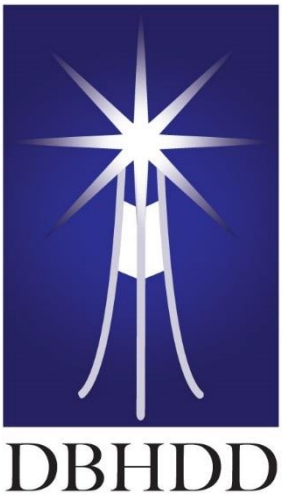
# 2015 Annual Mortality Report

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




Georgia Department of Behavioral Health and Developmental Disabilities

August 16, 2016

This is the second 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 (DBHDD). 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

List of Tables ..... 3
List of Figures ..... 4
Executive Summary ..... 5
Major Findings ..... 5
Utilization of Mortality Report Findings ..... 6
**About DBHDD** ..... 7
Vision ..... 7
Mission ..... 7
**About DBHDD Intellectual and Developmental Disability Services** ..... 7
**Scope of this Report** ..... 8
**Mortality in Adults in IDD Waiver Services** ..... 9
**Mortality Reviews** ..... 9
Mortality Review Process Enhancements ..... 11
**Causes of Death** ..... 12
Table 1: Leading Causes of Death ..... 13
**Analysis of IDD Waiver Data Related to Mortality** ..... 14
Age ..... 14
Table 2: Age Distribution of the Adult IDD Waiver Population, 2013 – 2015 ..... 15
Figure 1: Age Distribution of the Adult IDD Waiver Population, 2013 – 2015 ..... 15
Gender ..... 16
Table 3: Gender Distribution of the IDD Waiver Population, 2013 – 2015 ..... 16
Figure 2: Gender Distribution of the IDD Waiver Population, 2013 – 2015 ..... 16
Region ..... 17
Table 4: The Distribution of Adults Receiving IDD Waiver, 2013 - 2015 ..... 17
Figure 3: Adult IDD Waiver Population by Region, 2013 – 2015 ..... 17
Type of Medicaid Waiver ..... 18
Table 5: Distribution of Adult NOW and COMP Waiver Population, 2013 – 2015 ..... 18
Figure 4: Distribution of Adult NOW and COMP Waiver Population, 2013 – 2015 ..... 18
Residential Setting ..... 19
Table 6: Distribution of Adults in Residential Settings in IDD Waivers, 2013 – 2015 ..... 20
Figure 5: Distribution of Adults in Residential Settings in IDD Waivers, 2013 – 2015 ..... 20
Health Risk ..... 21

Table 7: HRST Health Care Levels ..... 21
Table 8: Distribution of HRST Scores for Adults Receiving IDD Waivers, 2013-2015 ..... 21
Figure 6: Distribution of HRST Scores for Adults Receiving IDD Waivers, 2013 – 2015 ..... 22
**Multiple Variable Analyses** ..... 23
Health Risk and Residential Setting ..... 23
Table 9: Residential Setting by HRST Score, 2015 ..... 23
Figure 7: CLA, Host Home, PCH Residential Setting by HRST Score, 2015 ..... 24
Figure 8: Independent, Live with Family/Relative/ Other Residential Setting by HRST Score, 2015 ..... 24
Health Risk and Age ..... 25
Table 10: HRST by Age Category ..... 25
**Mortality During 2015** ..... 26
Age and Mortality ..... 27
Table 11: GA IDD Mortality Rates by Age Category, 2013 – 2015 ..... 27
Figure 9: GA IDD Mortality Rate by Age Category, 2013 – 2015 ..... 28
Gender and Mortality ..... 29
Table 12: Number of Deaths, Average Age at death and Mortality Rate by Gender 2013 – 2015 ..... 29
Age, Residential Setting, and Mortality ..... 30
Table 13: Average Age at Death and Mortality rate by Residential Setting, 2015 ..... 31
Figure 10: Average Age at Death and Mortality Rate by Residential Setting, 2015 ..... 31
Health Risk and Mortality ..... 32
Figure 11: Mortality Rate by HRST Score, 2013 – 2015 ..... 32
Table 14: Mortality Rate by HRST Score, 2015 ..... 33
The Importance of Age and Health Risk ..... 33
Table 15: Final Logistic Regression Model with Death as Outcome, 2015 ..... 34
Table 16: Odds Ratio (OR) for HRST Scores, 2013 – 2015 ..... 34
Table 17: Odds Ratio (OR) for 10-Year Age Difference, 2013 – 2015 ..... 35
Key Findings ..... 35
Utilization of Mortality Report Findings ..... 36
**Appendix A**: Method for Mortality Review and Analysis ..... 37
**Appendix B**: Community Mortality Review Committee Policy ..... 39
**Appendix C**: Regions of DBHDD ..... 44
Figure 12: DBHDD Regional Map with State Hospital Locations ..... 45

## List of Tables

Table 1: Leading Causes of Death ..... 13

Table 2: Age Distribution of the Adult Waiver Population, 2013 – 2015 ..... 15

Table 3: Gender Distribution of the Waiver Population, 2013 – 2015 ..... 16

Table 4: The Distribution of Adults Receiving Waiver, 2013 - 2015 ..... 17

Table 5: Distribution of Adult NOW and COMP Waiver Population, 2013 – 2015 ..... 18

Table 6: Distribution of Adults in Residential Settings Receiving Waivers, 2013 – 2015 ..... 20

Table 7: HRST Health Care Levels ..... 21

Table 8: Distribution of HRST Scores for Adults Receiving Waivers, 2013 – 2015 ..... 21

Table 9: Residential Setting by HRST Score, 2015 ..... 23

Table 10: HRST by Age Category ..... 25

Table 11: Mortality Rates by Age Category, 2013 – 2015 ..... 27

Table 12: Number of Deaths, Average Age at Death, and Mortality Rate by Gender 2013 – 2015 ..... 29

Table 13: Average Age at Death and Mortality Rate by Residential Setting, 2015 ..... 31

Table 14: Mortality Rate by HRST Score, 2015 ..... 33

Table 15: Final Logistic Regression Model with Death as Outcome, 2015 ..... 34

Table 16: Odds Ratio (OR) for HRST Scores, 2013 – 2015 ..... 34

Table 17: Odds Ratio (OR) for 10-Year Age Difference, 2013 – 2015 ..... 35

## List of Figures

Figure 1: Age Distribution of the Adult Waiver Population, 2013 – 2015 ..... 15

Figure 2: Gender Distribution of the Adult Waiver Population, 2013 – 2015 ..... 16

Figure 3: Adult Waiver Population by Region, 2013 – 2015 ..... 17

Figure 4: Distribution of Adult NOW and COMP Waiver Population, 2013 – 2015 ..... 18

Figure 5: Distribution of Adults in Residential Settings Receiving Waivers, 2013 – 2015 ..... 20

Figure 6: Distribution of HRST Scores for Adults Receiving Waivers, 2013 – 2015 ..... 22

Figure 7: Community Living Arrangement Host Home, Personal Care Home Residential Setting by HRST Score, 2015 ..... 24

Figure 8: Independent, Live with Family/Relative/Other Residential Setting by HRST Score, 2015 ..... 24

Figure 9: Mortality Rate by Age Category, 2013 – 2015 ..... 27

Figure 10: Average Age at Death and Mortality Rate by Residential Setting, 2015 ..... 31

Figure 11: Mortality Rate by HRST Score, 2013 – 2015 ..... 32

Figure 12: DBHDD Regional Map with State Hospital Locations ..... 45

# 2015 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 second 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 identify indicators that may assist DBHDD in the prevention and treatment of certain illnesses that may lead to deaths or other illness 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 here.

This report includes data and information concerning adults who died during calendar year 2015 while receiving waiver-funded intellectual and developmental disability Medicaid waiver services (IDD waiver services) from DBHDD and its contracted providers. It also includes process information from the Department's Community Mortality Review Committee (CMRC) established to conduct thorough reviews of deaths of individuals receiving services by or through DBHDD community providers for the purpose of reducing morbidity or mortality and evaluating and improving the quality and efficiency of services rendered and causes of death that provide additional information concerning mortality for this population.

### Major Findings

In calendar year 2015, DBHDD served 11,760 adults (at least 18 years of age) with intellectual and developmental disabilities in IDD waiver services. A total of 147 deaths occurred in 2015; the 2015 mortality rate was 12.5 deaths per 1,000 individuals.[1] The respective mortality rates for 2013 and 2014 were 11.3 and 11.1 deaths per 1,000 individuals. The mortality rates do not differ significantly across any years.[2]

The leading causes of death among the IDD waiver population from 2013 to 2015 were respiratory disease, heart disease, sepsis, and pneumonia. Aspiration pneumonia appeared as a leading cause of death in 2015 but was not a leading cause of death in 2013 and 2014. Gastrointestinal disease was a leading cause of death in 2013 and 2014 but was not a leading cause of death in 2015.

---

[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.

DBHDD's Community Mortality Review Committee (CMRC) policy revisions became effective November 1, 2015. The revisions expanded the mortality reviews to include reviews of expected deaths that have a finding of abuse or neglect, or would otherwise warrant further review. The department developed an electronic database used to identify and track completion of corrective actions and CMRC recommendations necessary to improve quality of care.

Several variables were analyzed to determine their effect on mortality in 2015. These included age, residential setting, gender, and health risk. Major analytical findings mirror those from 2013 and 2014 analyses, including increasing health risk and increasing age are most strongly associated with mortality, while gender, residential setting, region, and other variables are not related to mortality.

Findings from the CMRC and this mortality report will continue to be reviewed by DBHDD to determine opportunities to improve the quality of care.

## Utilization of Mortality Report Findings

The observations and findings in this report will be presented to leadership of DBHDD, IDD, 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 the quality of care in specific areas vital to maintaining health.

The responsibility for the utilization of the information within this report is that of the director of the Division of IDD. The IDD Division 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 IDD in the community. DBHDD's reorganization provides a platform for clarified roles and responsibilities in addressing mortality in the IDD 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 assist the Division of IDD to accomplish improvement strategies; the Division of IDD has the responsibility to utilize these resources. The Division of IDD 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 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 (IDD) 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 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 IDD diagnosis who received services funded by NOW and COMP waivers (IDD waiver services) during the 2015 calendar year. During 2015, data systems for individuals receiving IDD waiver services were maintained separately from state-funded services, and the data between these systems varies. This report used the IDD 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 does not include data for children under the age of 18. Thirteen deaths of children were reported to DBHDD in 2015. 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.

## Mortality in Adults in IDD Waiver Services

The major findings from mortality reviews conducted during 2015 are presented in the first section below, followed by a description of the analysis of information known about causes of death during calendar year 2015. Next, findings from data analyses of the deaths of IDD waiver recipients are presented. The data analysis section reports the relationship of age, gender, residential setting, and health risk as they individually or in combination relate to mortality rates. Finally, the data analysis section considers all variables of interest together to determine the individual effect of each variable on the occurrence of death.

## Mortality Reviews

Mortality reviews promote safety by seeking to understand systems that are working well and those that need improvement. DBHDD's Community Mortality Review Committee (CMRC) reviews deaths and determines whether necessary and reasonable measures were taken to provide for the health, safety, and welfare of the individual receiving services, and to identify and mitigate future risks that could affect the health, safety, and welfare of other individuals receiving supports and services from DBHDD or its community providers. See Appendix B, *The DBHDD Community Mortality Review Committee (CMRC)* Policy, 04-108.

During 2014, the CMRC met nine times and reviewed 87 deaths. In 2015, the CMRC met 15 times and reviewed 90 deaths. In addition, 27 deaths of IDD individuals received an external mortality review. The department entered into a contract in fiscal year 2014 and has continued to contract with The Columbus Organization (Columbus) to review deaths of individuals who meet criteria for inclusion in the Americans with Disabilities Act Settlement Agreement class. Under this contract, Columbus uses physicians and nurses with experience in IDD to perform mortality reviews for class members, including reviews of those occurring since the effective date of the original Settlement Agreement (July 1, 2010). Columbus reviews the available documentation related to those deaths, including provider records for one year prior to the death, DBHDD investigations and recommendations, autopsies, death certificates, and any other obtainable and available information.

The increased number of CMRC reviews in 2015 is due to several factors. DBHDD chose to have an external review of all individuals with IDD in the settlement agreement who died after July 1, 2010. Additional meeting times were necessary to complete the DBHDD mortality reviews and to review the external mortality reports. Additionally, on November 1, 2015, the mortality review policy expanded the reviewable incident types to include Category 2 expected deaths. See Appendix B for definitions of deaths and the revised CMRC policy. (NOTE: While this report only covers deaths of individuals receiving IDD services, the CMRC also reviews deaths of individuals receiving behavioral health services.)

It should be noted that not all reported deaths are reviewed, and the number of deaths reviewed each year is different than the number of deaths reported for the year due to three primary reasons. First, in

2015, the CMRC reviewed a specific subset of deaths that were reported to DBHDD. This category of deaths includes all *unexpected deaths* of individuals:

- Receiving residential services or 24/7 community living support
- Occurring on the site of a community provider or in the company of staff of a community provider
- Absent without leave from residential services.

An unexpected death is defined as a death the cause of which is not attributed to a terminal diagnosis or a diagnosed disease where the reasonably expected outcome is death. Beginning in November 2015, the CMRC policy included a review of any Category 2 *expected death* determined by the DBHDD medical director or Office of Incident Management and Investigations (OIMI) director to require a review. An expected death is defined as a death the cause of which is attributed to a terminal diagnosis or diagnosed disease where the reasonably expected outcome is death. It includes the death of any individual:

- Receiving residential services or 24/7 community living support
- Occurring on the site of a community provider or in the company of staff of a community provider
- Absent without leave from residential services.

See Appendix B, *Definitions and Compliance with Recommended Components*, for a description of the types of deaths identified in the Community Incident Management Policy and reported to DBHDD.

The second reason that the number of deaths reviewed each year by the CMRC is not the same as the number of deaths reported to DBHDD in that year is that the report of the death and the review by the CMRC may not occur in the same calendar year. Deaths are not scheduled for review by the CMRC until the investigation has been completed (or reviewed by the external reviewer, when applicable), and the autopsy report has been received, if an autopsy was ordered.

The third reason the number of deaths reviewed each year by the CMRC is not the same as the number of deaths reported to DBHDD in a year is that the external reviewers continue to complete reviews of the ADA Settlement Agreement class which goes back to July 1, 2010. While unlikely, the number of reviews may coincide with the number of deaths in a given year; however, the two sets may likely not be identical.

At the conclusion of each review, Columbus recommends any systemic changes for providers or the department to OIMI. These recommendations are reviewed by the CMRC for any issues that were not identified by DBHDD investigators. Recommendations are sent to providers by OIMI. When recommendations include required corrective action plans, DBHDD's Office of Results Integration works with the providers to ensure compliance.

## Mortality Review Process Enhancements

In addition to implementing recommendations from mortality reviews, DBHDD continuously works to improve its mortality review process. Below are examples of actions the department took to enhance the process in calendar year 2015:

- Engaged the services of expert consultants from RPA, Ltd., to review and make recommendations for system improvements;
- Effected CMRC policy November 1, 2015, which includes a process for the medical director and the OIMI director to screen expected deaths and, at a minimum, refer to the CMRC any death where there is a finding of abuse or neglect or where there are other circumstances surrounding the death that are considered to warrant further review;
- Increased membership of the CMRC to include additional representatives with medical expertise, as well as representatives of external organizations and stakeholders;
- Provided training for all new CMRC members to ensure that they understood the goals of the CMRC, the review process, and their role in the process and as part of the committee;
- Continued to evaluate DBHDD's mortality review system using the standards checklist, "Evaluation of State MR/DD Mortality Review Systems: Criteria and Standards"[3];
- Implemented a Corrective Action Tracking System (CATS) database in October 2015 to manage and process deficient practices and confirm corrections have been made by requesting evidence of implementation. DBHDD's Office of Results Integration uses the CATS system to follow deficient practices and any corresponding recommendations and corrective actions that are described in quality reviews, audit reports, and reports concerning providers' performance. This includes compliance with contractual, regulatory, and programmatic requirements and CMRC and external mortality review recommendations;
- Implemented an emergency response process to review unexpected deaths, identify any risk or safety concerns, and complete an on-site safety review within 24 hours of receiving the report when deemed necessary. This rapid response process went into place on December 16, 2015. OIMI implemented an on-call system in which staff review death reports as they are received, and complete an initial analysis of the critical incident report and available clinical/case management information regarding the reported death, other individuals in the residence or served by the provider, and the provider. Regional field staff complete the on-site safety assessment when needed, as deemed by a review of available information.

The process improvements will provide for future data tracking and analysis to allow CMRC and DBHDD to review and consider data and findings from the CMRC process.

[3] Developed by S. D. Staugaitis, Ph.D.

## Causes of Death

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; the medical examiner or coroner's report; or as reported by law enforcement, the physician, or the family.

A summary of the causes of death as recorded in DBHDD's Reporting of Critical Incidents (ROCI) database follows. The leading causes of death among the IDD waiver population from 2013 to 2015 are respiratory disease, heart disease, sepsis, and pneumonia. Aspiration pneumonia appeared as a leading cause of death in 2015 but was not a leading cause of death in 2013 and 2014. Gastrointestinal disease was a leading cause of death in 2013 and 2014 but was not a leading cause of death in 2015.

Comparing the IDD population to U.S. mortality data (2014) and GA 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 the second leading cause of death in 2015 for the IDD 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 three leading causes of death in the IDD population in 2015. Therefore, the leading five causes of death in the U.S. and Georgia, and the most prevalent causes of death in the IDD population in 2015 were similar. For the next five leading causes of death (6-10), similarities are not as apparent. Most apparent similarities for the next five leading causes of death for the U.S. and Georgia compared to the 2015 IDD population was that septicemia, pneumonia, and Alzheimer's disease were in the six through 10 leading causes of death for the US and Georgia, whereas these illnesses were more likely to be in the leading five causes of death in the IDD population.

## Table 1: Leading Causes of Death

| | 2014 | 2010-2014 | 2013 | 2014 | 2015 |
|---|---|---|---|---|---|
| | **U.S.** | **Georgia** | **IDD Population** | | |
| **Rank** | *All Ages* | | *Adult Only* | | |
| **1** | Diseases of the Heart *23.4%* | Diseases of the Heart *21.9%* | Respiratory Disease *18.2%* | Heart Disease *21.9%* | Respiratory Disease *23.1%* |
| **2** | Malignant Neoplasms *22.5%* | Malignant neoplasms *21.7%* | Heart Disease *16.4%* | Respiratory Disease *17.4%* | Heart Disease *15.8%* |
| **3** | Chronic Lower Respiratory Diseases *5.6%* | Chronic Lower Respiratory Diseases 5.5% | Sepsis *12.1%* | Epilepsy/Seizures *7.1%* | Sepsis *8.5%* |
| **4** | Unintentional Injuries *5.2%* | Unintentional Injuries *5.0%* | Pneumonia *7.9%* | Sepsis *6.5%* | Pneumonia *8.5%* |
| **5** | Cerebrovascular Diseases *5.1%* | Cerebrovascular Diseases *5.0%* | Cancer *7.3%* | Cancer *6.5%* | Aspiration Pneumonia *8.5%* |
| **6** | Alzheimer's Disease *3.6%* | Alzheimer's Disease *3.0%* | Gastrointestinal Disease *6.7%* | Gastrointestinal Disease *6.5%* | Epilepsy/Seizures *3.6%* |
| **7** | Diabetes mellitus *2.9%* | Diabetes mellitus 2.9% | Epilepsy/Seizures *4.2%* | Pneumonia *5.8%* | Complications of Cerebral Palsy *3.6%* |
| **8** | Influenza and Pneumonia *2.1%* | Renal *2.3%* | Renal *4.8%* | Renal *3.9%* | Alzheimer's Disease *3.6%* |
| **9** | Renal *1.8%* | Influenza and Pneumonia *2.0%* | Aspiration Pneumonia *3.6%* | Peripheral Vascular Disease *3.9%* | Cancer *2.4%* |
| **10** | Suicide *1.6%* | Infections/Sepsis *2.0%* | Peripheral Vascular Disease *3.6%* | Aspiration Pneumonia *2.6%* | Peripheral Vascular Disease *2.0%* |

*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 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 IDD Waiver Data Related to Mortality

This section presents analyses of IDD waiver data related to mortality. First, the IDD waiver population is described by presenting analysis of key variables that are associated with mortality. Tables and charts include data from 2013 and 2014 for comparison purposes.

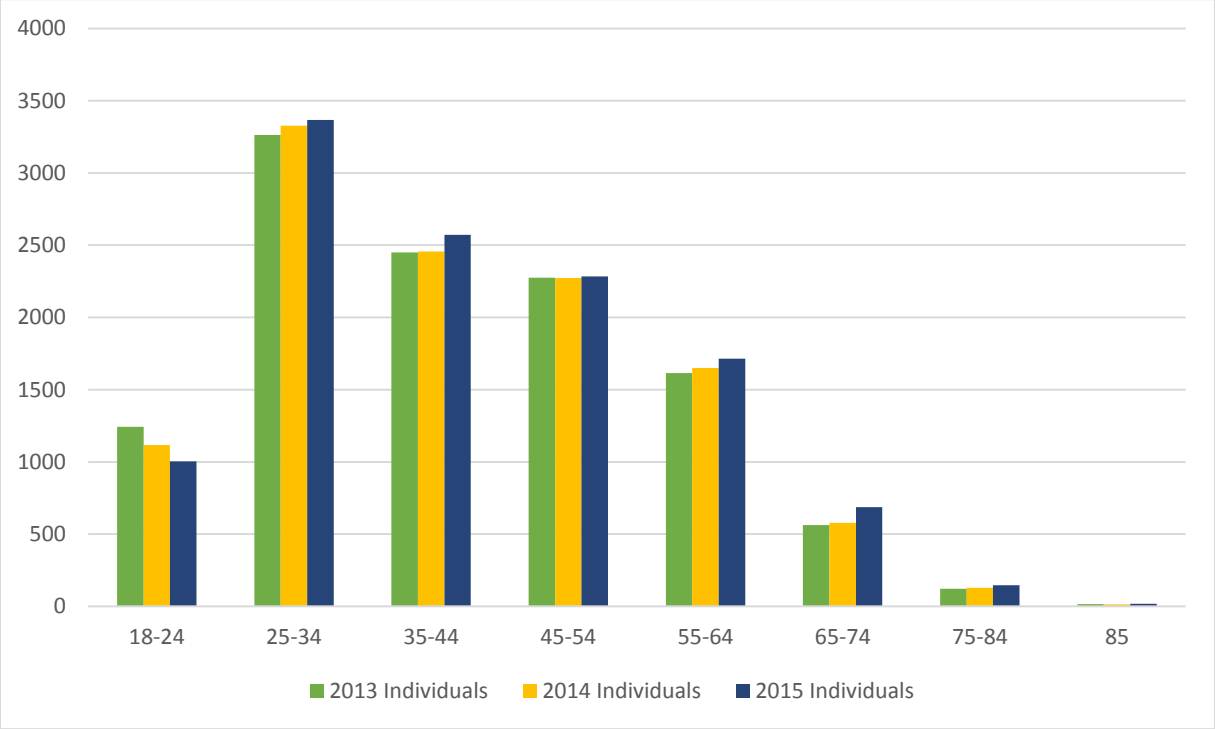
### Age

Table 2 and Figure 1 present the distribution of the IDD population by 10-year age groups. The average age of the adult IDD waiver population in 2015 was 42.2 years (SD = 14.2), which was slightly higher (statistically significant) than the average age of 41.6 years (SD = 14.1) in 2014 ($t = 3.30$, $df = 23{,}296.84$, $p < .001$). This difference indicates an aging population. The largest age group in each year was 25-34. More than half (55.9%) of the population is between 35 and 64 years. Just over one percent of the population is 75 or older.

Table 2: Age Distribution of the Adult IDD Waiver Population, 2013 – 2015

| Age | 2013 | | 2014 | | 2015 | |
|---|---|---|---|---|---|---|
| | Individuals | Percent | Individuals | Percent | Individuals | Percent |
| 18-24 | 1,243 | 10.8% | 1,116 | 9.7% | 970 | 8.2% |
| 25-34 | 3,263 | 28.3% | 3,327 | 28.8% | 3,368 | 28.6% |
| 35-44 | 2,450 | 21.2% | 2,456 | 21.3% | 2,574 | 21.9% |
| 45-54 | 2,275 | 19.7% | 2,273 | 19.7% | 2,282 | 19.4% |
| 55-64 | 1,614 | 14.0% | 1,651 | 14.3% | 1,715 | 14.6% |
| 65-74 | 563 | 4.9% | 577 | 5.0% | 687 | 5.8% |
| 75-84 | 121 | 1.0% | 128 | 1.1% | 147 | 1.3% |
| 85+ | 15 | 0.1% | 14 | 0.1% | 17 | 0.1% |
| Totals | 11,544 | 100.0% | 11,542 | 100.0% | 11,760 | 100.0% |

Figure 1: Age Distribution of the Adult IDD Waiver Population, 2013 – 2015



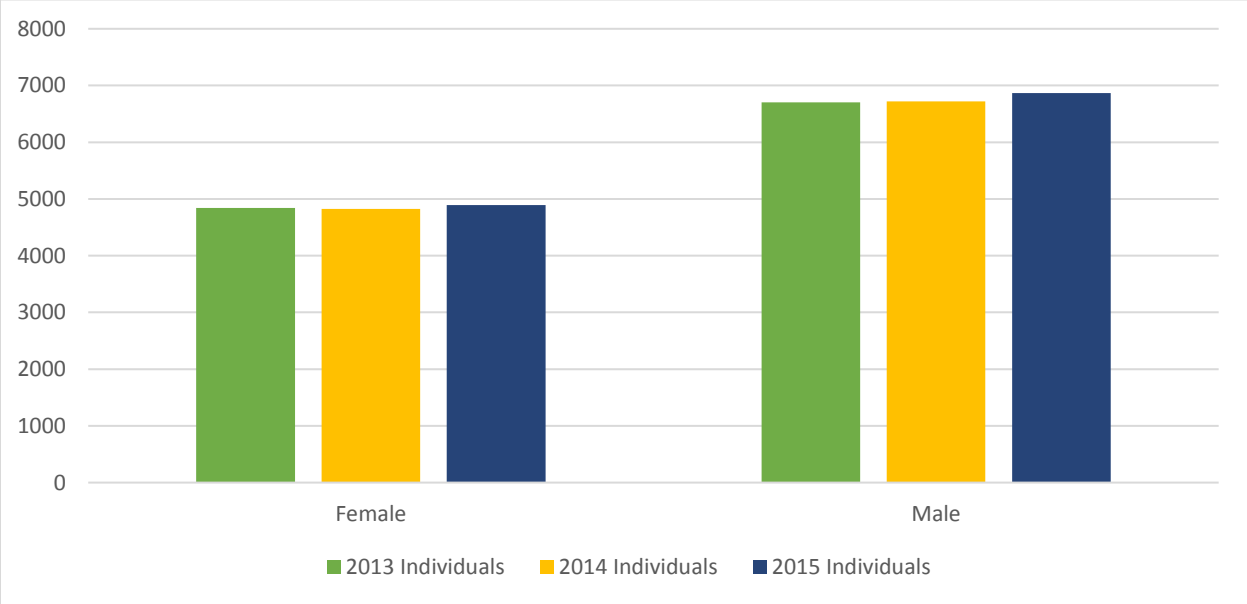
## Gender

Table 3 and Figure 2 show that the distributions of gender were statistically equal across the years 2013 to 2015.

### Table 3: Gender Distribution of the IDD Waiver Population, 2013 – 2015

| Gender | 2013 | | 2014 | | 2015 | |
|---|---|---|---|---|---|---|
| | Individuals | Percent | Individuals | Percent | Individuals | Percent |
| Female | 4,842 | 41.9% | 4,824 | 41.8% | 4,892 | 41.6% |
| Male | 6,702 | 58.1% | 6,718 | 58.2% | 6,868 | 58.4% |
| Total | 11,544 | 100.0% | 11,542 | 100.0% | 11,760 | 100.0% |

### Figure 2: Gender Distribution of the IDD Waiver Population, 2013 – 2015



## Region

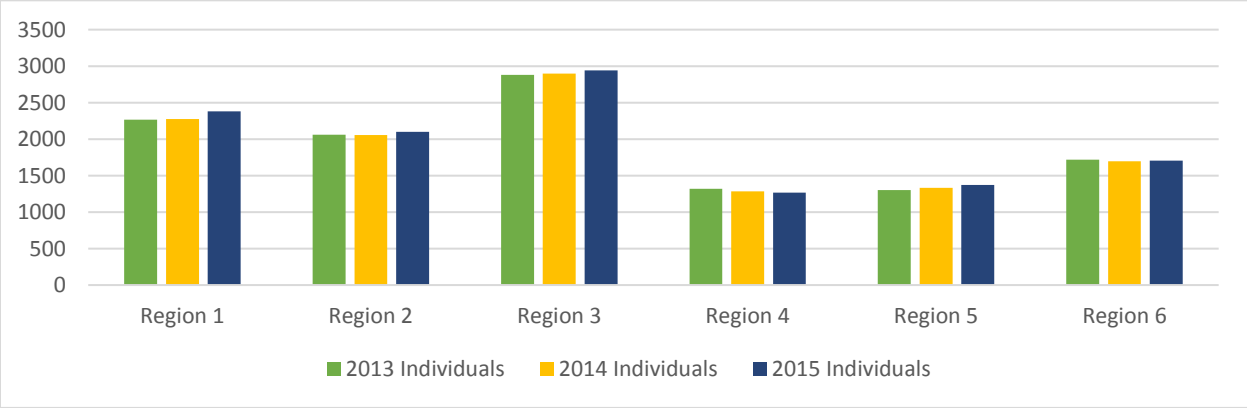
DBHDD serves individuals throughout the state in six geographic regions through a network of contracted providers. See Appendix C for a description of the regions.

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 2013 and 2015 (no statistical differences between proportions were found). Region 3, the most densely-populated region, had the largest population of individuals served (2,940, 25%); Regions 4 and 5 are less-populated areas and had the smallest population of individuals served (1,265, 10.8%; 1,372, 11.7%, respectively).

### Table 4: The Distribution of Adults Receiving IDD Waiver, 2013 - 2015

| Region | 2013 | | 2014 | | 2015 | |
|---|---|---|---|---|---|---|
| | Individuals | Percent | Individuals | Percent | Individuals | Percent |
| Region 1 | 2,266 | 19.6% | 2,275 | 19.7% | 2,381 | 20.2% |
| Region 2 | 2,060 | 17.8% | 2,055 | 17.8% | 2,098 | 17.8% |
| Region 3 | 2,880 | 24.9% | 2,899 | 25.1% | 2,940 | 25.0% |
| Region 4 | 1,317 | 11.4% | 1,284 | 11.1% | 1,265 | 10.8% |
| Region 5 | 1,302 | 11.3% | 1,331 | 11.5% | 1,372 | 11.7% |
| Region 6 | 1,719 | 14.9% | 1,698 | 14.7% | 1,704 | 14.5% |
| Total | 11,544 | 100.0% | 11,542 | 100.0% | 11,760 | 100.0% |

### Figure 3: Adult IDD Waiver Population by Region, 2013 – 2015



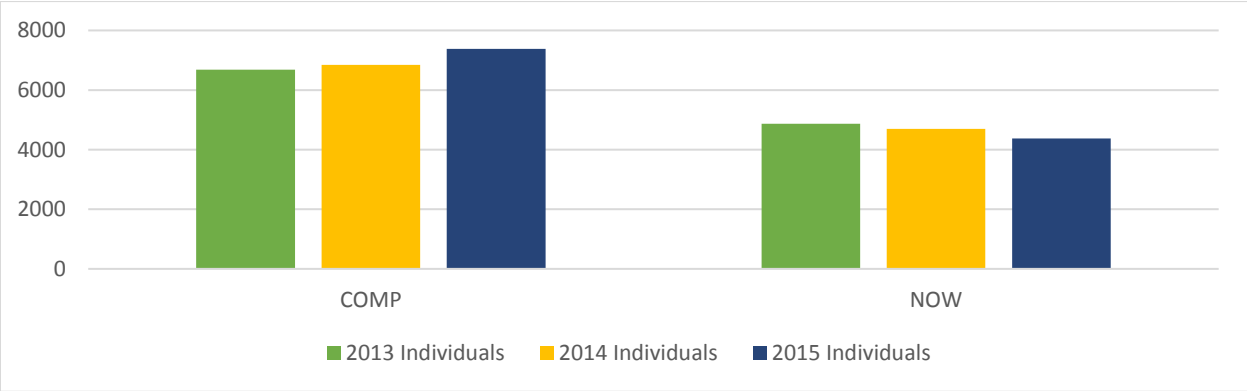
## Type of Medicaid Waiver

The number (and percent) of individuals receiving COMP waivers increased by 540 (7.9%) in 2015. The number of individuals receiving NOW waivers decreased by 322 (6.8%). Both of these changes were statistically significant ($z = 5.467$, $p < 0.0001$).

### Table 5: Distribution of Adult NOW and COMP Waiver Population, 2013 – 2015

| Waiver | 2013 | | 2014 | | 2015 | |
|---|---|---|---|---|---|---|
| | Individuals | Percent | Individuals | Percent | Individuals | Percent |
| COMP | 6,679 | 57.9% | 6,841 | 59.3% | 7,381 | 62.8% |
| NOW | 4,865 | 42.1% | 4,701 | 40.7% | 4,379 | 37.2% |
| Total | 11,544 | 100.0% | 11,542 | 100.0% | 11,760 | 100.0% |

### Figure 4: Distribution of Adult NOW and COMP Waiver Population, 2013 – 2015



## Residential Setting

Individuals who receive IDD services from the 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 (CLA): 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 (PCH): 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 family member. This category also includes 13 individuals whose residence in the Waiver Information System (WIS) is designated as "Foster Care." Finally, 36 individuals' residential setting was designated in WIS as "Other."

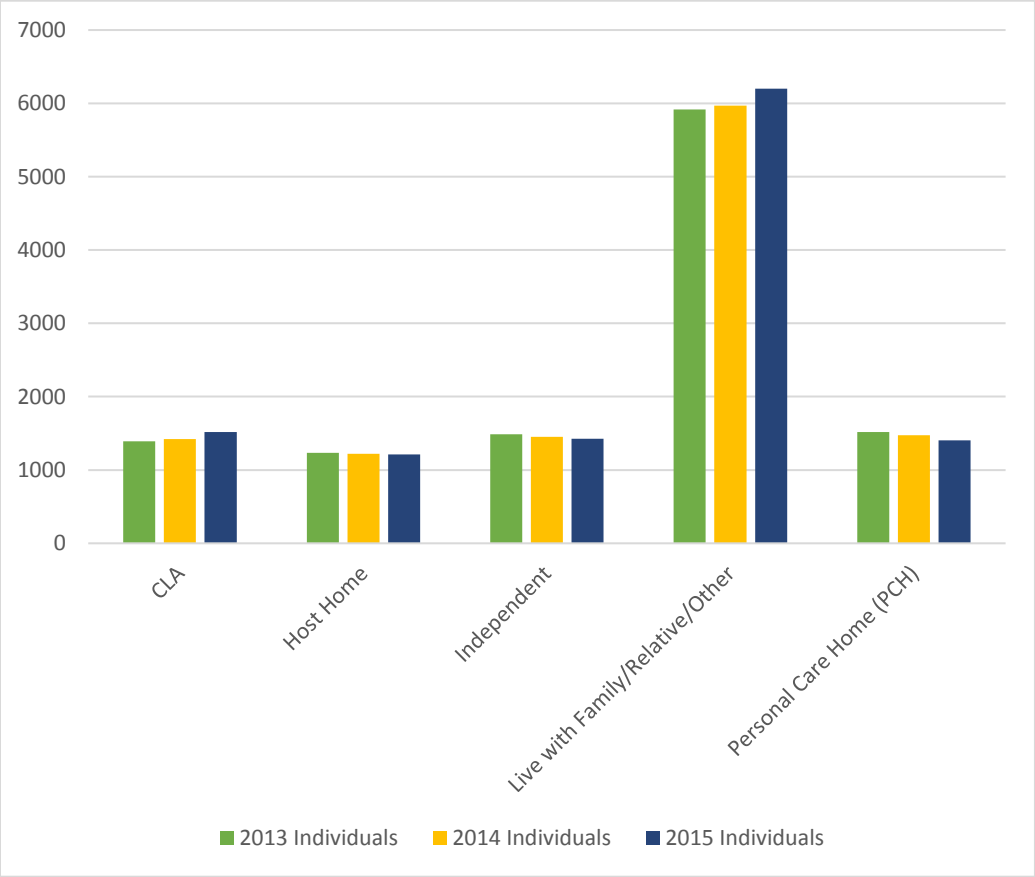
Host homes, CLAs, and PCHs are residential settings that can provide more intensive services and supports. Generally, individuals with greater support needs tend to reside in host homes, CLAs, and PCHs, though individuals and families may choose these settings to allow individuals the opportunity for increased independence and socialization.

The number and percent of individuals living in each type of residential setting was similar across all years. Slightly more than 64 percent lived independently or with a family/relative/other. Approximately 35 percent resided in more intensive service settings (host homes, CLAs, and PCHs).

Table 6: Distribution of Adults in Residential Settings in IDD Waivers, 2013 – 2015

| Residential | 2013 | | 2014 | | 2015 | |
|---|---|---|---|---|---|---|
| | Individuals | Percent | Individuals | Percent | Individuals | Percent |
| CLA | 1,392 | 12.1% | 1,420 | 12.3% | 1,519 | 12.9% |
| Host Home | 1,233 | 10.7% | 1,223 | 10.6% | 1,210 | 10.3% |
| Independent | 1,487 | 12.9% | 1,454 | 12.6% | 1,425 | 12.1% |
| Live with Family/Relative/Other | 5,915 | 51.2% | 5,970 | 51.7% | 6,200 | 52.7% |
| Personal Care Home (PCH) | 1,517 | 13.1% | 1,475 | 12.8% | 1,406 | 12.0% |
| Total | 11,544 | 100.0% | 11,542 | 100.0% | 11,760 | 100.0% |

Figure 5: Distribution of Adults in Residential Settings in IDD Waivers, 2013 – 2015



## 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 he or she needs to enable early identification 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. By policy, the HRST is completed to facilitate an individual's approval for community 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 point scores to rated items. The resulting numerical totals are assigned health care levels 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 IDD Waivers, 2013-2015

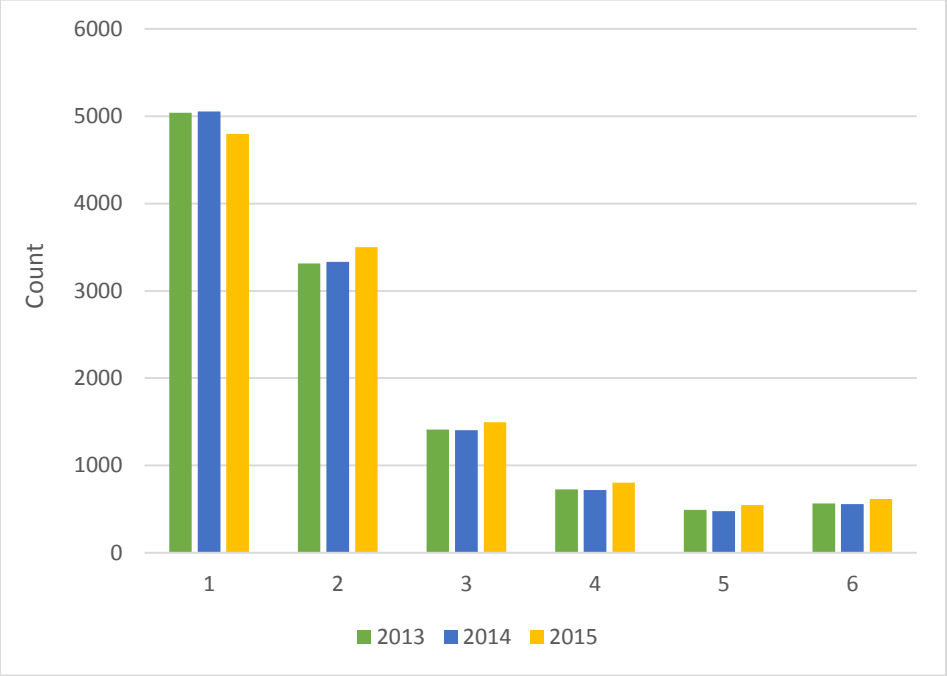
| HRST | 2013 | | 2014 | | 2015 | | Significance of 2014-2015 Change |
|---|---|---|---|---|---|---|---|
| | Count | % of population | Count | % of population | Count | % of population | |
| 1 | 5,039 | 43.7% | 5,053 | 43.8% | 4,799 | 40.8% | $z = -4.6039$, $p < .01$ |
| 2 | 3,313 | 28.7% | 3,332 | 28.9% | 3,500 | 29.8% | NS |
| 3 | 1,411 | 12.2% | 1,405 | 12.2% | 1,497 | 12.7% | NS |
| 4 | 725 | 6.3% | 719 | 6.2% | 802 | 6.8% | NS |
| 5 | 490 | 4.2% | 476 | 4.1% | 545 | 4.6% | NS |
| 6 | 566 | 4.9% | 557 | 4.8% | 617 | 5.2% | NS |
| Total | 11,544 | 100.0% | 11,542 | 100.0% | 11,760 | 100.0% | |

The most current HRST during 2015 was used for this 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 83.3 percent of the population; high-risk HRST scores accounted for 16.7 percent of the population. The distribution of each HRST remained similar across all levels except for HRST = 1, which decreased significantly, by 3 percent ($z = -4.6039$, $p < .01$).

The average HRST score for 2015 was 2.20 (SD = 1.422); the average HRST score for 2014 was 2.13 (SD = 1.392); and the average HRST score for 2013 was 2.13 (SD = 1.399). The average HRST scores across these three years were not statistically different from each other.

Figure 6: Distribution of HRST Scores for Adults Receiving IDD Waivers, 2013 – 2015



## Multiple Variable Analyses

The previous analysis section described the IDD 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, which was similar in 2015 compared to previous years. Categorized by type of residential setting, CLAs had the highest average HRST score (3.12, SD = 1.709); PCHs had the second highest average (2.52, SD = 1.406), and host homes had the lowest (2.39, SD = 1.369). To compare the means across more than two groups, a statistical analysis using a one-way ANOVA and post hoc analysis (results not shown) indicate that the average HRST score for CLAs was significantly higher than all other residential settings. The average HRST score for PCHs and host homes did not differ significantly.

Individuals living with family or friends had the lowest average HRST score (1.90, SD = 1.251), which was significantly lower than all other residential settings. The second lowest average HRST score was for individuals living in independent apartments or homes (2.09, SD = 1.327). This average was significantly lower than the average for all other residential settings, but it was significantly higher than the average for individuals living with family or friends.

In 2015, 68.7 percent of individuals with low-risk HRST scores resided in independent living arrangements or with family/relative/other. This indicates that most individuals with a low-risk HRST score live in settings that receive less intensive services compared to residential settings. In 2015, 54.4 percent of individuals with high-risk scores resided in residential settings characterized by higher service needs; 45.5 percent of individuals with high-risk scores resided independently or with family/relative/other. This means that individuals with high-risk levels live across all residential settings.

### Table 9: Residential Setting by HRST Score, 2015

| Residential Setting | Count by HRST | | | | | | | Percent by HRST | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | Total | 1 | 2 | 3 | 4 | 5 | 6 | Total |
| Community Living Arrangement (CLA) | 288 | 420 | 253 | 175 | 148 | 235 | 1,519 | 6.0% | 12.0% | 16.9% | 21.8% | 27.2% | 38.1% | 12.9% |
| Host Home | 359 | 422 | 208 | 103 | 60 | 58 | 1,210 | 7.5% | 12.1% | 13.9% | 12.8% | 11.0% | 9.4% | 10.3% |
| Independent Apartment/Home | 605 | 456 | 168 | 78 | 65 | 53 | 1,425 | 12.6% | 13.0% | 11.2% | 9.7% | 11.9% | 8.6% | 12.1% |
| Live with Family/ Relative/Other | 3,194 | 1,696 | 612 | 312 | 200 | 186 | 6,200 | 66.6% | 48.5% | 40.9% | 38.9% | 36.7% | 30.1% | 52.7% |
| Personal Care Home (PCH) | 353 | 506 | 256 | 134 | 72 | 85 | 1,406 | 7.4% | 14.5% | 17.1% | 16.7% | 13.2% | 13.8% | 12.0% |
| Total | 4,799 | 3,500 | 1,497 | 802 | 545 | 617 | 11,760 | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% |

Figure 7: CLA, Host Home, PCH Residential Setting by HRST Score, 2015

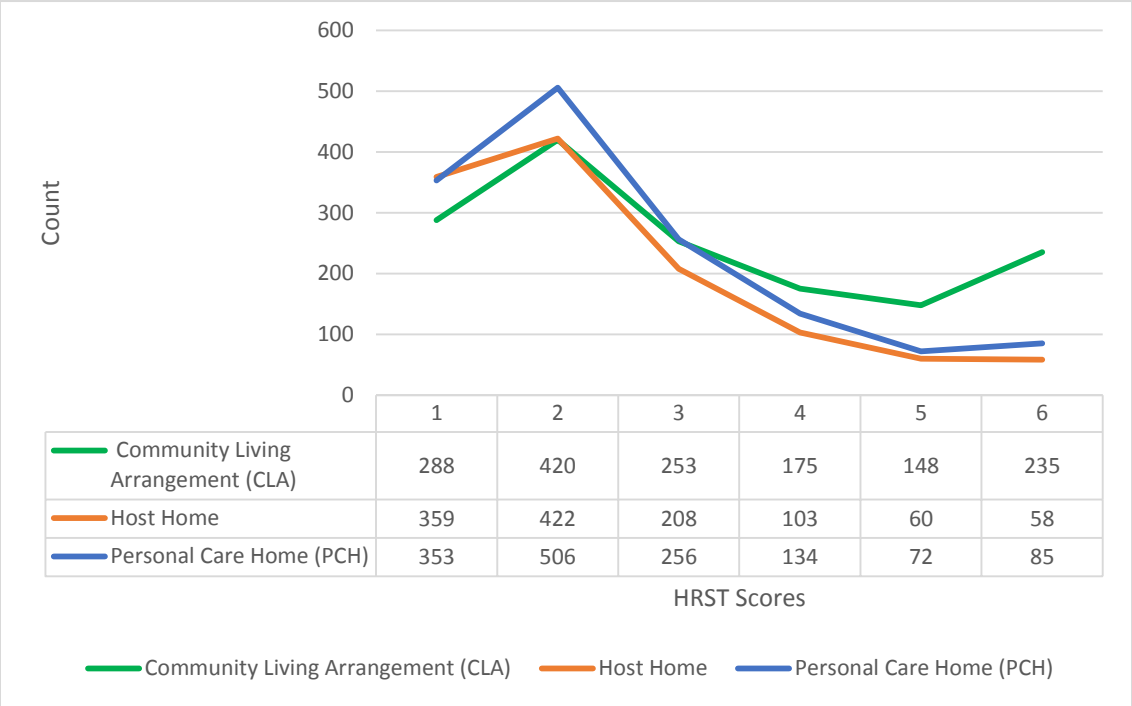
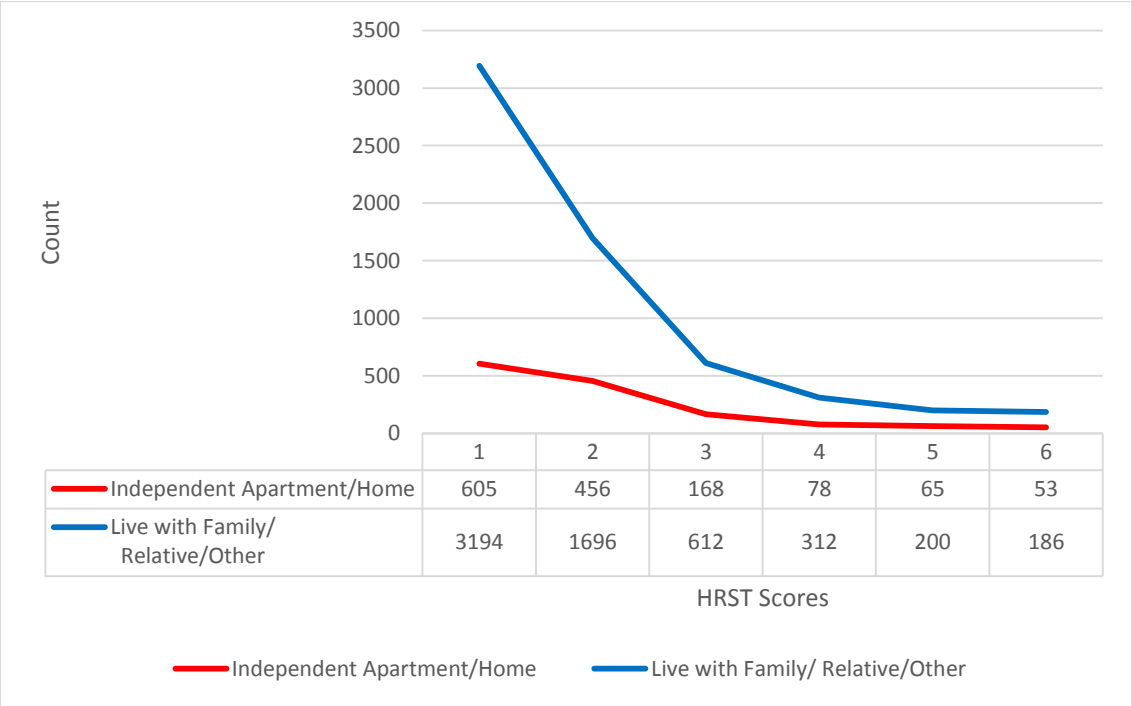



Figure 8: Independent, Live with Family/Relative/ Other Residential Setting by HRST Score, 2015



## 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 in their entire distribution across the first four age groups. Starting at age group 55-64, however, the older age groups have fewer individuals with low HRST scores, compared to the overall IDD waiver population, and older age groups have a higher proportion of individuals with higher HRST scores. Correlations between age (both as continuous and ordinal variables) indicate the association between HRST and age is weak (Pearson's $r = .099$, $p < .001$; Spearman's rho = .098, $p < .001$). Though both of these are statistically significant, the total variance explained in the association between age and health risk is about 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 are related to mortality, these variables would have independent (not interactive) effects.

### Table 10: HRST by Age Category

| Age | Count by HRST | | | | | | Total | Percent by HRST | | | | | | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 18-24 | 337 | 286 | 131 | 84 | 50 | 82 | 970 | 7.0% | 8.2% | 8.8% | 10.5% | 9.2% | 13.3% | 8.2% |
| 25-34 | 1,609 | 951 | 359 | 177 | 128 | 144 | 3,368 | 33.5% | 27.2% | 24.0% | 22.1% | 23.5% | 23.3% | 28.6% |
| 35-44 | 1,163 | 766 | 296 | 157 | 91 | 101 | 2,574 | 24.2% | 21.9% | 19.8% | 19.6% | 16.7% | 16.4% | 21.9% |
| 45-54 | 918 | 687 | 307 | 150 | 116 | 104 | 2,282 | 19.1% | 19.6% | 20.5% | 18.7% | 21.3% | 16.9% | 19.4% |
| 55-64 | 559 | 547 | 262 | 147 | 88 | 112 | 1,715 | 11.6% | 15.6% | 17.5% | 18.3% | 16.1% | 18.2% | 14.6% |
| 65-74 | 174 | 226 | 111 | 70 | 52 | 54 | 687 | 3.6% | 6.5% | 7.4% | 8.7% | 9.5% | 8.8% | 5.8% |
| 75-84 | 34 | 32 | 28 | 16 | 18 | 19 | 147 | 0.7% | 0.9% | 1.9% | 2.0% | 3.3% | 3.1% | 1.3% |
| 85+ | 5 | 5 | 3 | 1 | 2 | 1 | 17 | 0.1% | 0.1% | 0.2% | 0.1% | 0.4% | 0.2% | 0.1% |
| Total | 4,799 | 3,500 | 1,497 | 802 | 545 | 617 | 11,760 | 100.00% | 100.00% | 100.00% | 100.00% | 100.00% | 100.00% | 100.00% |

## Mortality During 2015

This section contains information on deaths reported to DBHDD among the IDD waiver population during calendar year 2015. Calendar years 2013 and 2014 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 2013 and 2014 were 11.3 and 11.1 deaths per 1,000 individuals. The 2015 mortality rate was 12.5 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, Massachusetts[4] 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] This 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 2015 IDD mortality rate for DBHDD, 12.5 deaths per 1,000. The mortality rate for these states combined in 2011 was 9.37,[5] which is significantly lower than the DBHDD 2015 IDD mortality rate ($z = 3.303$, $p = .001$).

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 2015 DBHDD IDD mortality rates ($z = -7.643$, $p < .0001$; $z = -5.643$, $p < .0001$, respectively). Massachusetts reported IDD mortality rates of 19.2 and 17.4 deaths per 1,000 in 2012 and 2013, respectively.[4] DBHDD's 2015 IDD mortality rates were significantly lower compared to Massachusetts' mortality rates in 2012 ($z = -4.5526$, $p < .001$) and in 2013 ($z = -3.5097$, $p = .0004$). This difference is particularly striking in that Massachusetts included in the denominator all individuals

[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.

receiving services, as well as those *eligible* for services, but included mortality information for only those individuals who actually *received* services in the numerator.

## Age and Mortality

The average age of death in 2014 was 51.66 years (SD = 16.44). The average age of death in 2015 was 54.19 (SD = 15.38). The average age of death increased by 2.53 years in 2015 over 2014, which was statistically significant ($t = 12.13$, $df = 23{,}193$, $p < .001$). This means that as a whole, individuals who died in 2015 lived about two and a half years longer than those that died in 2014. 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.[5]

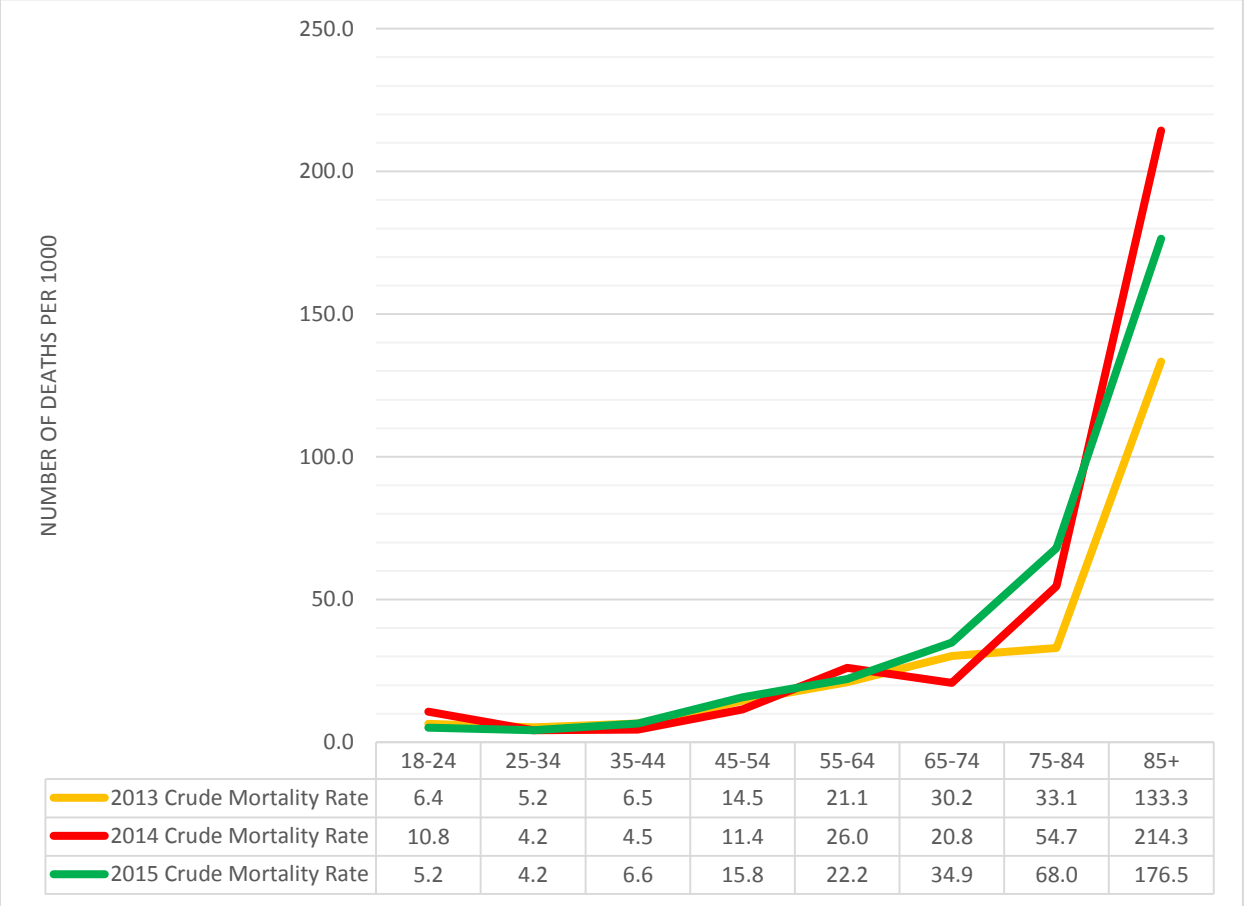
### Table 11: GA IDD Mortality Rates by Age Category, 2013 – 2015

| | | 18-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65-74 | 75-84 | 85+ | Total |
|---|---|---|---|---|---|---|---|---|---|---|
| **2013** | Adult Waiver Population | 1,243 | 3,263 | 2,450 | 2,275 | 1,614 | 563 | 121 | 15 | 11,544 |
| | No. of Deaths | 8 | 17 | 16 | 33 | 34 | 17 | 4 | 2 | 131 |
| | Percent of Deaths | 6.1% | 13.0% | 12.2% | 25.2% | 26.0% | 13.0% | 3.1% | 1.5% | 100.0% |
| | Crude Mortality Rate | 6.4 | 5.2 | 6.5 | 14.5 | 21.1 | 30.2 | 33.1 | 133.3 | 11.3 |
| **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 | 26.0 | 20.8 | 54.7 | 214.3 | 11.1 |
| **2015** | Adult Waiver Population | 970 | 3,368 | 2,574 | 2,282 | 1,715 | 687 | 147 | 17 | 11,760 |
| | No. of Deaths | 5 | 14 | 17 | 36 | 38 | 24 | 10 | 3 | 147 |
| | Percent of Deaths | 3.4% | 9.5% | 11.6% | 24.5% | 25.9% | 16.3% | 6.8% | 2.0% | 100.0% |
| | Crude Mortality Rate | 5.2 | 4.2 | 6.6 | 15.8 | 22.2 | 34.9 | 68.0 | 176.5 | 12.5 |

As in 2013 and 2014, mortality rates increase with increasing age (Table 11, Figure 9). In particular, between 2013 and 2015, the mortality rate for individuals between ages 45 and 54 exceeded the overall mortality rate for the entire population for each year. Statistical comparisons of mortality rates between corresponding age categories from 2015 to 2014 were not significantly different. The trends in Figure 9 are visually striking due to the absolute difference between 2013, 2014, and 2015 mortality rates for the 85+ age category, which were 133.3, 214.3, and 176.5 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.

## Figure 9: GA IDD Mortality Rate by Age Category, 2013 – 2015




| | 18-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65-74 | 75-84 | 85+ |
|---|---|---|---|---|---|---|---|---|
| 2013 Crude Mortality Rate | 6.4 | 5.2 | 6.5 | 14.5 | 21.1 | 30.2 | 33.1 | 133.3 |
| 2014 Crude Mortality Rate | 10.8 | 4.2 | 4.5 | 11.4 | 26.0 | 20.8 | 54.7 | 214.3 |
| 2015 Crude Mortality Rate | 5.2 | 4.2 | 6.6 | 15.8 | 22.2 | 34.9 | 68.0 | 176.5 |

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. Other research[5] 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, the mortality rates also increase more rapidly with increasing years after about 55 years of age.[7] These data combined indicate that age-specific mortality rates are similar for IDD populations across states and are similar to U.S. data for the general population, but with higher mortality rates among IDD populations.

[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 July 26, 2016.

## Gender and Mortality

Gender was not an explanatory variable in mortality in 2015. Gender was not an explanatory variable also in 2013 and 2014. The 2015 mortality rate for females was 12.9 and 12.2 for males, which was not statistically different. The average age of death for females was 55.9 and 52.9 for males.

### Table 12: Number of Deaths, Average Age at death and Mortality Rate by Gender 2013 – 2015

| | | Female | Male | Total |
|---|---|---|---|---|
| **2013** | Adult Waiver Population | 4,842 | 6,702 | 11,544 |
| | No. of Deaths | 47 | 84 | 131 |
| | Percent of Deaths | 35.9% | 64.1% | 100.0% |
| | Average Age at Death | 51.9 | 50.0 | |
| | Crude Mortality Rate | 9.7 | 12.5 | 11.3 |
| **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 | 55.9 | 52.9 | |
| | Crude Mortality Rate | 12.9 | 12.2 | 12.5 |

## Age, Residential Setting, and Mortality

The average age at death varies across residential settings. Generally, the mortality rate for each residential setting is reflective of the relative age and health status of the population that resides in each setting. The rate of mortality is higher in residential settings typically characterized by high-intensity of services to meet the higher levels of support needs. These relationships may have been found because increased health risk and age are associated with risk of mortality.

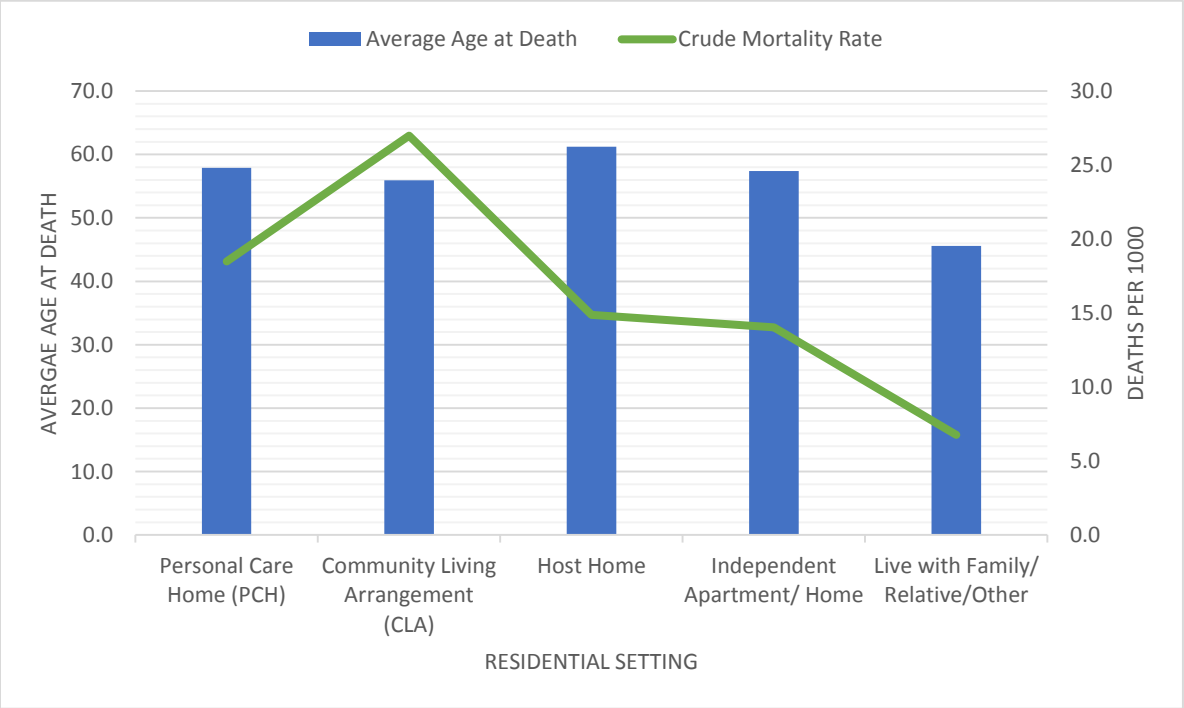
The average age of death was 54.2 (SD = 15.38) in 2015. The average age of death for residential settings ranged between 45.6 and 61.2 years. The average age of death for individuals who lived in less intensive residential settings was 49.4 (SD = 15.41). The average age of death for individuals who lived in more intensive settings was 57.66 (SD = 14.48). The difference between the average age of death for these two groups is statistically different ($t = 3.280$, $df = 126.686$, $p = .001$). This means that individuals who died in 2015 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 lowest mortality rate (6.8 deaths per 1,000); combined, this group had a mortality rate of 8.13, which is significantly lower than the rate for the total population (12.5 deaths per 1,000). Those who died within lower-intensity residential settings had a significantly higher health risk score (3.4) compared to the entire population and other service settings. Therefore, it is likely that the lowered life expectancy in the less intensive service setting may have been related to higher health risks for those individuals who died in 2015.

Residential-setting-specific mortality rates range from 6.8 to 27.0. The mortality rate for the three higher-intensity residential settings combined is 20.6. In 2014, the mortality rate for these three high-intensity residential setting combined was 18.7. The mortality rate for the two lower-intensity residential settings combined was 8.1 in 2015 and 6.9 in 2014. The mortality rates for 2014 and 2015 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 ($z = 5.7478$, $p < .0001$).

Table 13: Average Age at Death and Mortality rate by Residential Setting, 2015

| Residential Setting | Adult Population | Percent | % of Population 65+ | No. Deaths | Average Age at Death | Crude Mortality Rate |
|---|---|---|---|---|---|---|
| Personal Care Home (PCH) | 1,406 | 12.0% | 13.8% | 26 | 57.9 | 18.5 |
| Community Living Arrangement (CLA) | 1,519 | 12.9% | 11.3% | 41 | 55.9 | 27.0 |
| Host Home | 1,210 | 10.3% | 10.7% | 18 | 61.2 | 14.9 |
| Independent Apartment/ Home | 1,425 | 12.1% | 11.8% | 20 | 57.4 | 14.0 |
| Live with Family/ Relative/Other | 6,200 | 52.7% | 11.5% | 42 | 45.6 | 6.8 |
| Total | 11,760 | 100.0% | 11.7% | 147 | 54.2 | 12.5 |

Figure 10: Average Age at Death and Mortality Rate by Residential Setting, 2015



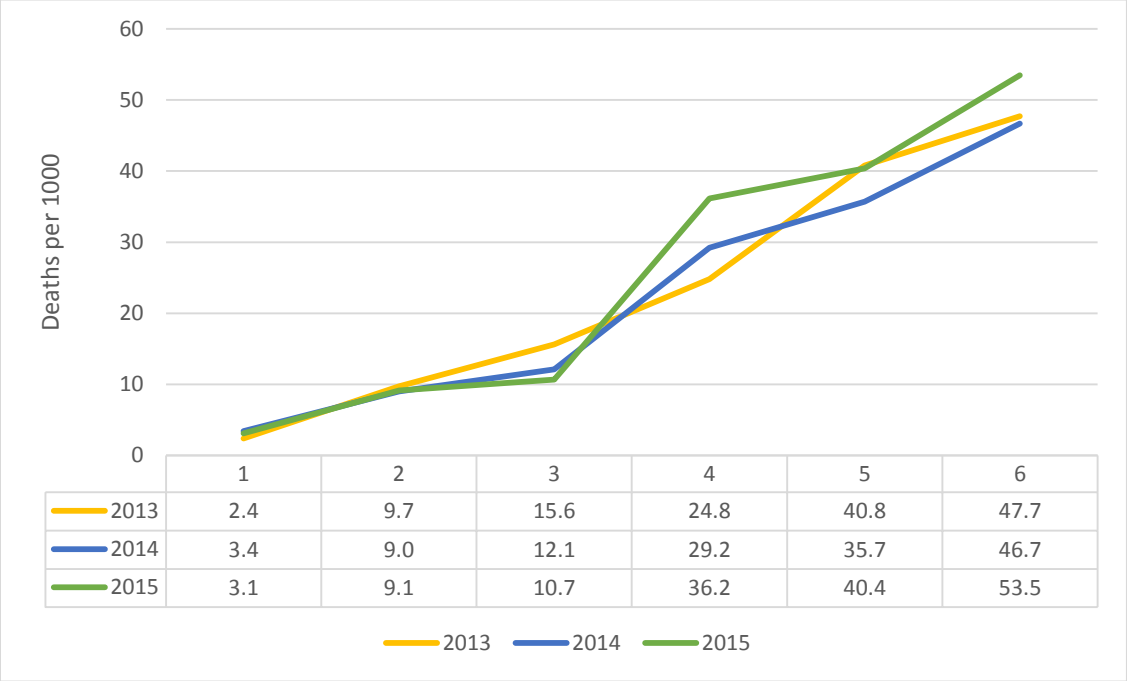
## Health Risk and Mortality

A clear relationship exists between increasing health risk score and mortality rate in 2015. Lower HRST scores (1-3) have mortality rates that are below the population mortality rates in 2015. The mortality rates associated with an HRST score of 4-6 exceed the overall population mortality rate of 12.5.

As mentioned, mortality rates increase with increasing HRST scores. The associated increase in mortality rate with each increase in HRST score is not necessarily significant. In fact, across 2013, 2014, and 2015, the difference between the mortality rates associated with a one-point increase in HRST score is only significant in five out of 15 instances across the three years. Therefore, the difference in associated mortality with an increase of one HRST level needs additional analysis (presented later) to determine whether an incremental increase in HRST score is a significant predictor of the risk of death. It should be noted, however, that there is a statistically significant increase in mortality rate with any two-point increase in HRST, as also was the case in 2013 and 2014.

The mortality rate for lower HRST scores (1-3) is 6.4; the mortality rate for the higher HRST scores (4-6) is 42.8, which is significantly higher ($z = 13.23$, $p < .0001$). Of particular note is the dramatic increase of mortality rates between 3 and 4; the mortality rate of HRST = 4 is three times as high as for HRST = 3. These analyses clearly indicate that health risk, especially higher health risk scores, are significant predictors of mortality.

### Figure 11: Mortality Rate by HRST Score, 2013 – 2015




| | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| 2013 | 2.4 | 9.7 | 15.6 | 24.8 | 40.8 | 47.7 |
| 2014 | 3.4 | 9.0 | 12.1 | 29.2 | 35.7 | 46.7 |
| 2015 | 3.1 | 9.1 | 10.7 | 36.2 | 40.4 | 53.5 |

Table 14: Mortality Rate by HRST Score, 2015

| HRST Score | 2015 | | | | |
|---|---|---|---|---|---|
| | Adult Waiver Population | No. Deaths | Percent of deaths | Crude Mortality Rate | Statistical significance between HRST Scores |
| 1 | 4,799 | 15 | 10.2% | 3.1 | |
| 2 | 3,500 | 32 | 21.8% | 9.1 | z = 3.61, p=.0003 |
| 3 | 1,497 | 16 | 10.9% | 10.7 | ns |
| 4 | 802 | 29 | 19.7% | 36.2 | z = 4.20, p=.01 |
| 5 | 545 | 22 | 15.0% | 40.4 | ns |
| 6 | 617 | 33 | 22.4% | 53.5 | ns |
| **Grand Total** | **11,760** | **147** | 100.0% | 12.5 | |

## The Importance of Age and Health Risk

Data analyses to this point have examined the relationship of age, gender, 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 and 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, residential setting, and health risk together are associated with mortality to determine which variables may be of key importance in understanding mortality.

An advantage of using logistic regression to determine the importance of each variable is that the information from the model can be used to calculate the odds ratio (OR) of an event occurring 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 analysis. 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, residential intensity setting, and HRST score were used together to analyze which variables were associated with death in 2015. Only age and HRST scores were significantly associated with occurrence of death. This means that when controlling for age and HRST scores, gender and the intensity of residential service setting were not significant predictors of the occurrence of death. The model using only HRST scores and age correctly classified 98.8 percent of the occurrences of individuals living or having died at the end of 2015. It should be noted that the logistic regression analysis for 2013 and 2014 were almost identical to 2015.

Table 15: Final Logistic Regression Model with Death as Outcome, 2015

| Variable | B | S.E. | Wald | df | Sig. | Exp(B) |
|---|---|---|---|---|---|---|
| Age | .047 | .006 | 71.565 | 1 | .000 | 1.048 |
| HRST | .509 | .047 | 115.258 | 1 | .000 | 1.663 |
| Constant | -8.113 | .332 | 564.288 | 1 | .000 | .000 |

The odds of dying increase significantly with each one-point increase in HRST score. At the lowest level (HRST = 1), the odds of dying are 1.66. With each point increase, the odds of dying increase exponentially, such that the odds of dying with an HRST score of 6 are 21.2. That is, the odds of dying with an HRST score of 6 are more than 12 times higher than an HRST of 1. The main finding is that each one-point increase in HRST score has a very strong relationship to the likelihood that death may occur, even at the lowest levels.

Table 16: Odds Ratio (OR) for HRST Scores, 2013 – 2015

| HRST | OR 2013 | OR 2014 | OR 2015 |
|---|---|---|---|
| 1 | 1.65 | 1.61 | 1.66 |
| 2 | 2.72 | 2.60 | 2.77 |
| 3 | 4.48 | 4.20 | 4.60 |
| 4 | 7.39 | 6.77 | 7.66 |
| 5 | 12.18 | 10.91 | 12.74 |
| 6 | 20.09 | 17.60 | 21.20 |

The odds of dying increase significantly with age. At 20 years old, the odds of dying are just barely more than one (i.e., 1.09), which indicates little risk of death for the youngest group. However, with each 10-year increase in age, the odds of dying increase exponentially, 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 more than 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.

### Table 17: Odds Ratio (OR) for 10-Year Age Difference, 2013 – 2015

| Age | OR 2013 | OR 2014 | OR 2015 |
|---|---|---|---|
| 20 | 1.07 | 1.08 | 1.09 |
| 30 | 1.52 | 1.61 | 1.78 |
| 40 | 2.16 | 2.41 | 2.81 |
| 50 | 3.06 | 3.60 | 4.50 |
| 60 | 4.35 | 5.37 | 7.20 |
| 70 | 6.17 | 8.00 | 11.52 |

The primary results of these analyses indicate two main points. First, models for 2013 to 2015 are very similar in that age and health risk scores were the two main predictors of death (and not gender or residential setting). Second, the model indicates possible opportunities to identify risk of death associated with age and HRST scores and to determine whether additional services or supports are needed.

## Key Findings

- The 2015 DBHDD IDD mortality rate was 12.5 deaths per 1,000 individuals. The 2015 mortality rate did not differ significantly from the DBHDD IDD mortality rates in 2013 and 2014.
- The 2015 DBHDD IDD mortality rate of 12.5 in all except one comparison with other states' mortality rates was significantly lower; however, caution should be used in interpreting or generalizing these differences.
- Analysis indicates lowest risk levels still carry a significant relationship to mortality, and mortality risks increase exponentially with increasing health risk scores. Furthermore, a one-point increase in health risk scores may be associated with an increase in mortality risk; a two-point increase in health risk scores significantly increases the likelihood of mortality.
- As within other states' IDD populations, mortality increases significantly after ages 45-54. This pattern also is found in the general U.S. population.
- Life expectancy for this population significantly increased by 2.53 years between 2014 and 2015. This means that as a whole, individuals who died in 2015 lived about two and a half years longer than those that died in 2014.
- Life expectancy for the 2015 IDD population (54.2 years) is comparable to the average age of death for IDD populations as reported in other state mortality reports and in published, peer-reviewed research (50.4 to 58.7 years).
- The leading five causes of death in the general population of the U.S. (2014) and Georgia (2010-2014) and the most prevalent causes of death in the DBHDD IDD population in 2015 were similar. The leading causes of death among the IDD waiver population from 2013 to 2015 were respiratory disease, heart disease, sepsis, and pneumonia (including aspiration pneumonia).
- Septicemia, pneumonia, and Alzheimer's disease were in the six through 10 leading causes of death for the U.S. (2014) and Georgia (2010-2014), whereas these illnesses were more likely to be in the leading five causes of death in in the 2015 IDD population.
- Region, gender, and residential setting are not significantly related to mortality.

## Utilization of Mortality Report Findings

The Office of Performance Analysis analyzed data from the causes of death and mortality factors for the IDD waiver population in 2015 to provide information on what DBHDD has learned about deaths, to identify trends or patterns, and to identify indicators that could assist DBHDD in the prevention and treatment of certain illnesses that may lead to deaths or other possible illness 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 here. The observations and findings in this report will be presented to the leadership of DBHDD, IDD, 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 the quality of care in specific areas vital to maintaining health.

The responsibility for the utilization of the information within this report is that of the director of the Division of IDD. The IDD Division 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 IDD in the community. DBHDD's reorganization provides a platform for clarified roles and responsibilities in addressing mortality in the IDD 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 assist the Division of IDD to accomplish improvement strategies; the Division of IDD has the responsibility to utilize these resources. The Division of IDD 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.

# 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 2015 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 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)

Due to the large number of statistical comparisons, the statistical significance level was set at $\alpha = 0.01$. Setting $\alpha = .01$ as the significance level is to compensate for finding significance due to increased chances afforded by multiple comparisons.

Crude mortality rates were calculated for the NOW and COMP Medicaid waiver population by age category, gender, and residence type. The specific methodology employed by this report to calculate mortality rates per 1,000 people throughout this report appears on the following page.

Crude Mortality Rate =

$$\frac{\text{(Number of people who died in calendar year x 1,000)}}{\text{(Number of people that received waiver service during the calendar year)}}$$

Caution should be used when comparing mortality rates across unlike methods and populations.

Deaths were included, regardless of death category, for all population-eligible individuals who died in 2015.

Analyses were conducted using SPSS© v. 23.0, 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 significance in predicting if death occurred. Variables that were indicated as not being significant predictors of death occurring were removed, and the model was recomputed. Those variables that were indicated as significant predictors were maintained in the model. This process continued until only significant predictor variables of death remained. Finally, the model was examined for meaningful relationships and interpretation.

# Appendix B: Community Mortality Review Committee Policy

FULL IMPLEMENTATION DATE – NOVEMBER 1, 2015

**APPLICABILITY**

All Department of Behavioral Health and Developmental Disabilities (DBHDD) Community Providers and subcontracted providers.

**POLICY**

DBHDD conducts thorough reviews of deaths of individuals receiving services by or through DBHDD community providers for the purpose of reducing morbidity or mortality and evaluating and improving the quality and efficiency of services rendered. All such reviews are conducted using the systematic interdisciplinary procedures described in this policy. Cooperation with the Community Mortality Review Committee (CMRC) is a requirement of all providers.

**PURPOSE**

The goals of this policy 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 recommend and/or implement corrective actions to improve the performance of DBHDD staff and systems;
- To make recommendations for appropriate enforcement actions;
- 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 make statewide action based on mortality information to systematically improve care.

**DEFINITIONS**

**Category I – Death-unexpected:** The cause of death is not attributed to a terminal diagnosis or diagnosed disease process where the reasonable expectation of the outcome is death. It includes the death of an individual receiving residential services or receiving 24/7 community living support; or a death occurring on site of a community provider; or a death in the company of staff of a community provider; or the death of an individual absent without leave from residential services. For the purposes of this policy, all suicides are considered unexpected deaths.

**Category II – Death-expected:** The cause of death is attributed to a terminal diagnosis or diagnosed disease process where the reasonable expectation of outcome is death. It includes the death of an individual receiving residential services or receiving 24/7 community living support; or a death occurring on site of a community provider; or a death in the company of staff of a community provider; or the death of an individual absent without leave from residential services.

**Category III – Death:** The death of any individual enrolled with DBHDD and actively receiving services. Excludes deaths defined as Category I – Unexpected, including suicide, and Category II – Expected. Includes the death of an individual receiving DD self-directed services.

**Community Provider:** Any person or entity providing community-based disability services through a contract with or authorized by DBHDD and/or providing Medicaid services authorized by DBHDD. Includes support coordination agencies and any state owned or operated community program. For purposes of this policy, the term provider includes organizations that provide services that are financially supported in whole or in part by funds authorized through DBHDD.

**Corrective Action Plan:** A document based on the investigative findings and developed by the provider and approved by DBHDD that identifies and analyzes problems within the provider organization and prescribes corrective action steps which, when implemented, are likely to prevent the recurrence of similar problems and improve the quality of services. A corrective action plan must identify the person(s) responsible for ensuring that action steps are completed and reviewed for efficacy and establish a schedule for completion and follow-up of all action steps and a process or method for monitoring the correction moving forward.

**Corrective Action Tracking System (CATS):** The DBHDD administered data system used to track deficiencies, recommendations, and corrective actions.

**PROCEDURES**

**A. Community Mortality Review Committee**

1. The DBHDD Community Mortality Review Committee (CMRC) is responsible for the oversight of community mortality activities including the following:
    a. Reviewing all internal and external investigative reports and mortality reviews;
    b. Determining whether necessary and reasonable measures were taken to provide for the health, safety, and welfare of the individual receiving services by a DBHDD provider;
    c. Determining statewide actions related to reducing risks including provider training, communication with providers relative to risks, alerts, and opportunities for learning and training;
    d. Identifying and mitigating any CMRC findings that could affect the health, safety, and welfare of other individuals receiving supports and services from DBHDD community providers; and
    e. Making recommendations to providers and DBHDD and ensuring that recommended activities have been completed and no further action is required.
2. The Commissioner of the Department appoints committee members and a committee chair.
3. Membership of the CMRC includes the following:
    a. DBHDD medical director;
    b. A physician who is knowledgeable of or experienced in delivering services to individuals who are receiving services through DBHDD;
    c. A registered nurse who is knowledgeable of or experienced in providing services to individuals with intellectual and developmental disabilities (I/DD);
    d. A registered nurse who is knowledgeable of or experienced in providing services to individuals receiving behavioral health services;

e. A representative from the Office of Quality Improvement;
f. A representative from the DBHDD Division of Accountability and Compliance;
g. Two DBHDD state-level managers with extensive program knowledge in intellectual and developmental disabilities (IDD);
h. A DBHDD state-level manager with extensive program knowledge in mental health (MH);
i. DBHDD state-level manager with extensive program knowledge in addictive diseases (AD);
j. DBHDD suicide risk prevention coordinator;
k. A representative from the Georgia Bureau of Investigation (GBI);
l. A representative from the Long-Term Care Ombudsman or Adult Protective Services;
m. A provider representative who is knowledgeable of or experienced in providing services to individuals with intellectual and developmental disabilities (IDD) services
n. A provider representative who is knowledgeable of or experienced in providing services to individuals receiving behavioral health services;
o. A representative of the DBHDD legal services unit;
p. Director, Office of Incident Management and Investigations (OIMI); and
q. Other DBHDD staff may be invited to a meeting for a particular purpose at the discretion of the CMRC Chair.

4. CMRC members are provided relevant documents for review at least 14 business days prior to the scheduled meeting. All records, documents and evidence are confidential and maintained securely;
5. CMRC members are responsible for the following:
    a. Reviewing the materials provided prior to the meeting;
    b. Maintaining confidentiality of the records received and CMRC deliberations;
    c. Identifying areas of potential conflict of interest and recusing him/herself from particular reviews as appropriate; and
    d. Participating in any required training on topics related to the responsibilities of the CMRC.
6. CMRC members who are not DBHDD employees sign a business associate agreement with DBHDD to preserve confidentiality of protected health information (PHI) about individuals.
7. A quorum consists of a minimum of seven (7) committee members, including a representative of the program area and a physician.
8. The Office of Incident Management and Investigations (OIMI) provides a Community Mortality Review Committee coordinator to staff the committee and its meetings. The CMRC coordinator is not a member of the CMRC.
9. The CMRC convenes as needed to meet the time frames established in this policy.

**B. Process**

1. The CMRC convenes to review all Category I deaths within 30 days of completion of all required investigations and reviews, including receipt of all relevant documents. Any Category II death identified by the DBHDD medical director and OIMI director are also reviewed.
2. The CMRC reviews relevant documents, including but not limited to the following:
    a. The death report;

b. OIMI's investigative report;
c. The death certificate, if available;
d. The autopsy report, if available; and
e. Any additional reviews, consultations or applicable documents.

3. DBHDD may identify specific populations for an independent mortality review for quality improvement purposes.
4. The committee reviews the causes of death and may reach conclusions regarding clinically suspected causes of death.
5. The committee reviews the classification of death (suicide, unexpected, expected) and may reach conclusions regarding the accurate classification.
6. The committee recommendations are documented in committee minutes, including timelines and the DBHDD staff responsible for follow up or implementation. Recommendations address the following:
    a. System performance improvement opportunities, including changes to policy and procedure or protocol;
    b. Gaps in staff/provider performance;
    c. Corrective actions needed, including changes to statewide standards of practice;
    d. Referrals, including referrals of clinicians to professional licensing boards or outside agencies or organizations, when evidence is presented that may indicate sub-standard clinical practice, fraud, or abuse;
    e. Unanswered issues needing further clarification, if any.
7. A community provider shall respond to any additional requests for information made by the CMRC within five (5) days of the provider's receipt of a request or more quickly if an expedited request is made.
8. The committee reviews all open recommendations and submitted implementation activities at the subsequent CMRC meeting.

**C. Follow-Up of CMRC Recommendations**

1. Any recommendation requiring a provider's corrective action or DBHDD review, consideration and action is communicated to the provider or the appropriate DBHDD division within 10 business days of the CMRC meeting. Requirements for corrective action plans are located in Reporting and Investigating Deaths and Critical Incidents in Community Services, 04-106.
2. The provider or division submits the response to the Division of Accountability and Compliance within 10 calendar days of the request.
3. The Division of Accountability and Compliance engages the appropriate subject matter expertise, reviews for adequacy, negotiates any inadequate responses, and accepts or approves the corrective action plans for implementation. The recommendations and corrective action plans (CAPS) are entered into the Corrective Action Tracking System for tracking and reporting purposes.
4. Reports on the status of each recommendation are provided to and reviewed by the CMRC until the activities are completed.
5. Once the corrective actions have been completed and verified, the CATS database is updated, verification is forwarded to the CMRC Chairperson, and the CAP is closed.

**D. Closing CMRC Reviews**

When the CMRC determines that necessary reviews and recommended activities have been completed or no further action is needed, the mortality review is closed.

**E. Confidentiality**

1. The proceedings, minutes, and records of the CMRC contain confidential information.
2. Any member, DBHDD employee, or other person who receives a request for documents, information, or testimony from the CMRC or relating to the CMRC shall contact the DBHDD Office of Legal Services for guidance and assistance.
3. No member shall provide CMRC records or minutes to any person or entity without approval from the DBHDD Office of Legal Services. Failure to comply with this provision will result in the member's removal from the CMRC.

**F. Annual Report**

1. DBHDD publishes an annual report on aggregate mortality data including number of deaths, causes of death, classification of death, and mortality trends and related information pertaining to the health and quality of care received by individuals served by DBHDD.
2. The report is published at the end of the state fiscal year for the prior calendar year and contains the following information:
    a. Aggregate data to include basic demographic information such as age and gender;
    b. Causes of death and classification of death;
    c. Descriptive analyses of patterns and trends over time;
    d. Recommendations regarding system performance improvement opportunities, including changes to policy and procedure or protocol; and
    e. Information regarding the community mortality review process.

**G. The CMRC is provided an opportunity to review and comment on the draft annual report prior to publication.**

**RELATED POLICIES**

Reporting and Investigating Deaths and Critical Incidents in Community Services, 04-106

# Appendix C: 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 abuse, 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 people).

**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.

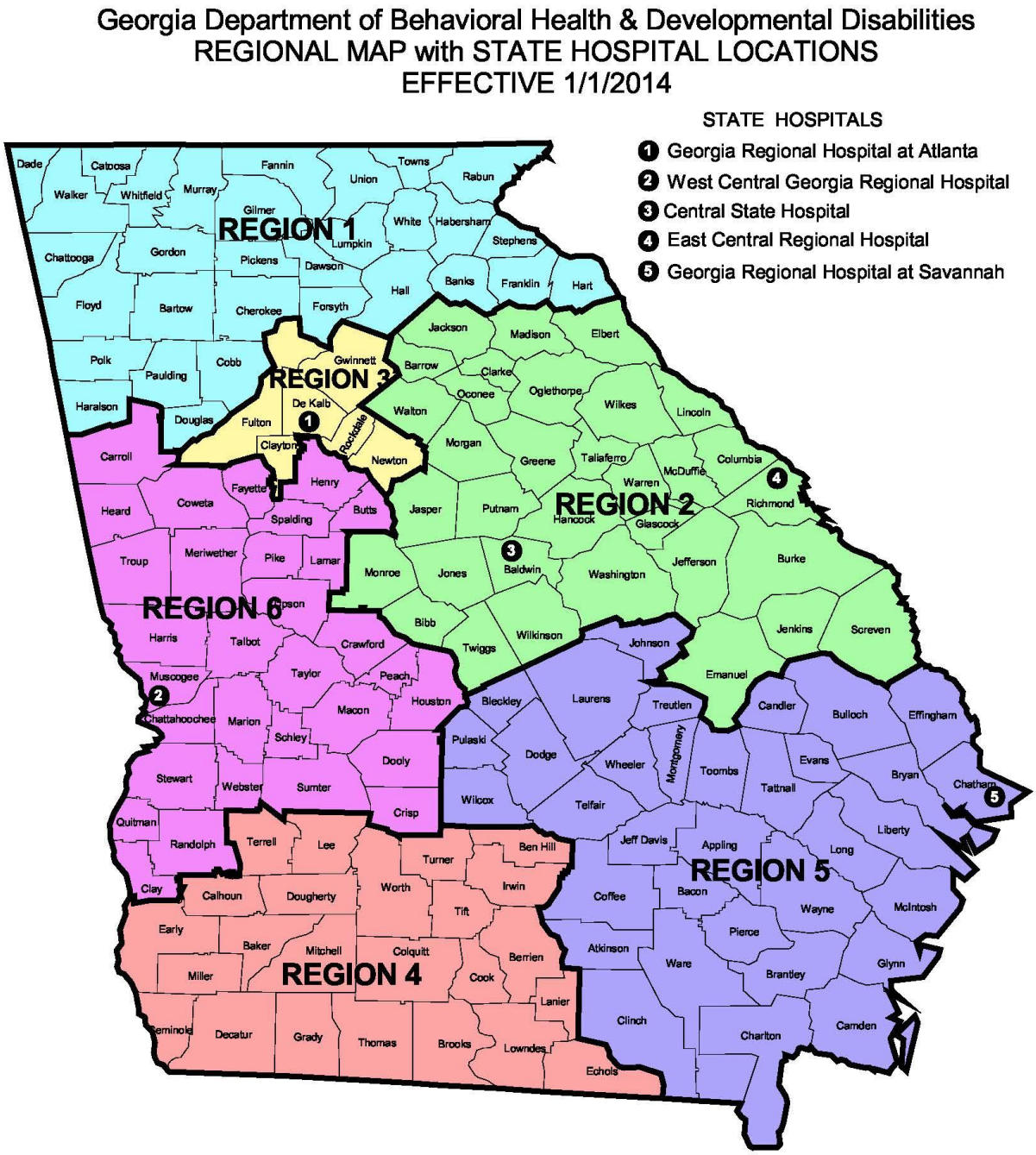



Figure 12: DBHDD Regional Map with State Hospital Locations