

# 2017 Annual Mortality Report

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



Georgia Department of Behavioral Health and Developmental Disabilities

August 16, 2018

This is the fourth annual report on mortality, mortality trends, and related information pertaining to the health and care received by individuals with intellectual and developmental disabilities who are 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.

## Table of Contents

Executive Summary .....	3
Major Findings .....	3
<b>About DBHDD .....</b>	<b>5</b>
Vision .....	5
Mission.....	5
<b>About DBHDD Intellectual and Developmental Disability Services .....</b>	<b>5</b>
<b>Scope of this Report.....</b>	<b>6</b>
<b>Causes of Death among the Intellectual and Developmental Disability Waiver Population .....</b>	<b>7</b>
Interpreting Statistical Tests .....	10
<b>Mortality During 2017 .....</b>	<b>11</b>
Age and Mortality .....	12
Health Risk and Mortality .....	15
Health Risk, Age and Mortality .....	18
The Central Importance of Age and Health Risk .....	18
<b>Community Mortality Review Committee and Deficient Practice Analysis .....</b>	<b>21</b>
Categories of Deaths.....	21
Purpose of CMRC .....	22
Membership.....	22
Process .....	22
Corrective Action Plans.....	23
Deficiency Tracking .....	23
Statewide Analysis of Number and Type of Deficient Practices .....	24
Critical Risk: Statewide.....	24
High Risk: Statewide .....	25
Regional Analysis of Number and Type of Critical and High Deficient Practices.....	25

Key Findings .....	27
<b>Appendix A: Method for Mortality Review and Analysis .....</b>	<b>28</b>
<b>Appendix B: Regions of DBHDD.....</b>	<b>31</b>
<b>Appendix C: NOW/COMP Population Demographics .....</b>	<b>33</b>
Age .....	33
Gender .....	34
Region .....	35
Type of Medicaid Waiver .....	36
Residential Setting .....	37

## List of Tables

Table 1: Leading Causes of Death .....	9
Table 2: Mortality Rates by Age Category, 2015-2017 .....	13
Table 3: HRST Health Care Levels .....	15
Table 4: Mortality Rate by HCL Score, 2017 .....	17
Table 5: Odds Ratio for HCL Difference, 2015-2017 .....	19
Table 6: Final Logistical Regression Model with Death as Outcome, 2017 .....	19
Table 7: Odds Ratio for 10 Year Age Difference, 2015-2017 .....	19
Table 8: Critical-Risk Count: Statewide .....	24
Table 9: High-Risk Count: Statewide .....	25
Table 10: Regional Analysis of Number and Type of Deficient Practices .....	26
Table 11: Age Distribution of the Adult IDD Waiver Population, 2015-2017 .....	33
Table 12: Gender Distribution of the Adult IDD Waiver Population, 2015-2017 .....	34
Table 13: Adult IDD Waiver Population by Region, 2015 - 2017 .....	35
Table 14: Distribution of Adult IDD Waiver Population, 2015 - 2017 .....	36
Table 15: Adult IDD Waiver Population by Residential Setting, 2015 - 2017 .....	37

## List of Figures

Figure 1: Mortality Rate by Age Category, 2015-2017 .....	14
Figure 2: Mortality Rate by HCL Score, 2015-2017 .....	17
Figure 3: DBHDD Regional Map with State Hospital Locations .....	32
Figure 4: Age Distribution of the Adult IDD Waiver Population, 2015-2017 .....	33
Figure 5: Gender Distribution of the Adult IDD Waiver Population, 2015-2017 .....	34
Figure 6: Adult IDD Waiver Population by Region, 2015 - 2017 .....	35
Figure 7: Distribution of Adult IDD Waiver Population, 2015 - 2017 .....	36
Figure 8: Adult IDD Waiver Population by Residential Setting, 2015 - 2017 .....	37

# 2017 DBHDD Mortality 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 fourth 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 2017 while receiving intellectual and developmental disability Medicaid waiver services from DBHDD and its contracted providers.

### Major Findings

In calendar year 2017, DBHDD served 12,435 adults (at least 18 years of age) with intellectual and developmental disabilities in waiver services. A total of 204 deaths occurred in 2017; the 2017 mortality rate was 16.4 deaths per 1,000 individuals.<sup>1,2</sup> The respective mortality rates for 2015 and 2016 were 12.5 and 14.0 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. (2015), Georgia (2016), and DBHDD 2017 waiver populations. Five 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

---

<sup>1</sup> 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."

<sup>2</sup> 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.

developmental disabilities served by DBHDD in 2017, were similar to past years' findings. Five of the leading causes of death for the 2017 intellectual and developmental disability population that were not common to the top causes of death in the U.S. and Georgia during 2015 and 2016 included disability, aspiration pneumonia, sepsis, gastrointestinal diseases, and epilepsy/seizures.

Several variables were analyzed to determine their effect on mortality in 2017. These included age, gender, health risk, residential setting, and region. Major analytical findings from 2015 through 2016 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 2017, increasing 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. The most common provider deficiencies that required corrective action were linked to individual care and prevention, specifically:

Individual care and prevention (15, 83.3% of all critical/high deficiencies)

- Response to emergency/change
- Assessment and treatment plans
- Medical care needs
- Medication management

The overlap among the areas above account for 15 of the 18 identified critical or high deficient practices. Though corrective action plans are intended to remediate deficient provider practices and mitigate further risk, the prevalence (83%) of the abovementioned common deficient practices may indicate areas for systemic 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 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 defined as 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](http://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 2017 calendar year. During 2017, 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 2017.

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.

## 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.

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. Beginning in 2016, 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).<sup>3</sup>

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 2017 are heart disease, sepsis, disability, aspiration pneumonia, and respiratory diseases. Save for respiratory diseases, all these causes appeared as a leading cause of death in 2016.

---

<sup>3</sup> (2017). Retrieved from [https://www.cdc.gov/nchs/data/dvs/2a\\_2017.pdf](https://www.cdc.gov/nchs/data/dvs/2a_2017.pdf). Accessed June 8, 2017.

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 the 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 U.S. and Georgia causes of death were not available for 2017. Comparing the intellectual and developmental disability population to U.S. mortality data (2015) and Georgia mortality data (2016), 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 2017 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 2017. 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 2017 were similar.

***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 2017 were similar.***

Five of the leading causes of death in 2017 were not common to the top causes of death in the U.S. and Georgia during 2015 and 2016:

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

Table 1: Leading Causes of Death

	2015	2016	2015	2016	2017
	U.S.	Georgia	Intellectual and Developmental Disability Population		
Rank	All Ages		Adult Only		
1	Heart Diseases 23.4%	Heart Diseases 29.8%	Respiratory Diseases 23.1%	Heart Diseases 21.2%	Heart Diseases 22.9%
2	Malignant Neoplasms 22.0%	Malignant Neoplasms 21.1%	Heart Diseases 16.8%	Disability 12.4%	Sepsis 17.1%
3	Chronic Lower Respiratory Diseases 5.7%	Chronic Lower Respiratory Diseases 10.0%	Sepsis 8.5%	Aspiration Pneumonia 11.2%	Disability 11.8%
4	Unintentional Injuries 5.4%	Unintentional Injuries 8.5%	Pneumonia 8.5%	Sepsis 11.2%	Aspiration Pneumonia 11.2%
5	Cerebrovascular Diseases 5.2%	Alzheimer's Disease 8.2%	Aspiration Pneumonia 8.5%	Hypertension 8.2%	Respiratory Diseases 10.0%
6	Alzheimer's Disease 4.1%	Endocrine, nutritional and metabolic diseases 4.3%	Epilepsy/ Seizures 3.6%	Cancer 7.6%	Cancer 8.8%
7	Diabetes mellitus 2.9%	Mental and Behavioral disorders 3.8%	Complications of Cerebral Palsy 3.6%	Pneumonia 6.5%	Pneumonia 7.1%
8	Influenza and Pneumonia 2.1%	Digestive system diseases 3.4%	Alzheimer's Disease 3.6%	Respiratory Disease 6.5%	Epilepsy/ Seizures 5.9%
9	Renal 1.8%	Infectious and Parasitic diseases 3.0%	Cancer 2.4%	Epilepsy/ Seizures 6.5%	Gastrointestinal Disease 2.9%
10	Suicide 1.6%	Reproductive and Urinary system diseases 3.0%	Peripheral Vascular Disease 2.0%	Unintentional Injuries 5.9%	Renal 2.4%

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.

**Five of the leading causes of death in 2017 were not common to the top causes of death in the U.S. and Georgia during 2015 and 2016:**

**Disability**

**Aspiration pneumonia**

**Sepsis**

**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 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.

## Mortality During 2017

This section contains information on deaths reported to DBHDD among the intellectual and developmental disability waiver population during calendar year 2017. Calendar years 2015 and 2016 are included for comparison purposes. Appendix A describes the method used to collect and analyze information and data contained in this section.

The mortality rate for 2015 was 12.5 deaths per 1,000 individuals. The mortality rate for 2016 was 14.0 deaths per 1,000 individuals. The 2017 mortality rate was 16.4 deaths per 1,000 individuals; the mortality rates do not differ significantly across 2015 – 2017.

**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<sup>4</sup> 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 some individuals with an IQ above 70 who have functional support needs; however, some of these individuals were receiving only case coordination.<sup>5</sup> 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.

DBHDD searched for additional, newer IDD mortality reports and published scientific literature for comparison, to no avail. 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 2017 intellectual

***The 2017 mortality rate was 16.4 deaths per 1,000 individuals; the mortality rates do not differ significantly across 2015 – 2017.***

---

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

<sup>5</sup> 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.

and developmental disability mortality rate for DBHDD, 16.4 deaths per 1,000.

The mortality rate for these states combined in 2011 was 9.37,<sup>5</sup> which is significantly lower than the DBHDD 2017 mortality rate ( $|z| = 7.47$ ,  $p < .001$ ).

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),<sup>6</sup> which were significantly higher than the 2017 DBHDD mortality rates ( $|z| = 5.403$ ,  $p < .001$ ;  $|z| = 2.528$ ,  $p = .006$ , respectively). Massachusetts reported mortality rates of 19.2 and 17.4 deaths per 1,000 in 2012 and 2013, respectively.<sup>4</sup> DBHDD's 2017 mortality rates were not significantly lower compared to Massachusetts' mortality rates in 2012 or 2013. The variability in ranges may reflect the differences in population and criteria of the study, as noted above.

## Age and Mortality

The average ages of death in 2015 and 2016 were 53.69 (SD = 15.40) and 53.54 years (SD = 15.40) respectively. The average age of death in 2017 was 53.48 (SD = 15.18). The average age of death increased by .05 years from 2016 to 2017; however, that change was not statistically significant. This means that as a whole, individuals who died in 2017 lived about the same length of time as those who died in 2016. 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.

***Individuals who died in 2017 lived about the same length of time as those who died in 2016.***

---

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

Table 2: Mortality Rates by Age Category, 2015-2017

		Age Category								Total
		18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
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	4.10%	9.50%	12.90%	23.10%	26.50%	15.60%	6.80%	1.40%	100.00%
	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	3.50%	12.90%	12.40%	15.90%	28.80%	21.80%	3.50%	1.20%	100.00%
	Crude Mortality Rate	6	6.4	7.8	11.8	27	52.2	34.1	100	14
2017	Adult Waiver Population	1,058	3,508	2,783	2,284	1,838	743	203	18	12,435
	No. of Deaths	3	26	30	43	55	29	17	1	204
	Percent of Deaths	1.47%	12.75%	14.71%	21.08%	26.96%	14.22%	8.33%	0.49%	100.00%
	Crude Mortality Rate	2.8	7.4	10.8	18.8	29.9	39.0	83.7	55.6	16.4

As in 2015 and 2016, mortality rates increase with increasing age (Table 2, Figure 1). In particular, between 2015 and 2017, 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.

***As in 2015 and 2016, mortality rates increase with increasing age.***

***The mortality rate consistently rises above the population mortality group in the 45-64 age range.***

Statistical comparisons of mortality rates between corresponding age categories from 2016 to 2017 were not significantly different. This is different than in the 2015-2016 comparison where the 65-74 groups yielded a statistically significant difference in mortality rates.

As noted above, the mortality rate for the age group 45-54 increases above the overall mortality rate for the population.

From there, the mortality rate increases with age. (This pattern did not occur for the 85+ group in 2016, but such a fluctuation is not abnormal for such a small subgroup.)

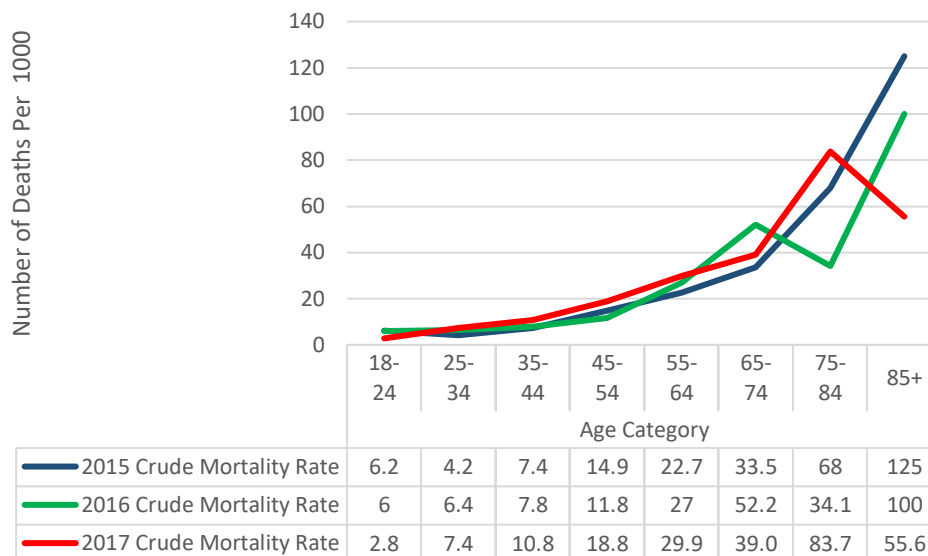
Other

research<sup>7</sup>

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.<sup>7</sup> 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.<sup>8</sup>

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; however, for the DBHDD intellectual and developmental disability population, the intellectual and developmental disability mortality rate is higher than those of the U.S. and Georgia and begins increasing about 10 years earlier relative to general populations.

Figure 1: Mortality Rate by Age Category, 2015-2017



<sup>7</sup> National Vital Statistics Report, Vol. 64 No. 2, February 16, 2016, p. 7. [http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64\\_02.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf), accessed June 8, 2017.

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

## 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 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 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.

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.

Table 3: HRST Health Care Levels

HRST: Health Care Levels (HCL)		
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

The average HCL score for 2017 was 2.35 (SD = 1.482); the average HCL score for 2016 was 2.26 (SD = 1.453); and the average HRST score for 2015 was 2.20 (SD 1.422). The average HCL scores across these three years were each statistically different from each other, 2016 to 2017 ( $|t| = -3.226$ ,  $df = 23,902$ ,  $p = .001$ ), showed an increase and 2015 to 2017 showed an increase as well ( $|t| = 8.0214$ ,  $df = 24,169$ ,  $p\text{-value} < 0.001$ ). This means that, on the whole, there is a statistically significant increase in the amount of measured health risk in this population over time.

Similar to previous years, there is statistical association between health risk score and mortality rate in 2017. Lower HCL scores (1-3) have a group mortality rate (8.8 deaths per 1,000) that is below the population mortality rate in 2016 (16.4 deaths per 1,000). The mortality rates associated with an HCL score of (4-6) exceed the overall population mortality rate by a large margin (47.9 deaths per 1,000). The mortality rate for lower HCL scores (1-3) is significantly higher than the mortality rate for the higher HCL scores ( $|z| = 13.585$ ,  $p = < .001$ ).

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 2017 data indicates that this pattern continues to hold true. Therefore, consistent with previous years, it is important to consider a one-point change in health risk scores to address increasing mortality risk 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).

***It is important to consider a one-point change in health risk scores to address increasing mortality risk that occurs with a two-point health risk score increase.***

Mortality analyses of 2013-2016 data 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 undertook 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. Confirmatory factor analysis, structural equation modeling, and hierarchical cluster analysis revealed that the HCL is a valid and reliable scale for mortality analysis. Based on the analysis, it was apparent that the HRST items, subscales, and HCL were reliable, and that the HCL has the most utility in understanding the relationship between mortality and health risk. (These analyses are not shown in this report due to their highly-technical nature.)

Figure 2: Mortality Rate by HCL Score, 2015-2017

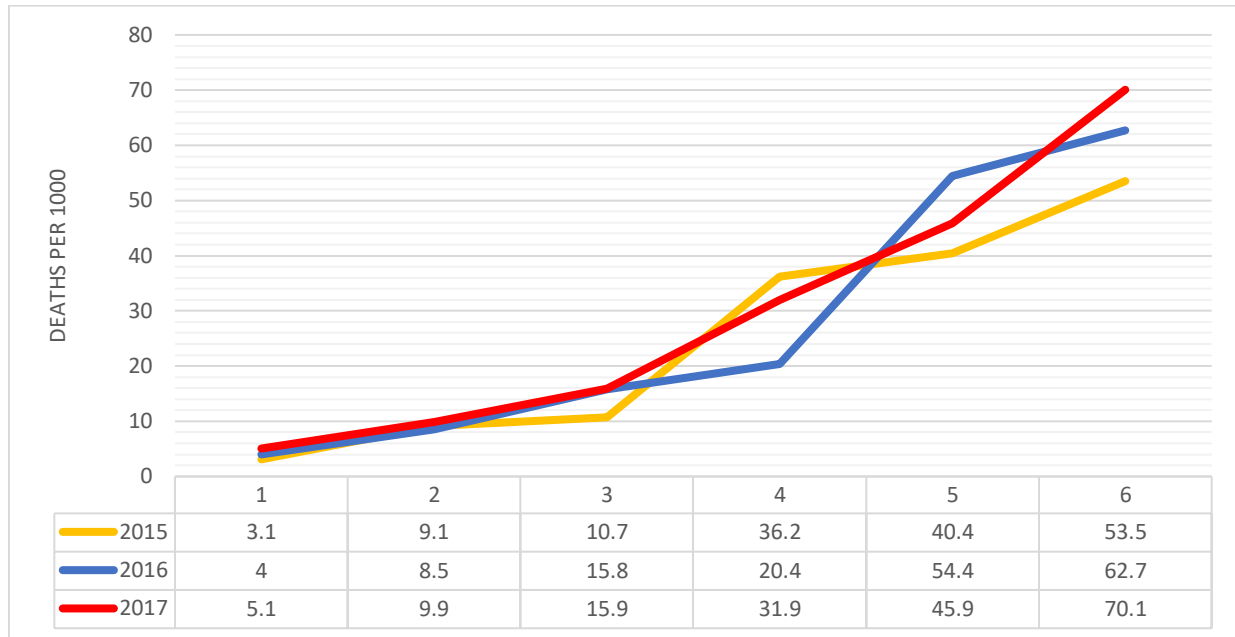


Table 4: Mortality Rate by HCL Score, 2017

HCL Score	2017				
	Adult Waiver Population	# Deaths	Percent of deaths	Crude Mortality Rate	Statistical significance between HCL Scores
1	4,543	23	11.27%	5.1	-----
2	3,645	36	17.65%	9.9	$ z  = 2.559$ , $p = 0.005$
3	1,823	29	14.22%	15.9	NS
4	939	30	14.71%	31.9	$ z  = 2.762$ , $p = 0.003$
5	676	31	15.20%	45.9	NS
6	785	55	26.96%	70.1	NS
<b>Grand Total</b>	<b>12,411</b>	<b>204</b>	<b>100%</b>	<b>16.4</b>	

## Health Risk, Age and Mortality

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. HCL scores 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  $r = .08$ ,  $p < .001$ ). 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.

## The Central Importance of Age and Health Risk

Data analyses to this point have examined variables 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.

Age, gender, region, intensity of residential intensity setting, and HCL score were used together to analyze which variables were associated with death in

***Age, gender, region, intensity of residential intensity setting, and HCL score were used together to analyze which variables were associated with death in 2017. Only age and health risk scores were significantly associated with occurrence of death.***

2017. 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 analyses for 2015-2017 are very similar.

Table 5: Final Logistical Regression Model with Death as Outcome, 2017

Variable	B	S.E.	Wald	df	Sig.	Odds Ratio <sup>1</sup>
Age	.044	.005	9.365	1	0	1.045
HCL	.499	.041	12.26	1	0	1.648

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., .001101288). However, with each 10-year increase in age, the odds of dying increase multiplicatively, such that the odds of dying at 40 doubles to age 20; the odds of dying at 50 are more than three 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 7 is 18. Each odds ratio represents the increase in odds from that age.) Note that the estimated coefficient representing the association between age and mortality was the same in 2016 and 2017, so columns will be the same.

The odds of dying increase significantly with increasing health care level scores. Those with an HCL score of 3 had an estimated five times higher increase in odds of having died in 2017. Those with HCL scores of six had 23.62 times increased odds of having died in 2017. This relationship indicates that the odds of death increase exponentially with increasing HCL scores in 2017.

Table 6: Odds Ratio for HCL Difference, 2015-2017

HCL	OR 2015	OR 2016	OR 2017
1	1.66	1.69	1.65
2	2.77	2.87	2.71
3	4.60	4.86	4.47
4	7.66	8.23	7.36
5	12.74	13.94	12.12
6	21.20	23.62	19.97

***The odds of dying increase significantly with increasing health care level scores. This relationship indicates that the odds of death increase exponentially with increasing HCL scores in 2017.***

Table 7: Odds Ratio for 10 Year Age Difference, 2015-2017

Age	OR 2015	OR 2016	OR 2017
20	1.08	1.09	1.09
30	1.71	1.69	1.69
40	2.41	2.63	2.63
50	4.22	4.08	4.08
60	6.62	6.34	6.34
70	10.38	9.86	9.86

Figures 3 and 4 are called “forest plots.” They display the estimates of the odds ratios on the y-axis plotted against individual groups on the x-axis. Each individual group is displayed as a comparison to a baseline group; the HCL plot compares each HCL score to the HCL score of 1 and the age plot compares each age to 18 years old. Therefore, people who are 50 years old have a 4.09-factor increase in odds of having died in 2017 compared to 18-year-olds among this population.

The red dots in Figures 3 and 4 are the odds ratio estimates themselves, and the black dots are the estimates of a 99-percent confidence interval. A 99-percent confidence interval can be interpreted as a range of values that a researcher believes will contain the true odds ratio for the association in light of the sample data. In this case, it means that there is a 99-percent confidence that the true multiplicative increase in odds of mortality from HCL 1 to HCL 4 is somewhere between 6.14 and 3.27. Any overlapping ranges do not represent a statistically significant difference in odds ratios; so, this plot allows for quick assessment of accuracy and evaluation of differences between estimates.

It is worth noting that death is a relatively rare outcome; therefore, even a large increase in odds (such as with the upper values of HCL 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 to the discussion about statistical analysis on page 10.)

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 2017 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 2017, which is presented next.

Figure 3: Forest Plot of HCL

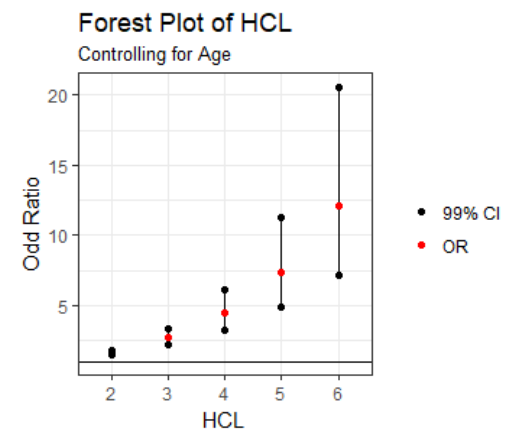
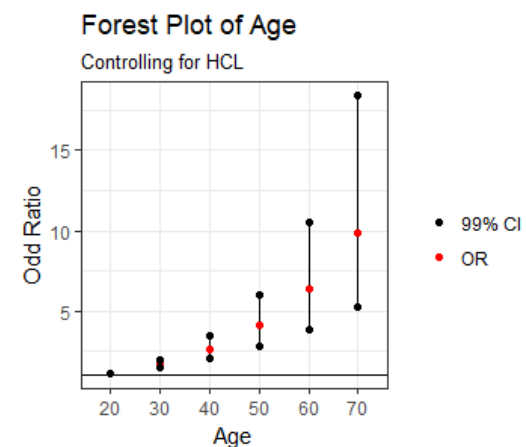


Figure 4: Forest Plot of Age



## 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, and can be viewed by clicking on the hypertext.

### 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—unanticipated death not attributed to the natural course of a diagnosis or a diagnosed disease where the reasonable expectation or outcome is death (previously known as Category 1)—or expected—attributed to a terminal diagnosis or a diagnosed disease where the reasonable expectation or outcome is death (previously known as Category 2). The CMRC reviews all expected and unexpected deaths identified for review by the DBHDD medical director or director of the Office of Provider Certification & Services Integrity.

## 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, legal staff, programmatic staff, investigative staff, a representative from the Georgia Bureau of Investigations, 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 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; and to 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;

**Person Responsible:** Identification of the person or people responsible for the fulfillment of each corrective action;

**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, or 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 2017 CMRC and CATS data and analysis are presented as baseline performance. Not all deaths are reviewed by the CMRC; 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 and not having a representative sample of all intellectual and developmental disability deaths reviewed by CMRC, 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. DBHDD required 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.

In 2017 there were 23 practices deemed to have 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. 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.

This report will now turn to providing analysis of critical- and high-risk deficient practices – the ones with the most potential for adverse outcomes.

#### Critical Risk: Statewide

Provider practices identified in 2017 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 individual care and prevention, 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. As mentioned earlier, DBHDD requires providers to submit a corrective action plan to address critical-risk provider practices.

Table 8: Critical-Risk Count, 2017: Statewide

<b>Critical Risk</b>	<b>6</b>
<b>Individual Care &amp; Prevention</b>	<b>5</b>
Assessments & Treatment Plans	1
Medical Care Needs	1
Medication Management	1
Response to Emergency/Change in Condition	2
<b>Program Planning &amp; Leadership</b>	<b>1</b>
Human Resources & Training	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: individual care and prevention is the most common high-risk practice area, specifically, providers failing to respond to changes in individuals' condition, attending to medical care needs, and failure to respond appropriately to emergencies.

Table 9: High-Risk Count, 2017: Statewide

<b>High Risk</b>	<b>12</b>
<b>Individual Care &amp; Prevention</b>	<b>10</b>
Assessments & Treatment Plans	3
Documentation	1
Medical Care Needs	2
Medication Management	1
Response to Emergency/Change in Condition	3
<b>Program Planning &amp; Leadership</b>	<b>2</b>
Program Requirements	1
Supervision & Oversight	1

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

Regions 2 and 3 had the largest number of identified critical deficient practices and accounted for 66.7 percent of critical-risk provider practices identified.

Regions 4 and 5 both had 16.7 percent of the critical deficient provider practices identified. Regions 2, 3, and 5 had the highest number of deficient practices that were identified as having high risk to individuals, each with 3 deficiencies accounting for 25 percent of the high-risk deficiencies. It should be noted, however, that there was no statistically significant difference between each region's number of deficient practices compared to overall state.

***There was no statistically significant difference between each region's number of deficient practices compared to overall state.***

Table 10: Regional Analysis of Number and Type of Deficient Practices, 2017

Region	Count			Region	Percent	
	Population	Critical-risk Deficiencies	High-risk Deficiencies		Critical-risk Deficiencies	High-risk Deficiencies
1	2,612	0	1	1	0.0%	8.3%
2	2,140	2	3	2	33.3%	25.0%
3	3,148	2	3	3	33.3%	25.0%
4	1,287	1	0	4	16.7%	0.0%
5	1,519	1	3	5	16.7%	25.0%
6	1,729	0	2	6	0.0%	16.7%
Total	12,435	6	12	Total	100%	100%

The main points concerning deficient practices identified in the course of CMRC reviews, when considering the 18 combined critical- and high-risk practices conjointly (that require a corrective action plan), one notices substantial overlap in one area:

Individual care and prevention (15, 83.3% of all critical/high deficiencies)

- Response to emergency/change
- Assessment and treatment plans
- Medical care needs
- Medication management

The overlap among the areas above account for 15 of the 18 identified critical or high deficient practices. Though corrective action plans are intended to remediate deficient provider practices and mitigate further risk, the prevalence (83%) of the abovementioned common deficient practices may indicate additional areas for improvement.

## Key Findings

The 2017 DBHDD NOW and COMP waiver mortality rate was 16.4 deaths per 1,000 individuals. The 2017 mortality rate did not differ significantly from the DBHDD NOW and COMP waiver mortality rates in 2015 and 2016.

---

Increasing age (as in previous years) is significantly associated with the occurrence of mortality.

---

Increasing health risk was associated with mortality in 2015-2017.

---

In 2015 and 2017, mortality increased markedly for individuals in the 45-54 age group. In 2016, mortality increases markedly after ages 55-64; increased risk of mortality as a result of increasing age is also found in the general U.S. and Georgia populations.

---

Life expectancy for the 2017 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. (2015), Georgia (2016), DBHDD 2017 NOW and COMP waiver population. 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 NOW and COMP waiver population in 2017 were similar.

---

Five of the leading causes of death for the 2017 NOW and COMP waiver population were not common to the top causes of death in the U.S. and Georgia during 2015 and 2016 included disability, aspiration pneumonia, sepsis, gastrointestinal disease, and epilepsy/seizures.

---

The most common deficient provider practices that required corrective action centered on individual care and prevention, 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.

---

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 children under the age of 18. 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.

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 2017 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) 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 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) HCL 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.

## **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 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:** This 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 individuals whose residence in the Waiver Information System (WIS) is designated as "foster care." Finally, 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.

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

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 2017.

Analyses were conducted using R,<sup>9</sup> 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:** 0 = Female      1 = Male

**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.

---

<sup>9</sup> 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:

- Overseeing statewide initiatives;
- Developing new services and expand existing services as needed;
- Monitoring the services being received by consumers to ensure quality and access;
- Investigating and resolve complaints; and
- Conducting special investigations and reviews when warranted.

### Region Descriptions (map on following page):

**Region 1** covers 31 predominantly rural counties of Northwest and Northeast Georgia

**Region 2** covers 33 counties of East and Central Georgia

**Region 3** covers 6 counties, which includes the capital city of Atlanta

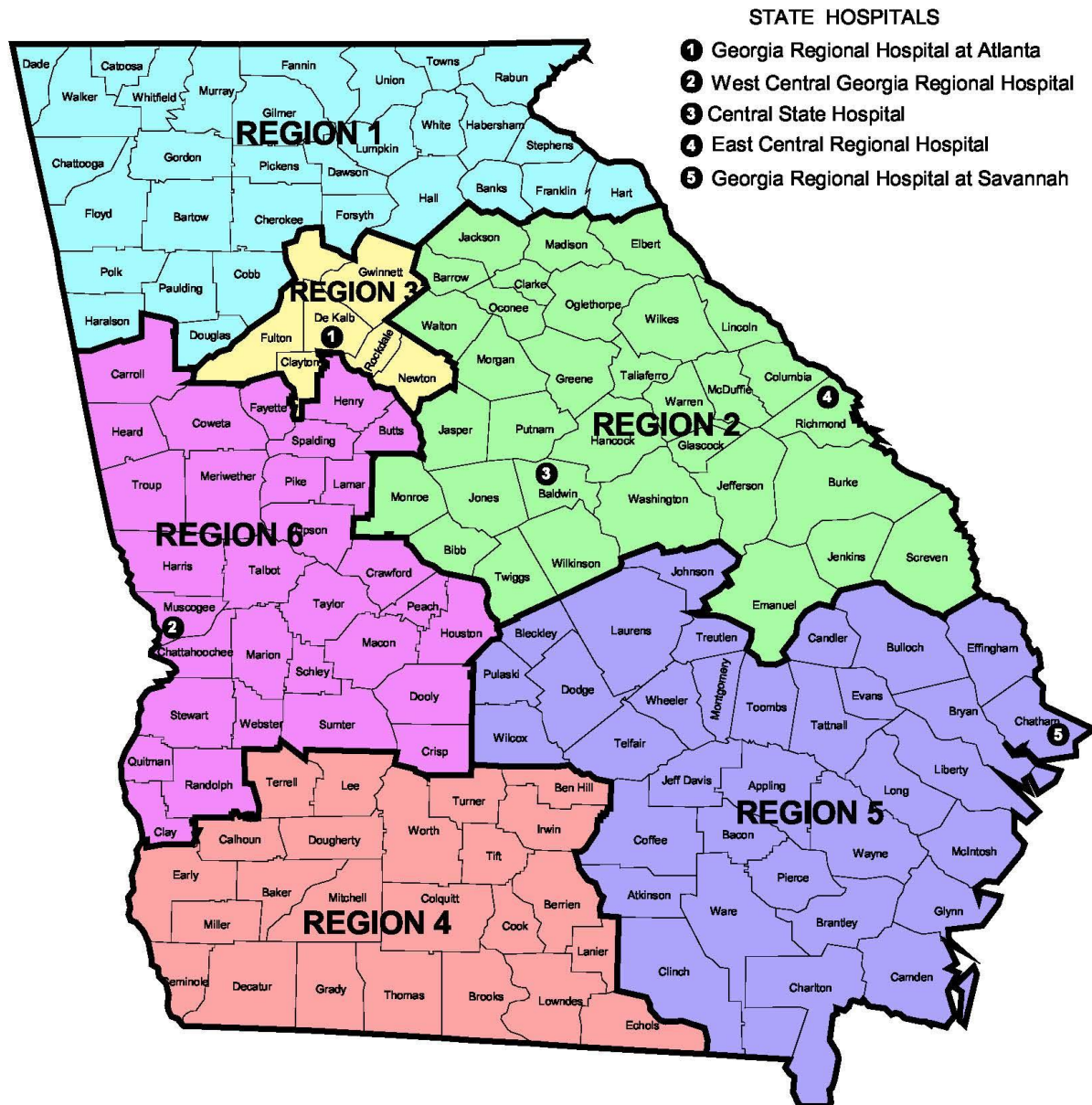
**Region 4** covers 24 predominantly rural counties in Southwest Georgia

**Region 5** covers 34 counties in Southeast Georgia

**Region 6** covers 31 counties in West-Central Georgia

Figure 3: 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: NOW/COMP Population Demographics

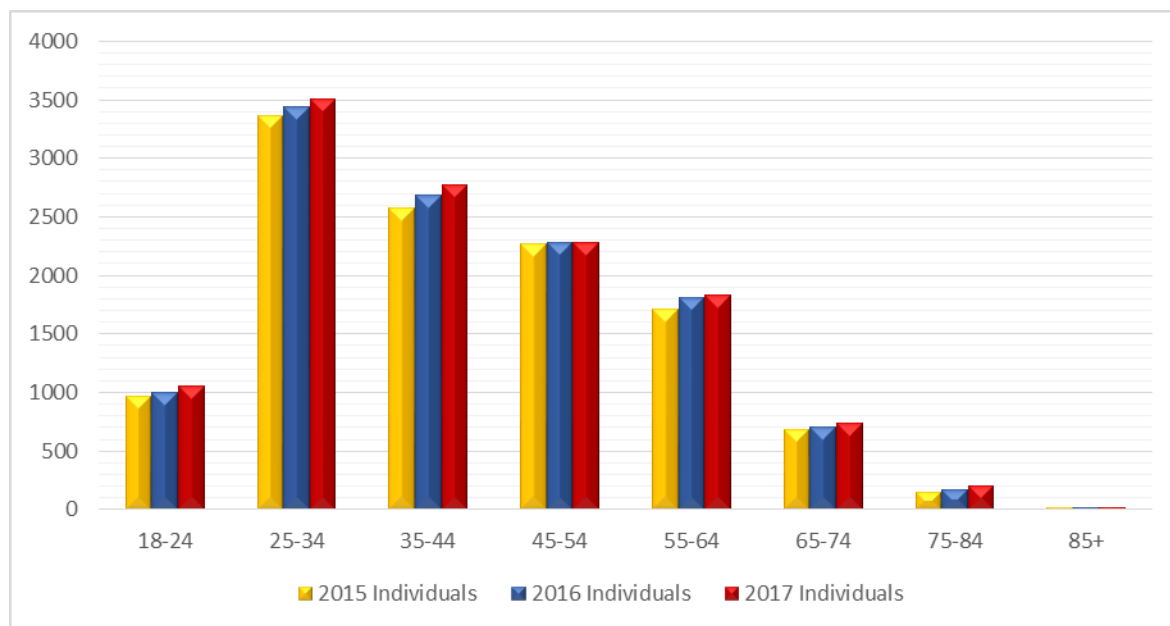
### Age

The following table 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 2017; when applicable, the age was calculated as the duration between the individual's birth date and the date of death.

Table 11: Age Distribution of the Adult IDD Waiver Population, 2015-2017

Age	2015		2016		2017	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
18-24	971	8.26%	1,002	8.25%	1,058	8.51%
25-34	3,368	28.64%	3,450	28.39%	3,508	28.21%
35-44	2,576	21.90%	2,690	22.14%	2,783	22.38%
45-54	2,280	19.39%	2,286	18.81%	2,284	18.37%
55-64	1,716	14.59%	1,818	14.96%	1,838	14.78%
65-74	686	5.83%	709	5.83%	743	5.98%
75-84	147	1.25%	176	1.45%	203	1.63%
85+	16	0.14%	20	0.16%	18	0.14%
Totals	11,760	100.00%	12,151	100.00%	12,435	100.00%

Figure 4: Age Distribution of the Adult IDD Waiver Population, 2015-2017



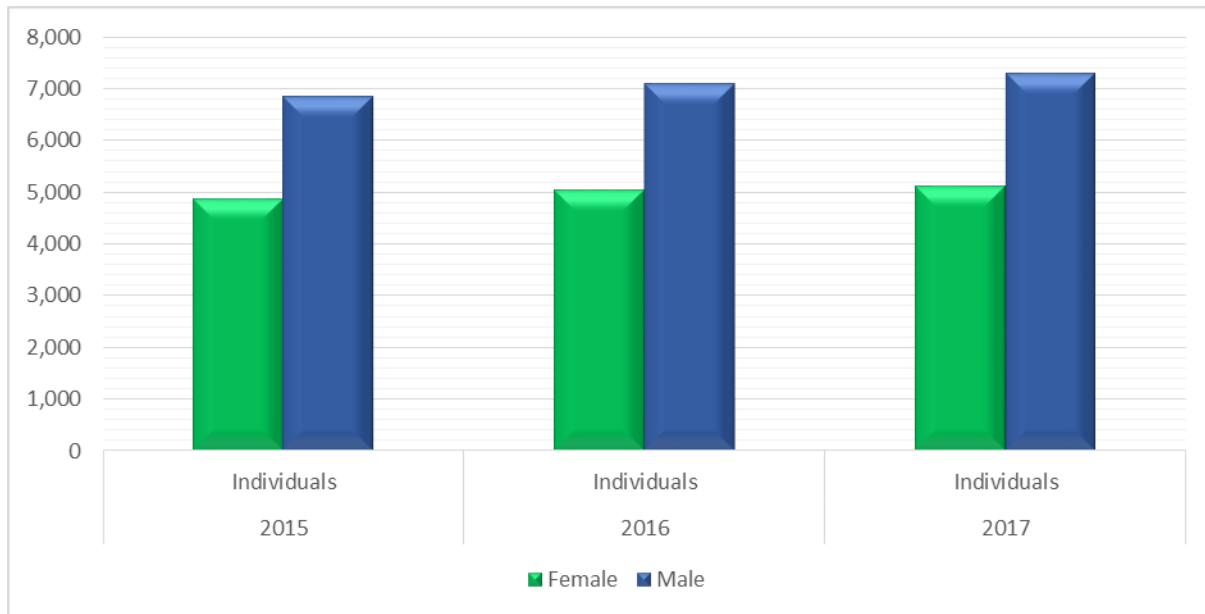
## Gender

The following table and figure show that the distributions of gender were equal across the years 2015 to 2017.

Table 12: Gender Distribution of the Adult IDD Waiver Population, 2015-2017

Gender	2015		2016		2017	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Female	4,892	41.59%	5,044	41.51%	5,117	41.15%
Male	6,868	58.41%	7,107	58.49%	7,318	58.85%
Total	11,760	100.00%	12,151	100.00%	12,435	100.00%

Figure 5: Gender Distribution of the Adult IDD Waiver Population, 2015-2017



## Region

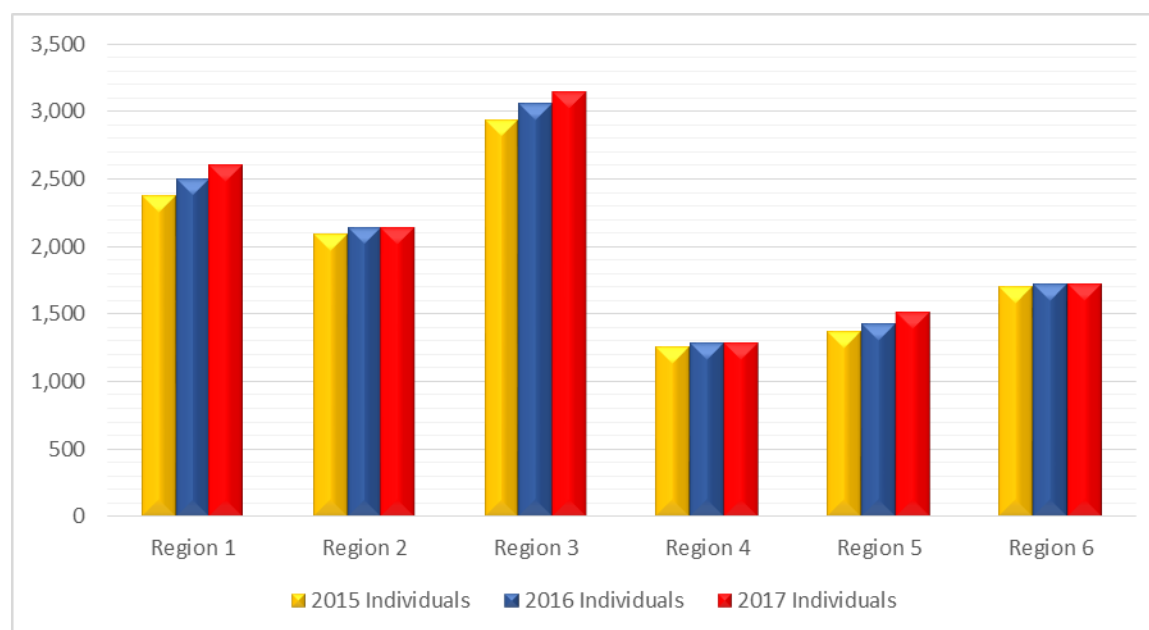
DBHDD serves individuals throughout the state in six geographic regions through a network of contracted providers. See Appendix B for a description of the regions.

The following show the regional distribution of waiver participants. Region 3, the most densely-populated region, had the largest population of individuals served (3,148, 25.32%); Regions 4 and 5 are less-populated areas and had the smallest population of individuals served (1,287, 10.35%; 1,579, 12.22%, respectively).

Table 13: Adult IDD Waiver Population by Region, 2015 - 2017

Region	2015		2016		2017	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Region 1	2,381	20.25%	2,501	20.58%	2,612	21.01%
Region 2	2,098	17.84%	2,148	17.68%	2,140	17.21%
Region 3	2,940	25.00%	3,062	25.20%	3,148	25.32%
Region 4	1,265	10.76%	1,285	10.58%	1,287	10.35%
Region 5	1,372	11.67%	1,431	11.78%	1,519	12.22%
Region 6	1,704	14.49%	1,724	14.19%	1,729	13.90%
Total	11,760	100.00%	12,151	100.00%	12,435	100.00%

Figure 6: Adult IDD Waiver Population by Region, 2015 – 2017



## Type of Medicaid Waiver

The number (and percent) of individuals receiving COMP waivers increased by 323 in 2017. The number of individuals receiving NOW waivers decreased by 39.

Table 14: Distribution of Adult IDD Waiver Population, 2015 – 2017

Waiver	2015		2016		2017	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
COMP	7,381	62.76%	7,773	63.97%	8,096	65.11%
NOW	4,379	37.24%	4,378	36.03%	4,339	34.89%
Total	11,760	100.00%	12,151	100.00%	12,435	100.00%

Figure 7: Distribution of Adult IDD Waiver Population, 2015 – 2017

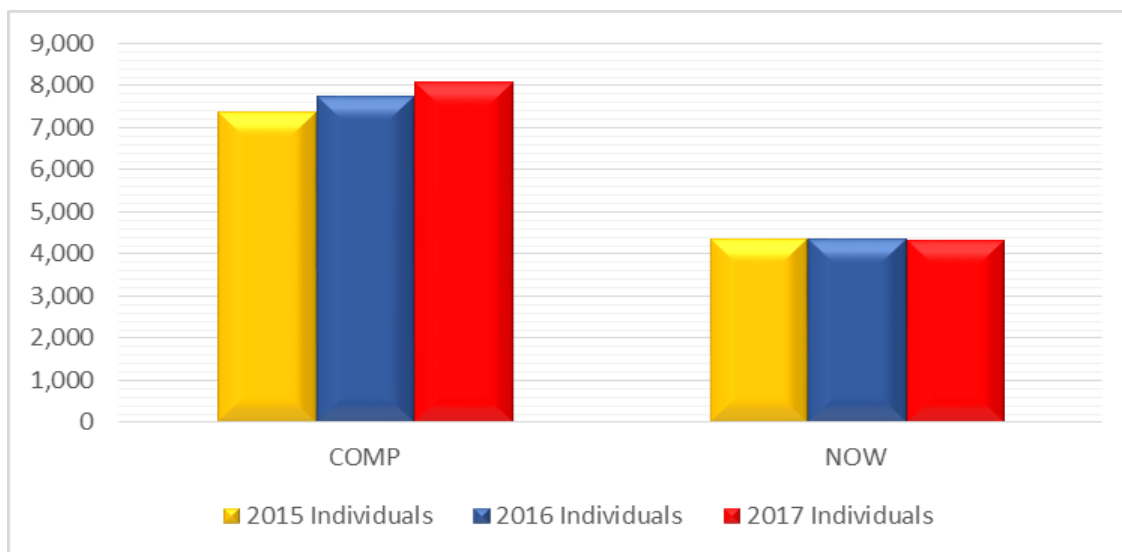


Table 15: Adult IDD Waiver Population by Residential Setting, 2015 – 2017

Residential	2015		2016		2017	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Community Living Arrangement	1,519	12.92%	1,615	13.29%	2,081	16.74%
Host Home	1,210	10.29%	1,222	10.06%	1,305	10.49%
Independent	1,425	12.12%	1,443	11.88%	1,409	11.33%
Live with Family/Relative/Other	6,200	52.72%	6,534	53.77%	6,701	53.89%
Personal Care Home	1,406	11.96%	1,337	11.00%	939	7.55%
Total	11,760	100.00%	12,151	100.00%	12,435	100.00%

Figure 8: Adult IDD Waiver Population by Residential Setting, 2015 - 2017

