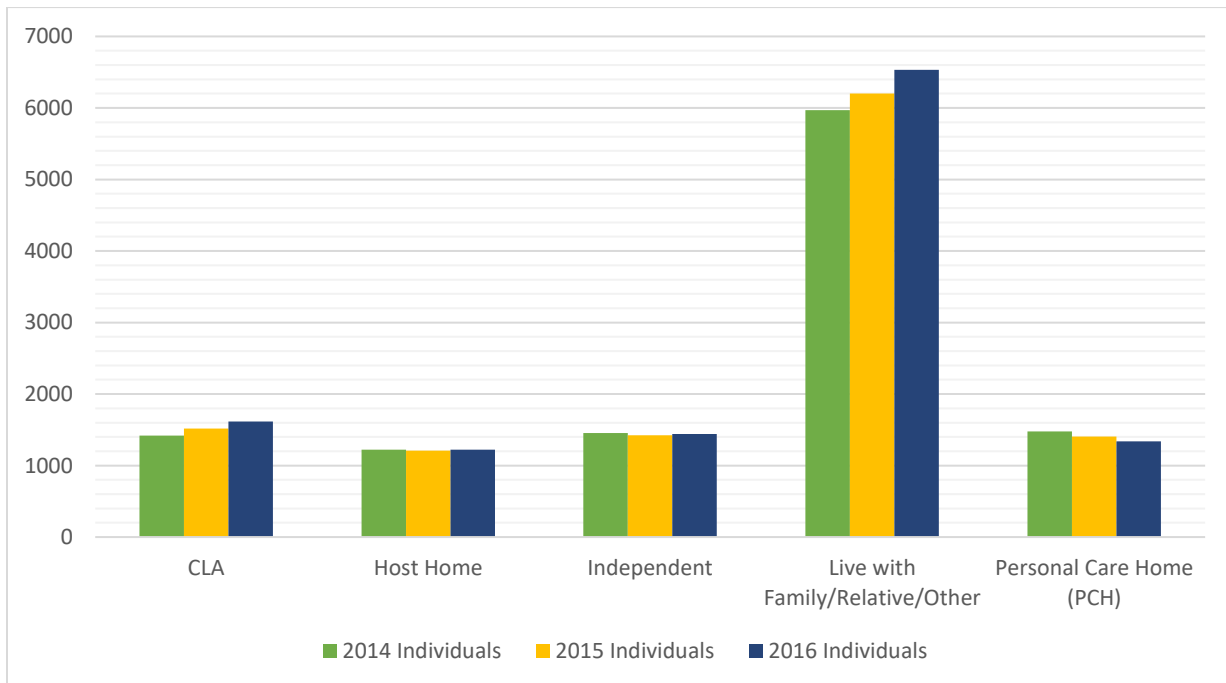
The number and percent of individuals living in each type of residential setting was similar across all years besides two categories in 2014 and 2016. The percent of people who were living in personal

care homes changed from 12.78% in 2014 to 11.00% in 2016; that change was statistically significant ($|z| = 4.225, p < .0001$). The proportion of people who were living independently changed from 12.60% in 2014 to 11.88% in 2016; that change was also statistically significant ($|z| = 3.158, p < .001$). Slightly fewer than 65% lived independently or with a family/relative/other in 2016, and approximately 35 percent resided in more intensive service settings (host homes, community living arrangements, and personal care homes).

Table 6: Distribution of Adults in Residential Settings in Intellectual and Developmental Disability Waivers, 2014-2016

Residential	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Community Living Arrangement	1,420	12.30%	1,519	12.92%	1,615	13.29%
Host Home	1,223	10.60%	1,210	10.29%	1,222	10.06%
Independent	1,454	12.60%	1,425	12.12%	1,443	11.88%
Live with Family/Relative/Other	5,970	51.72%	6,200	52.72%	6,534	53.77%
Personal Care Home	1,475	12.78%	1,406	11.96%	1,337	11.00%
Total	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 5: Distribution of Adults in Residential Settings in Intellectual and Developmental Disability Waivers, 2014-2016



Health Risk

The Health Risk Screening Tool (HRST) is a standardized mechanism used to determine an individual's vulnerability to potential health risks and the supports she or he needs to enable 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 facilitate 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.

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 7 below shows the risk level designations and points associated with each of the six health care levels used as a part of the HRST.

Table 7: HRST Health Care Levels

HRST: Health Care Levels		
Level 1:	(Low Risk)	0 to 12 points
Level 2:	(Low Risk)	13 to 25 points
Level 3:	(Moderate Risk)	26 to 38 points
Level 4:	(High Moderate Risk)	39 to 53 points
Level 5:	(High Risk)	54 to 68 points
Level 6:	(Highest Risk)	69 or greater

Table 8: Distribution of HRST Scores for Adults Receiving Intellectual and Developmental Disability Waivers, 2014-2016

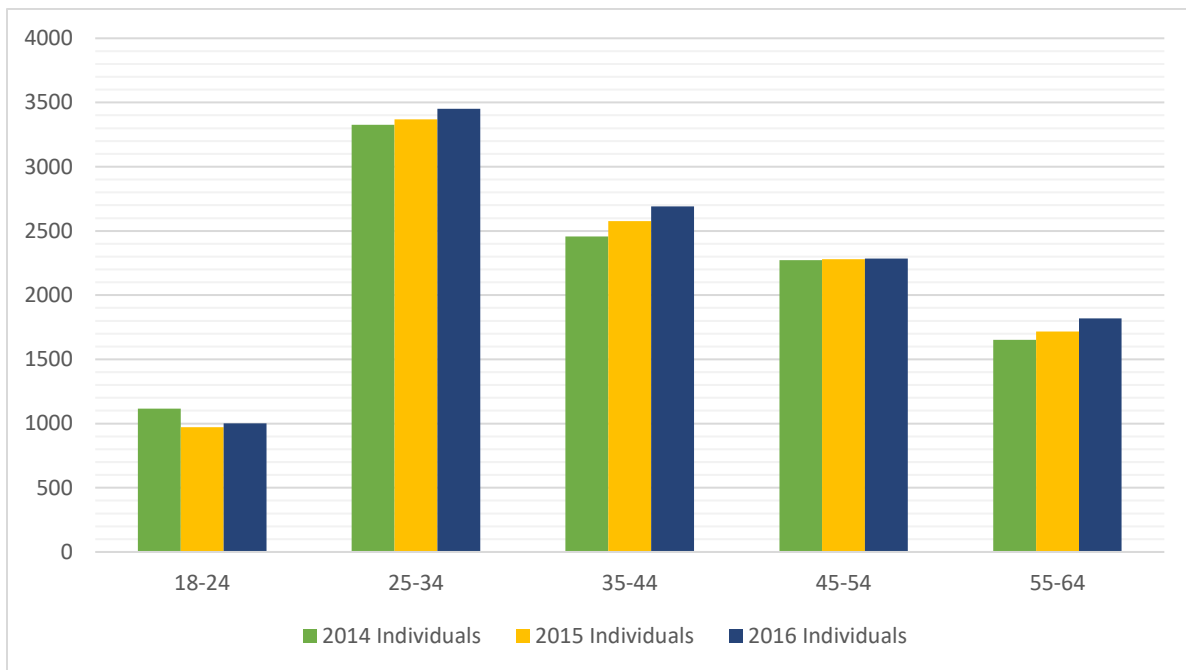
HRST	2014		2015		2016		Significance of 2015-2016 Change
	Count	% of population	Count	% of population	Count	% of population	
1	5,053	43.8%	4,799	40.8%	4,733	38.97%	z = 2.895 , p < .01
2	3,332	28.9%	3,500	29.8%	3,627	29.87%	NS
3	1,405	12.2%	1,497	12.7%	1,645	13.55%	NS
4	719	6.2%	802	6.8%	833	6.86%	NS
5	476	4.1%	545	4.6%	588	4.84%	NS
6	557	4.8%	617	5.2%	718	5.91%	NS
Total	11,542	100.0%	11,760	100.0%	12,144	100.00%	

The most current HRST during 2016 was used for this analysis. Seven individuals had missing values for the HRST field; so, the totals for tables involving HRST will be 12,144 instead of 12,151. Those individuals' other data were used in all non-HRST analysis. To manage the health and wellness of

individuals, DBHDD considers the individual assessment data and reasons for each score in addition to the actual HRST score. For the purposes of this report, HRST scores of 1, 2, and 3 are considered to be low-risk scores; HRST scores of 4, 5, and 6 are considered to be high risk. Low-risk HRST scores accounted for 82.4 percent of the population; high-risk HRST level accounted for 17.6 percent of the population. The distribution of each HRST remained similar across all levels except for HRST = 1, in which the number of individuals decreased significantly, by 1 percent ($|z| = 2.895$, $p < .01$).

The average HRST score for 2016 was 2.26 (SD = 1.453); the average HRST score for 2015 was 2.20 (SD = 1.422); and the average HRST score for 2014 was 2.13 (SD = 1.392). The average HRST scores across these three years were statistically different from each other, 2016 to 2015 ($|t| = 3.226$, $df = 23,902$, $p = .013$), 2016 to 2014 ($|t| = 7.025$, $df = 23,684$, $p < .001$). This means that, on the whole, there is a statistically significant increase in the amount of measured health risk in this population over time.

Figure 6: Distribution of HRST Scores for Adults Receiving Intellectual and Developmental Disability Waivers, 2014-2016



Multiple Variable Analyses

The previous analysis section described the intellectual and developmental disability waiver population by looking at one variable at a time. This section looks at relationships between two or more variables and their association to mortality.

Health Risk and Residential Setting

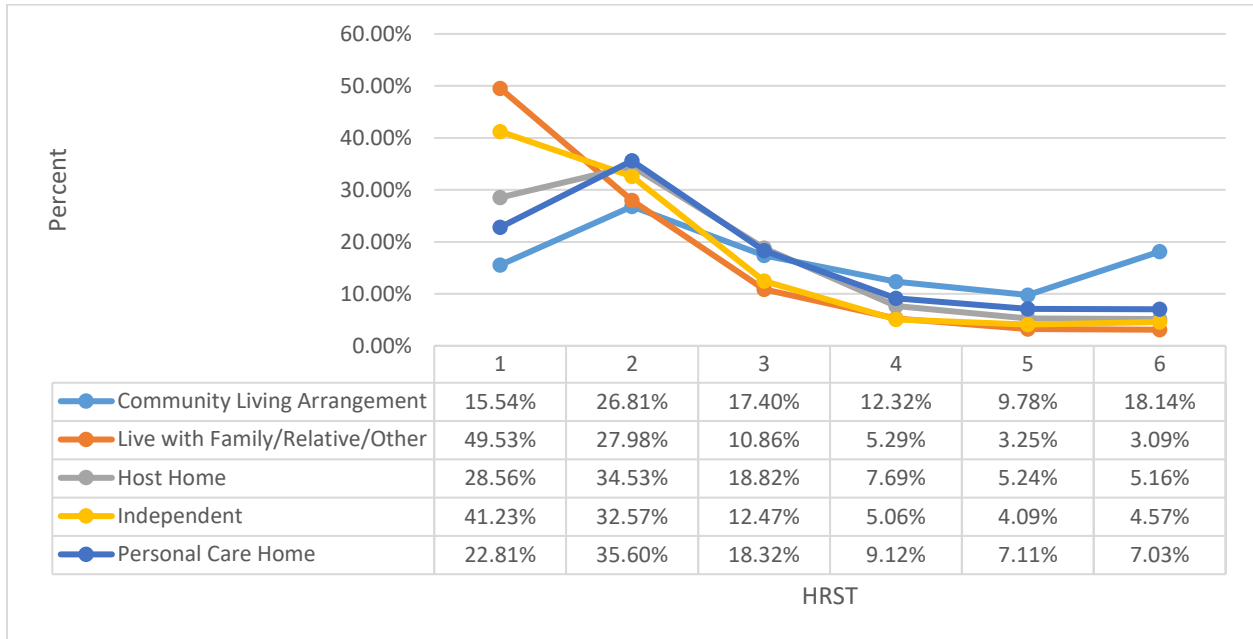
It is useful to consider the distribution of health risk scores across residential settings. Because host homes, personal care homes, and community living arrangements were categorized as the “high-intensity” residential settings, it is logical that higher HRST scores are distributed differently within those residential settings. For example, approximately 18 percent of people living in community living arrangements had a HRST score of six; in contrast, approximately three percent of people living with family, relatives, or other had a health care level of six. The percentages for other health care level groups within different living situations are presented in Figure 7. The percentages show that both low- and high-health risk individuals as categorized by health care level are present in all settings.

Categorized by type of residential setting, community living arrangements had the highest average HRST score 3.28 (SD = 1.720); personal care homes had the second highest average HRST score 2.63 (SD = 1.464), and live with family/relative/other had the lowest 1.94 (SD = 1.265). To compare the means across more than two groups, a statistical analysis using a one-way analysis of variance (ANOVA) indicated that the average HRST scores were different for the different residential settings. This result is concurrent with the information in Figure 7 which shows that a larger proportion of the high-intensity HCLs are in community living arrangements and personal care homes.

Table 9: Residential Setting by HRST Score, 2016

HRST	Residential Setting					Total
	Community Living Arrangement	Live with Family/ Relative/ Other	Host Home	Independent Apartment/ Home	Personal Care Home	
1	251	3,233	349	595	305	4,733
2	433	1,826	422	470	476	3,627
3	281	709	230	180	245	1,645
4	199	345	94	73	122	833
5	158	212	64	59	95	588
6	293	202	63	66	94	718
Total	1,615	6,527	1,222	1,443	1,337	12,151
Percentage	13.29%	53.72%	10.06%	11.88%	11.00%	100%

Figure 7: Residential Setting by HRST Score, 2016



Health Risk and Age

Health risk and age are important factors that need to be considered when investigating mortality. Within this population, high-level risk is 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. HRST scores are distributed similarly within each age group. Correlations between age (both as continuous and ordinal variables) indicate the association between HRST and age is weak (Pearson's $r = .08$, $p < .001$). 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.

Table 10: HRST by Age Category, 2016

Age	Count by HRST						Total	Percent by HRST						Total
	1	2	3	4	5	6		1	2	3	4	5	6	
18-24	275	329	154	87	57	94	996	5.8%	9.1%	9.4%	10.4%	9.7%	13.1%	8.2%
25-34	1,552	999	383	209	139	167	3,449	32.8%	27.5%	23.3%	25.1%	23.6%	23.3%	28.4%
35-44	1,215	773	319	151	103	129	2,690	25.7%	21.3%	19.4%	18.1%	17.5%	18.0%	22.2%
45-54	896	667	342	148	111	122	2,286	18.9%	18.4%	20.8%	17.8%	18.9%	17.0%	18.8%
55-64	570	582	298	145	99	124	1,818	12.0%	16.0%	18.1%	17.4%	16.8%	17.3%	15.0%
65-74	189	219	110	73	60	58	709	4.0%	6.0%	6.7%	8.8%	10.2%	8.1%	5.8%
75-84	34	49	35	19	18	21	176	0.7%	1.4%	2.1%	2.3%	3.1%	2.9%	1.4%
85+	2	9	4	1	1	3	20	0.0%	0.2%	0.2%	0.1%	0.2%	0.4%	0.2%
Total	4,733	3,627	1,645	833	588	718	12,144	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Mortality During 2016

This section contains information on deaths reported to DBHDD among the intellectual and developmental disability waiver population during calendar year 2016. Calendar years 2014 and 2015 are included for comparison purposes. Appendix A describes the method used to collect and analyze information and data contained in this section.

The respective mortality rates for 2014 and 2015 were 11.1 and 12.5 deaths per 1,000 individuals. The 2016 mortality rate was 14.0 deaths per 1,000 individuals; the mortality rates do not differ significantly across any years.

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, Massachusetts⁴ included all individuals who were eligible for services in the study population, regardless of whether or not 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.⁵ 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 or 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.

A search for peer-reviewed research for comparison data yielded data from four states. Compared to research 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 2016 intellectual and developmental disability mortality rate for DBHDD, 14.0 deaths per 1,000. The mortality rate for these states combined in 2011 was 9.37,⁵ which is significantly lower than the DBHDD 2016 mortality rate ($|z| = 4.999$, $p < .001$).

This report 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),⁶ which were significantly higher than the 2016 DBHDD mortality rates ($|z| = 6.736$, $p < .001$; $|z| = 3.898$, $p < .001$, respectively). Massachusetts reported mortality rates of 19.2 and 17.4 deaths per 1,000 in 2012 and 2013, respectively.⁴ DBHDD's 2016 mortality rates were significantly lower compared to Massachusetts' mortality rates in 2012 ($|z| = 3.465$, $p < .001$) and in 2013 ($|z| = 2.382$, $p = .009$). This difference is particularly striking in that Massachusetts included in the denominator all individuals receiving services, as well as those *eligible* for services, but included mortality information for only those individuals who

⁴ Commonwealth of Massachusetts, Executive Office of Health & Human Services, Department of Developmental Services. 2012 & 2013 Mortality Report.

⁵ 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.

⁶ Tennessee Department of Intellectual and Developmental Disabilities, Annual Mortality Report, 2013-2014 Fiscal Year.

actually *received* services in the numerator. DBHDD also searched for additional states' mortality reports as well as peer-reviewed mortality statistical reports, to no avail.

Age and Mortality

The average age of death in 2015 was 53.69 (SD = 15.40). The average age of death in 2016 was 53.54 years (SD = 15.40). The average age of death decreased by .15 years from 2015 to 2016; however, that change was not statistically significant. This means that as a whole, individuals who died in 2016 lived about the same length of time as those who died in 2015. The average age of death reported here falls within the 2009-to-2011 range for Connecticut, Louisiana, Ohio, and New York (combined), which was 50.4 to 58.7 years.

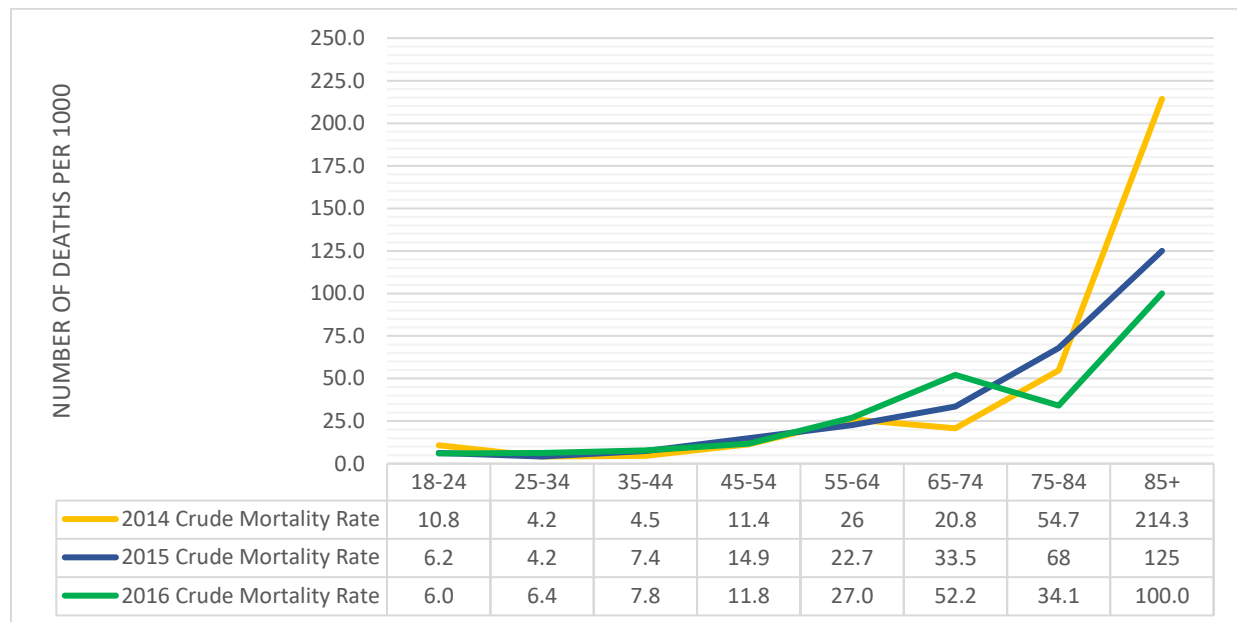
Table 11: Mortality Rates by Age Category, 2014-2016

		Age Category								Total
		18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
2014	Adult Waiver Population	1,116	3,327	2,456	2,273	1,651	577	128	14	11,542
	No. of Deaths	12	14	11	26	43	12	7	3	128
	Percent of Deaths	9.4%	10.9%	8.6%	20.3%	33.6%	9.4%	5.5%	2.3%	100.0%
	Crude Mortality Rate	10.8	4.2	4.5	11.4	26	20.8	54.7	214.3	11.1
2015	Adult Waiver Population	971	3,368	2,576	2,280	1,716	686	147	16	11,760
	No. of Deaths	6	14	19	34	39	23	10	2	147
	Percent of Deaths	4.1%	9.5%	12.9%	23.1%	26.5%	15.6%	6.8%	1.4%	100.0%
	Crude Mortality Rate	6.2	4.2	7.4	14.9	22.7	33.5	68	125	12.5
2016	Adult Waiver Population	1,002	3,450	2,690	2,286	1,818	709	176	20	12,151
	No. of Deaths	6	22	21	27	49	37	6	2	170
	Percent of 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

As in 2014 and 2015, mortality rates increase with increasing age (Table 11, Figure 8). In particular, between 2014 and 2015, 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 above this population level occurred in the 55-64 population.

Statistical comparisons of mortality rates between corresponding age categories from 2016 to 2015 were not significantly different, with the exception of the 65-74 group. The trends in Figure 8 are visually striking due to the absolute difference among 2014, 2015, and 2016 mortality rates for the 85+ age category, which were 214.3, 125.0, and 100.0 deaths per 1,000, respectively. The differences among proportions, however, were not statistically significant due to the small numbers of individuals in the 85+ age category. It is difficult to generalize mortality rate differences for the 85+ age group due to the low number of individuals in this category, as well as the small number of deaths. Also remarkable is the increase in the mortality rate in the 65-74 group. The difference between mortality rates in these groups is statistically significant between 2014 and 2016, indicating that this group's mortality rate has increased in recent years.

Figure 8: Mortality Rate by Age Category, 2014-2016



As noted above, the mortality rate for the age group 55-64 increases above the overall mortality rate for the population. From there, the mortality rate increases with age. (This pattern did not occur for the 75-84 group in 2016, but such a fluctuation is not abnormal for such a small subgroup.)

Other research⁷ found that mortality rates 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.⁷ The 2015 Georgia mortality rate for the 55-64-year-old category is 11.6 deaths per 1,000, and it increases with increasing age after 55.⁸

⁷ National Vital Statistics Report, Vol. 64 No. 2, February 16, 2016, p. 7.

http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf, accessed June 8, 2017.

⁸ <https://oasis.state.ga.us/oasis/webquery/qryMortality.aspx>, accessed June 8, 2017.

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., Georgia, and the DBHDD intellectual and developmental disability population, though the intellectual and developmental disability mortality rate is higher than those of the U.S. and Georgia.

Gender and Mortality

Gender was not an explanatory variable in mortality in 2014-2016. The 2016 mortality rate for females was 15.3 and 13.1 for males; the difference between the two was not statistically different. The average age of death for females was 56.4 and 51.2 for males.

Table 12: Number of Deaths, Average Age at Death and Mortality Rate by Gender 2014-2016

		Female	Male	Total
2014	Adult Waiver Population	4,824	6,718	11,542
	No. of Deaths	59	69	128
	Percent of Deaths	46.1%	53.9%	100.0%
	Average Age at Death	51.9	51.4	
	Crude Mortality Rate	12.2	10.3	11.1
2015	Adult Waiver Population	4,892	6,868	11,760
	No. of Deaths	63	84	147
	Percent of Deaths	42.9%	57.1%	100.0%
	Average Age at Death	55.4	52.4	
	Crude Mortality Rate	12.9	12.2	12.5
2016	Adult Waiver Population	5,044	7,107	12,151
	No. of Deaths	77	93	170
	Percent of Deaths	45.3%	54.7%	100.0%
	Average Age at Death	56.4	51.2	
	Crude Mortality Rate	15.27	13.09	14.0

Age, Residential Setting, and Mortality

The average age of death was 53.5 (SD = 15.40) in 2016. The average age of death for residential settings ranged between 44.0 and 59.0 years. The average age of death for individuals who lived in less-intensive residential settings was 46.4 (SD = 15.56). The average age of death for individuals who lived in more-intensive settings was 57.83 (SD = 16.67). The difference between the average age of death for these two groups is statistically different ($|t| = 4.863$, $df = 119.79$, $p < .001$). This means that individuals who died in 2016 who resided in more-intensive residential service settings lived longer than those who received services in less-intensive service settings.

It should be noted, however, that individuals living with family, friends, or others had the second lowest mortality rate (8.3 deaths per 1,000); combined, the lower-intensity residential setting group had a mortality rate of 8.02, which is significantly lower than the rate for the total population 14.0 deaths per 1,000 ($|z| = 3.863$, $p < .001$). The lowered average age at death in the living with family friends or others group makes it seem like those living at home may have a higher risk of death than others. That is not the case: the population of people living at home is much younger on average than those in other settings; so, the average age of death is naturally lower regardless of the mortality rate. This result and further analysis are presented in Appendix C.

Residential-setting-specific mortality rates range from 6.9 to 36.5. The mortality rate for the three higher-intensity residential settings combined is 25.4. In 2015, the mortality rate for these three high-intensity residential setting combined was 20.6. The mortality rate for the two lower-intensity residential settings combined was 8.0 in 2016 and 8.1 in 2015. The mortality rates for 2015 and 2016 do not differ significantly between similar categories of residential settings. The mortality rate for the high-intensity service setting, however, is significantly higher than the lower-intensity service setting mortality rate in 2016 ($|z| = 7.743$, $p < .0001$).

Table 13: Average Age at Death and Mortality Rate by Residential Setting, 2016

Residential Setting	Adult Population	Percent	% of Population 65+	No. Deaths	Average Age at Death	Crude Mortality Rate
Personal Care Home (PCH)	1,337	11.0%	14.73%	31	58.2	23.2
Community Living Arrangement (CLA)	1,615	13.3%	11.64%	59	57.6	36.5
Host Home	1,222	10.1%	10.88%	16	58.2	13.1
Independent Apartment/ Home	1,443	11.9%	12.54%	10	59.0	6.9
Live with Family/ Relative/Other	6,534	53.8%	3.15%	54	44.0	8.3
Total	12,151	100.0%	7.45%	170	53.5	14.0

Health Risk and Mortality

Similar to previous years, there is statistical association between health risk score and mortality rate in 2016. Lower HRST scores (1-3) have a group mortality rate (7.6 deaths per 1,000) that is below the population mortality rate in 2016 (14.0 deaths per 1,000). The mortality rates associated with an HRST score of (4-6) exceed the overall population mortality rate by a large margin (29.9 deaths per 1,000).

The mortality rate for lower HRST scores (1-3) is 7.6; the mortality rate for the higher HRST scores (4-6) is 43.95, which is significantly higher ($|z| = 12.958$, $p < 0.001$). The disparity between consecutive levels four and five was the largest (20.4 and 54.42 deaths per 1,000 individuals, respectively) ($|z| = 3.461$, $p < 0.001$). It should be noted that despite the visual separation of mortality rates between health care levels five and six (Figure 9), these two mortality rates are not statistically different. These analyses clearly indicate that increasing health risk was significantly associated with mortality, which is especially true for health care levels five and six. In other words, particular attention should be given to health care levels five and six due to their significant association with mortality.

Results from previous years have consistently indicated that a two-point increase in health care level scores is associated with a significant association with mortality. Analysis of 2016 data indicate that this pattern holds still, though there is a significant increase in the mortality rate between health care levels one and two. Therefore, consistent with previous years, it is important to consider a one-point change in health risk scores to address the increased association between increasing health risk and mortality that occurs with a two-point health risk score increase. Furthermore, particular attention should be given to health care level four (in addition to health care levels five and six). First, health care level four is the health risk level that moves above the overall population mortality rate. Secondly, an increase of one health care level score above four would move individuals into a level of risk more significantly associated with mortality (i.e., health care level five/six).

DBHDD has begun further analyses to identify additional information that may provide further understanding of the relationship among health status, health risk, and mortality. For example, mortality analyses of 2013-2016 data have used the health care level of the HRST to understand the relationship between health risk and mortality; the health care level is a summary score. The HRST also provides subscale- and item-level information that may indicate particular health conditions or risks that may be related to mortality, even when the overall summary score provided by the health care level does not. DBHDD is undertaking careful analyses of these subscales and items in the context of mortality outcomes, along with analysis of additional information, to attempt to identify additional findings that may be useful to reduce the risk of unnecessary deaths. These analyses, observations, and findings will be presented to the Division of Developmental Disabilities and DBHDD when they become available.

Figure 9: Mortality Rate by HRST Score, 2014-2016

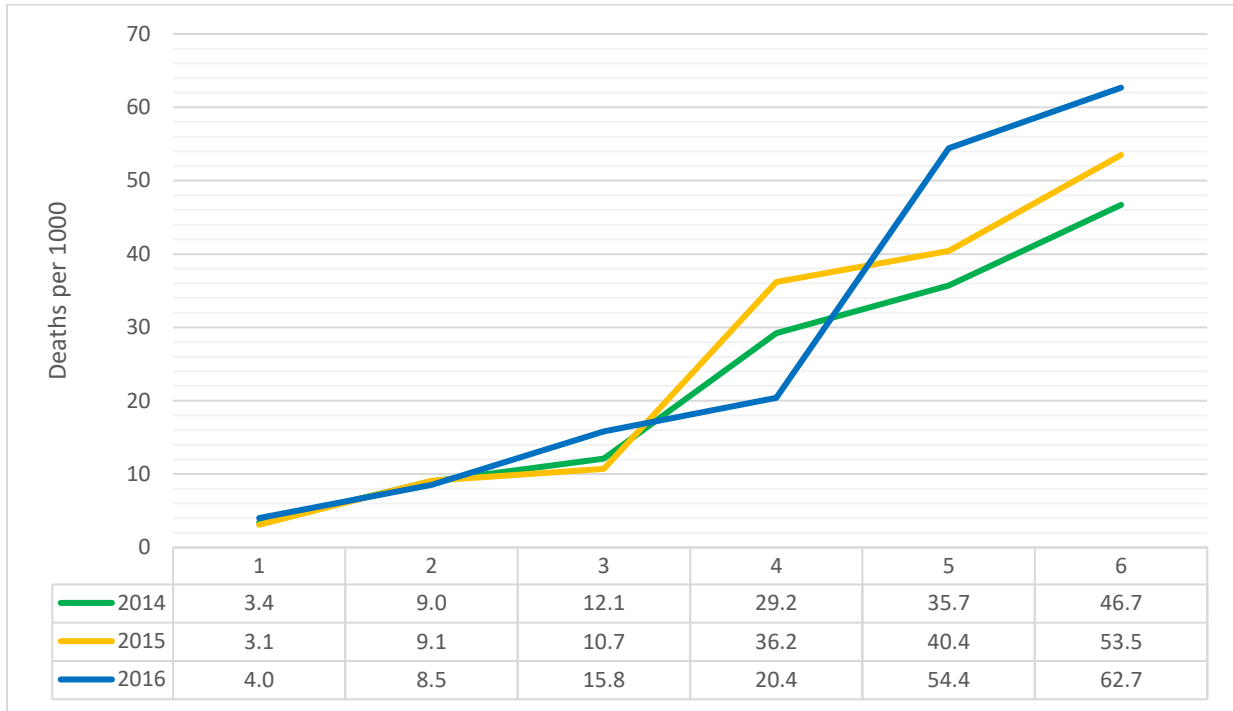


Table 14: Mortality Rate by HRST Score, 2016

HRST Score	2016				
	Adult Waiver Population	No. Deaths	Percent of deaths	Crude Mortality Rate	Statistical significance between HRST Scores
1	4,733	19	11.2%	4.0	(z = 2.664, p = 0.003)
2	3,627	31	18.2%	8.5	(z = 2.361, p = 0.009)
3	1,645	26	15.3%	15.8	NS
4	833	17	10.0%	20.4	(z = 3.461, p < 0.001)
5	588	32	18.8%	54.4	NS
6	718	45	26.5%	62.7	
Grand Total	12,144	170	100.00%	14.0	

The Importance of Age and Intensity of Residential Setting

Data analyses to this point have examined the relationship of age, gender, region, residential setting, and health risk as they individually, or in pairs, relate to mortality. Examining the contribution of one variable or a small set of variables at a time to mortality rates is useful. 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. Subsequent discussion in this report considers how age, gender, region, residential setting, and health risk together are associated with mortality to determine which variables may be of key importance in understanding it.

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. That means, logistic regression analysis about, for example, 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 in that the information from the model can be used to calculate the odds ratio that an event occurred given the effect of one or more variables. An odds ratio is a measure of association between a variable and an outcome occurring, such as death in these analyses. 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. An odds ratio of 1 indicates that the variable of interest does not affect the odds of death occurring; odds ratios greater than 1 indicate that the variable is associated with higher odds of death occurring; odds ratios less than 1 indicate that the variable is associated with lower odds of death occurring.

Age, gender, region, intensity of residential intensity setting, and HRST score were used together to analyze which variables were associated with death in 2016. Only age and health risk scores were significantly associated with occurrence of death. This means that when controlling for age and health risk level, region, gender, and residential setting were not significantly associated with the occurrence of death. It should be noted that the logistic regression analysis for 2013-2016 are very similar.

Table 15: Final Logistical Regression Model with Death as Outcome, 2016

Variable	B	S.E.	Wald	df	Sig.	Exp(B)
Age	.044	.005	8.560	1	.000	1.045
HCL	.527	.044	11.970	1	.000	1.695

The odds of dying increase significantly with increasing age. According to the logistic regression model estimates of association, at 20 years old, the odds of dying are small (i.e., .0008797). However, with each 10-year increase in age, the odds of dying increase multiplicatively, such that the odds of dying at 40 almost triples compared to age 20; the odds of dying at 50 are more than four times greater than at 20. Finally, by age 70, the odds of dying are almost 10 times higher than they are at 20. The main point

made here is that increasing age has a very strong, exponential relationship to the likelihood that death may occur. (The referent age for Table 17 is 18. Each odds ratio represents the increase in odds from that age.)

The odds of dying increase significantly with increasing health care level scores. Those with an HRST score of 3 had an estimated five times higher increase in odds of having died in 2016. Those with HRST scores of six had 23.62 times increased odds of having died in 2016. This relationship indicates that the odds of death increases exponentially with increasing HRST scores in 2016.

It is worth noting that death is a relatively rare outcome; so, even a large increase in odds (such as with the upper values of HRST and age), does not mean that someone with these attributes is in great danger of death; it only means that people in those groups were more *likely* than others to experience the death. It is also worth noting that statistical association does not indicate causation. (Refer back to the discussion about statistical analysis on page 11.)

Table 16: Odds Ratio for 10 Year Age Difference, 2013-2016

HCL	OR 2013	OR 2014	OR 2015	OR 2016
1	1.65	1.61	1.66	1.69
2	2.72	2.60	2.77	2.87
3	4.48	4.20	4.60	4.86
4	7.39	6.77	7.66	8.23
5	12.18	10.91	12.74	13.94
6	20.09	17.60	21.20	23.62

Table 17: Odds Ratio for 10 Year Age Difference, 2013-2016

Age	OR 2013	OR 2014	OR 2015	OR 2016
20	1.07	1.08	1.08	1.09
30	1.52	1.61	1.71	1.69
40	2.16	2.41	2.41	2.63
50	3.06	3.60	4.22	4.08
60	4.35	5.37	6.62	6.34
70	6.17	8.00	10.38	9.86

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 and COMP waivers during the 2016 calendar year. Statistical analyses are useful for identifying factors or variables and trends that are associated with mortality, which provides information for improvement of service quality. It is also helpful to consider other, more detailed mortality data from mortality reviews that were conducted in 2016, which is presented next.

Community Mortality Review Committee and Deficient Practice Analysis

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 effective November 1, 2015.

Categories of Deaths

The department's incident management policy, [Reporting and Investigating Deaths and Critical Incidents in Community Services, 04-106](#), is an integral part of the CMRC process. This policy requires providers to self-report deaths (and other critical incidents). It identifies categories of deaths and incidents based on risk and establishes reporting timeframes and investigation requirements accordingly. Not all deaths require an investigation or a review by the CMRC.

The CMRC reviews deaths of individuals served by the DBHDD who meet the following criteria:

- Receive residential services or 24/7 community living support;
- Die on the site of a community provider or in the company of staff of a community provider; or
- Are absent without leave from residential services.

Further, the deaths identified above may be unexpected—not attributed to the natural course of a diagnosis or a diagnosed disease where the reasonably expected outcome is death (Category 1)—or expected—attributed to a terminal diagnosis or a diagnosed disease where the reasonably expected outcome is death (Category 2). The CMRC reviews all Category 1 deaths and Category 2 deaths identified for review by the DBHDD medical director or director of Office of Incident Management and Investigations.

Purpose of CMRC

The CMRC reviews factual information to determine ways to improve the quality of services. The goals of the CMRC include the following:

- To conduct mortality reviews using a clinical and systematic interdisciplinary review of deaths;
- To evaluate the quality and efficiency of services and supports to the individual;
- To evaluate compliance of the provider with applicable laws, rules, regulations, and standards;
- To identify possible gaps in services;
- To make referrals to other governmental entities of identified individual and system issues;
- To monitor support systems and programmatic operations to ensure reasonable medical; educational, legal, social, or psychological interventions were being provided prior to deaths;
- To ensure that risk factors for mortality are identified and prevention strategies implemented; and
- To recommend statewide action based on mortality information to improve care systematically.

Membership

The CMRC represents a multidisciplinary, inter-professional team consisting of physicians, including the DBHDD medical director, nurses and other health care professionals, quality improvement staff, legal staff, program staff, investigative staff, representatives from advocacy organizations, and representatives from the provider community. The variety of professionals with differing experiences and responsibilities brings different knowledge and perspectives to the mortality review process and serves to improve the quality of the mortality review findings.

Process

The CMRC is a significant source of information and a major component of DBHDD's quality improvement system, and reflects the department's ongoing commitment to reviewing and learning from critical information gathered during investigations of deaths of individuals served by the department. DBHDD is committed to a systematic, thoughtful, and detailed review of deaths and the opportunity such a review presents for organizational learning and corrections at the provider, department, and system levels.

The CMRC meets at least monthly to review all internal and external investigative reports and mortality reviews. The CMRC seeks to determine whether necessary and reasonable measures were taken to provide for the health, safety, and welfare of the individual receiving services; what statewide actions may reduce risks, including provider training, communication with providers relative to risks, alerts, and opportunities for learning and training; identify and mitigate any findings that could affect the health, safety, and welfare of other individuals; and make recommendations to providers and DBHDD. These recommendations are evaluated to identify deficient practices. When deficient practices are identified, they are managed by DBHDD through a corrective action plan tracking system.

Corrective Action Plans

A corrective action plan is a plan developed by the reviewed entity as a response to deficient practices/problems identified in a written report. The following elements are present in an acceptable corrective action plan:

Identified Cause: The cited entity's determined cause of the deficient practice and the method that the entity used to determine the cause;

Corrective Action: A plan that contains the steps or actions that have been or will be taken to correct the deficient practice and address the identified cause;

Target Date: An anticipated date for the accomplishment of the corrective action; and

Measures of Effectiveness/Monitoring: A description of how the entity will monitor the corrections to ensure that the corrective actions have successfully resolved the issues.

Deficiency Tracking

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. CMRC reviews may reveal no deficient practices, and CMRC reviews may reveal multiple deficient practices for each

death, resulting in tracking multiple deficiencies and corrective actions. 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](#).

The analysis of deficient practices and deficiency tracking presented below is based on data from CATS. These 2016 CMRC and CATS data and analysis are presented as baseline performance. Not all deaths are reviewed by the CMRC, and DBHDD has requested an external agency review 11 cases that were not completed at the time of this report were written and, therefore, not included in these analyses.

The CMRC purposively selects deaths for review based on policy. Deaths reviewed are not selected to be a representative sample of deaths for the DBHDD intellectual and developmental disability population each year.

Due to small sample sizes, not having all data from some external reviews, not having a representative sample of all intellectual and developmental disability deaths reviewed by CMRC, and having only one year of data, statistical analysis is not advisable at this time. Finally, the reader is cautioned from generalizing findings and observations from the CMRC analysis below to the DBHDD intellectual and developmental disability population.

Statewide Analysis of Number and Type of Deficient Practices

DBHDD distinguishes between “deficient practices” and “recommendations.” 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. A corrective action plan is required for critical-, high-, and moderate-risk practices. DBHDD required providers to submit corrective action plans for 138 deficient practices that were identified as either placing the individual or having the potential to place individuals at critical-, high-, and moderate-risk levels.

Seventy-nine practices were deemed to have low risk. (Providers were requested to correct these.) Recommendations made as the result of a CMRC review are sent to the provider. DBHDD requests providers respond or comment to recommendations identified as the result of CMRC reviews.

Critical Risk: Statewide

Provider practices identified in 2016 with the potential for causing or having caused serious injury, harm, impairment or death to individuals were related to health and safety. The most common critical-risk provider practices centered on health and wellness/medical, including failure to respond to an apparent change in individuals’ health condition and failure to respond to an emergency in a manner that would protect the welfare of the individual. In 10 instances, provider practices were classified as neglectful, which also was a commonly-identified critical-risk practice. (DBHDD refers instances of abuse, neglect, and exploitation to external investigative agencies, as appropriate.) As mentioned earlier, DBHDD requires providers to submit a corrective action plan to address critical-risk provider practices. At the time this report was written, most issues were resolved/closed.

Table 18: Critical-Risk Count: Statewide

CRITICAL RISK	29
Health & Safety	29
Abuse/Neglect/Exploitation	10
Neglect	10
Coordination of Care	1
Communication/Collaboration	1
Health and Wellness/Medical	13
Response to change in condition	6
Response to emergency	7
Medication Management	3
Medication errors	2
Storage, dispensing, administration	1
Physical Environment and Life Safety/Emergency Planning	1
Emergency and disaster planning	1
Staff Issues	1
Scheduling/availability of staff	1

High Risk: Statewide

Deficiencies at the high-risk level have resulted in a negative outcome to an individual. A closer examination of the high-risk provider practices that may cause harm to individuals shows similarities with the critical-risk practices: health and safety is the most common high-risk practice area. Again, health and wellness/medical had the most areas of concern, specifically, providers failing to respond to changes in individuals’ condition, attending to medical care needs, and failure to respond appropriately to emergencies. Four instances of neglectful provider practices were identified as high risk. (DBHDD refers instances of abuse, neglect, and exploitation to external investigative agencies, as appropriate.)

Table 19: High-Risk Count: Statewide

HIGH RISK	25
Compliance	4
Abuse/Neglect/Exploitation	1
Neglect	1
Health and Wellness/Medical	1
Physical care, wellness, preventative	1
Leadership/Governing Body	1
Supervision and Oversight	1
Planning and Program Integrity	1
Scope of Practice	1
Health & Safety	21
Abuse/Neglect/Exploitation	3
Neglect	3
Coordination of Care	2
Communication/collaboration	2
Health and Wellness/Medical	9
Medical care needs	3
Response to change in condition	4
Response to emergency	2
Leadership/Governing Body	1
Oversight of Service Provision	1
Medication Management	1
Monitoring	1
Provision of Care and Treatment	4
Assessment/treatment planning	1
Special Needs Issues	2
Adherence to treatment plan	1
Training	1
Training for Individualized Care	1

Moderate Risk: Statewide

Deficiencies at the moderate-risk level have the potential to result in no more than minimal physical, mental, or psychosocial discomfort. The most common moderate-risk provider practice area was related to provider practices concerning the health and safety of individuals. Health and safety-deficient practices including failure to attend appropriately to medical care needs, failure to respond to changes in condition, and failure to respond to emergencies. Overall, however, the single most common deficient practice was failure to document care adequately.

Table 20: Moderate-Risk Count: Statewide

MODERATE RISK	84
Compliance	19
Documentation of Care	1
Progress/Clinical note	1
Financial	1
Billing integrity, justification	1
Leadership/Governing Body	3
Oversight of Service Provision	1
Policy, procedure, protocol development	2
Planning and Program Integrity	4
Adherence to service guidelines/requirements	2
Information Management	1
Screening, referral, eligibility processes	1
Provision of Care and Treatment	1
Individual Engagement	1
Risk Management/Quality Improvement	7
Failure to report incidents	5
Failure to conduct investigation	1
Quality Improvement Process and Systems Issues	1
Staff Issues	2
Staff Credentialing, qualifications, competence	2
Health & Safety	62
Abuse/Neglect/Exploitation	1
Neglect	1
Coordination of Care	3
Communication/collaboration	3
Documentation of Care	21
Medication documentation	6
Miscellaneous	1
Progress/Clinical notes	12
Tracking sheets	2
Health and Wellness/Medical	17
Medical care needs	7
Response to change in condition	6
Response to emergency	4
Infection Control	1
Universal Precautions	1
Leadership/Governing Body	2
Oversight of Service Provision	1
Policy, procedure, protocol development	1

Medication Management	3
Medication Errors	2
Storage, dispensing, administration	1
Provision of Care and Treatment	10
Adherence to treatment plan	3
Assessment/treatment planning	3
Individual Engagement	1
Miscellaneous	1
Special Needs Issues	1
Unauthorized Service Provision	1
Risk Management/Quality Improvement	1
Failure to report incidents	1
Training	3
Policy & Procedure training	1
Required Training/Licensure/Certification	1
Training for Individualized Care	1
Operational	3
Documentation of Care	1
Progress/Clinical notes	1
Provision of Care and Treatment	2
Billing Integrity, justification	2

Regional Analysis of Number and Type of Deficient Practices

Region 2 had the largest number of identified critical deficient practices and accounted for 24.1 percent of critical-risk provider practices identified. Region 5 had 20.7 percent of the critical deficient provider practices identified. Regions 2 and 3 had the highest number of deficient practices that were identified as having high risk to individuals (8, 32.0%; 7, 28%, respectively). Regions 4 and 2 had the most deficient practices that were identified as posing moderate risk to individuals (30, 35.7%; 21, 25%, respectively).

When one considers the 138 total number of critical-, high-, and moderate-risk practices that were identified during the CMRC (recalling that these levels of deficient practices require corrective actions to be submitted to DBHDD), Regions 2 and 4 have the highest number of these levels of deficient practices (each having 36, 26.1%), which account for 52.2 percent of all critical-, high-, and moderate-level risk practices identified. Region 3 had 30 critical-, high-, and moderate-level deficiencies combined, which accounted for 21.7 percent of all deficiencies of these levels. It should be noted, however, that Region 3 has the highest number of individuals being served, as well as the highest number of CMRC reviews where no deficiencies were identified. In comparison, then, Regions 2 and 4 are consistently identified as standing out from other regions in terms of having deficient practices that place individuals at critical-, high-, and moderate-risk levels of potential harm. It should be noted that Region 2 served 863 more individuals than Region 4, indicating that Region 4 stands out most as having deficient provider practices identified as part of mortality reviews.

Table 21: Regional Analysis of Number and Type of Deficient Practices

Region	Count					
	Population	Critical Deficiencies	High Deficiencies	Moderate Deficiencies	Low Deficiencies	No Deficiencies Found
1	2,501	3	3	8	13	9
2	2,148	7	8	21	16	10
3	3,062	4	7	19	18	9
4	1,285	4	2	30	24	8
5	1,431	6	4	2	1	3
6	1,724	5	1	4	7	3
Total	12,151	29	25	84	79	42

Region	Percent				
	Critical Deficiencies	High Deficiencies	Moderate Deficiencies	Low Deficiencies	No Deficiencies Found
1	10.3%	12.0%	9.5%	16.5%	21.4%
2	24.1%	32.0%	25.0%	20.3%	23.8%
3	13.8%	28.0%	22.6%	22.8%	21.4%
4	13.8%	8.0%	35.7%	30.4%	19.0%
5	20.7%	16.0%	2.4%	1.3%	7.1%
6	17.2%	4.0%	4.8%	8.9%	7.1%

The main points concerning deficient practices identified in the course of CMRC reviews, when considering the 138 combined critical-, high-, and moderate-risk practices conjointly (that require a corrective action plan), one notices substantial overlap in three areas:

Health and Wellness Medical (40, 28.9% of all critical/high/moderate deficiencies)

- Deficient response to change in condition
- Deficient response to an emergency
- Deficient response to medical care needs

Neglect (15, 10.9% of all critical/high/moderate deficiencies)

Documentation of Care (23, 16.7% of all critical/high/moderate deficiencies)

- Deficient progress/clinical notes
- Deficient medication documentation

The overlap among the areas above account for 78 of the 138 identified deficient practices that require a corrective action plan. Though corrective action plans are intended to remediate deficient provider practices and mitigate further risk, the prevalence (57%) of the abovementioned common deficient practices may indicate additional areas for improvement.

Key Findings

- The 2016 DBHDD NOW and COMP waiver mortality rate was 14.0 deaths per 1,000 individuals. The 2016 mortality rate did not differ significantly from the DBHDD NOW and COMP waiver mortality rates in 2014 and 2015.
- The 2016 DBHDD NOW and COMP waiver mortality rate of 14.0 in all except one comparison with other states' mortality rates was significantly lower; however, caution should be used in interpreting or generalizing these differences.
- Increasing age (as in previous years) is significantly associated with the occurrence of mortality.
- Increasing health risk was associated with mortality in 2013-2016.
- In 2013-2015, mortality increased markedly after the age group of 45-54. This year, mortality increases markedly after ages 55-64—a pattern also found in the general U.S. and Georgia populations.
- Life expectancy for the 2016 NOW and COMP waiver population (53.5 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 disease was the leading cause of death in the general populations of U.S. (2014), Georgia (2015), DBHDD 2016 NOW and COMP waiver population. As in past years, at least half of the top 10 leading causes of causes of death in the U.S. and Georgia and the most prevalent causes of death in the NOW and COMP waiver population in 2016 were similar.
- Four of the leading causes of death for the 2016 NOW and COMP waiver population were not common to the top causes of death in the U.S. and Georgia during 2014 and 2015 included disability, aspiration pneumonia, sepsis, and epilepsy/seizures.
- DBHDD required providers to submit corrective action plans for 138 deficient practices that were identified as either placing the individual or having the potential to place individuals at risk. As of the date this report was written, most of the reviews identifying deficient practices were closed.
- The most common deficient provider practices that required corrective action centered on health and wellness/medical, including failure to respond to an apparent change in individuals' health condition, such as failures in responding to a person's medical needs, failure to respond to an emergency in a manner that would protect the welfare of the individual.
- Fifteen provider actions were identified as neglectful, and deficient practices regarding documentation of progress/clinical notes/medication were also among most common.
- 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)

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 and 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 of 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 and COMP waiver during 2016 were categorized into the waiver where they were last enrolled.

The data used to calculate mortality rates per 1,000 people by age group and type of residence was supplied by the Waiver Information System (WIS) Medicaid information system and Reporting of Critical Incidents (ROCI). WIS Medicaid information 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 was 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 Status Risk Screening Tool (HRST) score (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 $\alpha = .01$. Setting $\alpha = .01$ 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.

$$\text{Crude Mortality Rate} = \frac{(\text{Number of people who died in calendar year} \times 1,000)}{(\text{Number of adults who received waiver service during the calendar year})}$$

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 2016.

Analyses were conducted using R,⁹ including tests of significance and logistic regression. In order to facilitate the interpretation of coefficients, variables were not transformed. The variables used for the logistic regression follow:

Death (outcome): 0 = No death 1 = Death

Age: Continuous

Gender: Female = 0 Male = 1

HRST: Continuous (1-6)

Intensity of Residential Setting

Lower Intensity = 0

Independent apartment/home

Live with family/relative/caretaker/friend

Higher Intensity = 1

Personal care home

Community living arrangement

Host home

All variables were entered into a single step, 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.

⁹ R Core Team. (2016). R: A Language and Environment for Statistical Computing. R Foundation for Statistical Computing, Vienna, Austria. <https://www.R-project.org>.

Appendix B: Regions of DBHDD

The DBHDD system of services is administered through six regional field offices. Each field office is responsible for the following:

- Communicating and implementing department policy at the local level;
- Developing annual regional plans in conjunction with the regional advisory councils;
- Managing allocated funds and contracting with providers for mental health, substance use disorder, and intellectual and developmental disability services for individuals eligible to receive these services through the public sector;
- Facilitating and determining eligibility for intellectual and developmental disability services, managing the planning lists, and authorizing services;
- Managing the provider network by routinely meeting with providers to improve existing services, plan for the implementation of new services, ensure consumer access to services, and improve quality of services;
- Developing and promoting effective working relationships with all stakeholders in the region, through regular meetings with providers, consumers, individuals, family members, advocates, elected officials, regional advisory council members, and other social service agencies; and
- Investigating and resolving complaints and conducting special investigations as needed.

Region Descriptions (map on following page):

Region 1 covers 31 predominantly rural counties of Northwest and Northeast Georgia (total population: more than 2.5 million).

Region 2 covers 33 counties of East and Central Georgia (total population: 1.27 million).

Region 3 covers 6 counties, which includes the capital city of Atlanta (total population: 2.9 million).

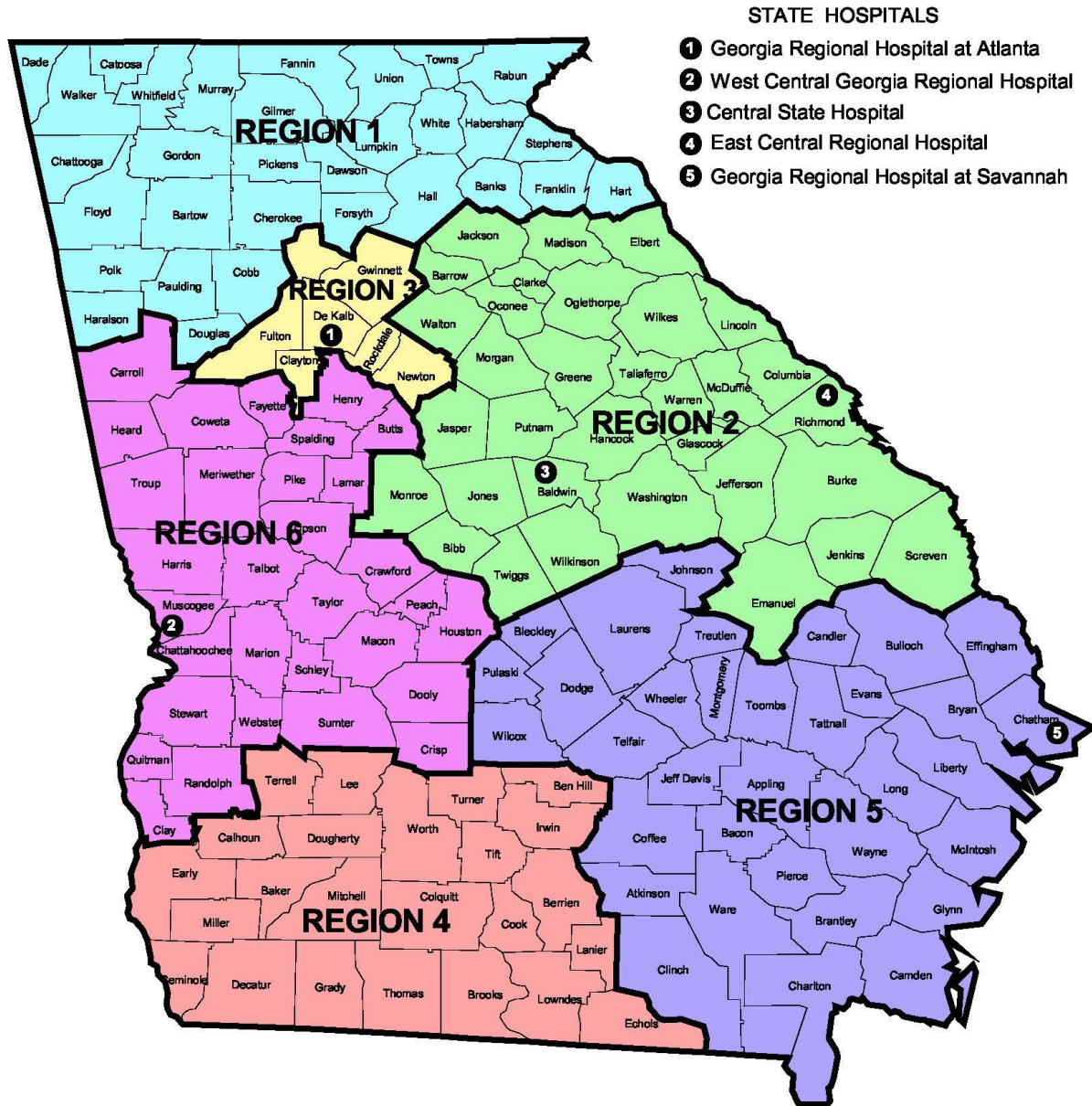
Region 4 covers 24 predominantly rural counties in Southwest Georgia (total population: 611,590).

Region 5 covers 34 counties in Southeast Georgia (total population: 1.1 million).

Region 6 covers 31 counties in West-Central Georgia (total population: 1.37 million). Two-thirds of the region is rural.

Figure 10: DBHDD Regional Map with State Hospital Locations

**Georgia Department of Behavioral Health & Developmental Disabilities
REGIONAL MAP with STATE HOSPITAL LOCATIONS
EFFECTIVE 1/1/2014**



Appendix C: Logistic Regression for Living at Home

The population of individuals living at home with their family, a friend, or someone else had lower mortality rates in 2016 than many of the other more-intensive living situations; yet, the population's average age of death was lower than others. A logistic regression model was generated using only the individuals in the family, friend, or other residential setting category. The results are the same as those for the overall population. The association between age and mortality remained much like the overall model. The association between HRST and mortality was also largely the same; so, there are no differences between variables and their respective associations to mortality for those in the aforementioned population and others in the waiver population examined in the primary analysis.

It was found, however, that the distribution of individuals living at home with family/relative/other had a lower average age than any of the other living situations. The average ages of death are presented in Table 22. Their low average age of death is an effect of the low age of the population. This way, the population can have a low mortality rate yet a low average age of death.

Table 22: Logistic Regression Model with Death as Outcome, 2016

Variable	B	S.E.	Wald	df	Sig.	Exp(B)
HCL	.492	.079	6.218	1	.000	1.636
Age	.039	.009	4.170	1	.000	1.039

Table 23: Statistics on Age Stratified by Living Situations

Living Situation	Mean	SD	Median
Independent	48.106	13.557	47.675
Live with Family/Relative/Other	37.871	12.647	35.071
PCH	49.881	13.738	51.180
CLA	47.235	14.487	47.949
Host Home	44.269	15.361	42.852