DBHDD

Georgia Department of Behavioral
Health and Developmental
Disabilities

2013/2014
Annual Mortality Report

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

August 15, 2015

This is the first annual report on mortality, mortality trends and related information pertaining to the health and quality of 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 resulting from the Georgia DBHDD 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

Table of Figures

2014 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 a part of DBHDD's quality management and improvement system. This is the first annual mortality report published by the Georgia Department of Behavioral Health and Developmental Disabilities (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 could assist DBHDD in the prevention and treatment of certain illnesses that may lead to deaths or other illness in the future.

This report includes data and information concerning adults who died during calendar years 2013 and 2014 while receiving waiver-funded intellectual and developmental disability Medicaid waiver services (IDD waiver services) from DBHDD and its contracted providers. It also includes information from the Community Mortality Review Committee (CMRC) and causes of death that will provide additional information concerning mortality for this population. The information gained from these reviews and Mortality Review Report is used to identify trends and help direct training and education needs to provide information to service providers regarding risk reduction and best practices.

Major Findings

In calendar year 2013, the DBHDD served 11,544 adults (over the age of 18 years) with intellectual and developmental disabilities in IDD waiver services. In calendar year 2014, the DBHDD served 11,542 adults in these waivers. A total of 131 deaths occurred for IDD waiver service recipients in 2013, resulting in a mortality rate[1] of 11.3 deaths per thousand people. In 2014, a total of 128 deaths occurred for IDD waiver service recipients, for a mortality rate of 11.1 deaths per thousand people. The difference between the mortality rates for these two years is not statistically significant.[2]

---

[1] The mortality rate utilized in this report is a crude mortality rate that 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 by "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.

The average age at death for this population was 50.7 years in 2013 and 51.7 years in 2014. The difference between the average ages at death was not statistically different.

The leading causes of death for this population in 2013 and 2014 were as follows:

- Pulmonary disease was the leading cause of death in both years.
- Cardiovascular disease was the second-ranked cause of death in both years.
- Infections and Nervous System disorders were the third leading cause of death; however, in 2014 infections dropped to the fourth leading cause of death.
- Gastrointestinal issues (bowel obstructions, bleeds) were the fifth leading cause of death.

The information about causes of death will be used by DBHDD to identify risks that may trigger the need to review, revise, or establish procedures to reduce the risk of illness and death. The causes of death information is also being used to inform the Division of Developmental Disabilities and the Office of Learning and Organizational Development in designing current and future Developmental Disabilities Learning Collaborative trainings.

The Department has a Community Mortality Review Committee (CMRC) that reviews deaths. Recommendations for provider and systemic changes are highlighted in this report. DBHDD is developing an electronic database that will be used to identify and track completion of corrective actions and recommendations necessary to improve quality of care. Findings from the CMRC and this report will continue to be reviewed by DBHDD to determine possible training and educational development to increase the quality of care.

Finally, findings from data analysis of the deaths of IDD waiver recipients are presented. Age, gender, residential setting, region of service, and health risk scores were analyzed to determine their relationship to mortality and deaths occurring for 2013 and 2014. The analyses indicate that patterns between and among mortality-related variables are similar across 2013 and 2014. Based upon the data analyzed, patterns of mortality in the IDD population are associated with a number of important factors:

- Gender, region, and residential setting were not found to be statistically significant predictors of death occurring in both 2013 and 2014.
- Increasing age had the strongest association to the risk of death. Analyses indicated that consideration should be given to assessing health risk more frequently with increasing age, specifically starting at age 45, regardless of residential setting, gender, health risk scores[3], or region of service.
- These analyses also highlight the importance of assessing health risk more frequently as health risks change. DBHDD already specifies that health risk

---

[3] As measured by the Health Risk Screening Tool (HRST)

reassessment should occur when significant health events or changes in health, functional or behavioral status occurs. Health risk scores and changes in health risk scores over time can be used as triggers for evaluation and modification of individualized service and care plans. These analyses suggest further consideration should be given to reassessment of health risk more frequently for a period of time after an individual's health risk score increases by even one point until the individual's individualized service and care plan has been evaluated, modified, and implemented. This recommendation includes all individuals regardless of service intensity of residential setting, gender, age, or region.

DBHDD will continue to work with internal and external expertise to consider how DBHDD's new organizational structure, including the new Division of Performance Management and Quality Improvement and Division of Accountability and Compliance will play a significant role in DBHDD's future utilization of this important information in conjunction with the Division of Developmental Disabilities and the Office of Wellness and the Office of Learning and Organizational Development.

This report provided information about what DBHDD has learned about deaths, identified trends and patterns as well as indicators that will assist DBHDD in the development of polices, processes, and trainings to improve care related to certain illnesses that may lead to deaths. Whether it involves systemic or programmatic change, DBHDD is committed to its continued review of all available data to know what is working and what needs improvement. The 2015 Mortality Report will benefit from the initial efforts and findings reported here.

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 waiver programs and obligations of other state agencies prohibit comparison of mortality rates or generalization of findings. DBHDD has used caution not to compare mortality rates across unlike methods and populations.

About DBHDD

The Georgia Department of Behavioral Health and Developmental Disabilities provides treatment and support services to people with behavioral health challenges 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 IDD Services

As DBHDD continues to shift from an institutional-based model of health care delivery to a community-based system of care, individuals with intellectual and developmental disabilities (IDD) will have the opportunity to live in the most independent and inclusive setting possible. A developmental disability is a chronic condition that develops before a person reaches age 22 and limits his/her ability to function mentally and/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 provides home settings and care to individuals who do not live with their families or on their own.

All 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 and availability of services and other community resources.

The Department of Behavioral Health and Developmental Disabilities serves as the operating agency for two 1915c Medicaid Waiver Programs approved initially in 2007 when the two programs transitioned and expanded into their current form. The Medicaid waiver programs operate under the names *Comprehensive Supports Waiver*

(COMP) and *New Options Waiver (NOW)*. Both waiver programs provide home and community-based services to individuals who, but for the provision of such services, would require a level of care comparable to that provided in Intermediate Care Facilities for persons with intellectual and developmental disabilities (ICF-IDDs), the costs of which would be reimbursed under the Medicaid State Plan. The Centers for Medicare and Medicaid Services offers this option to States through application initially and every five years thereafter through waiver renewal. As in all Medicaid programs, the services and administrative costs are funded through a federal/state match agreement. A complete description of DBHDD 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 calendar years 2013 and 2014. During 2013 and 2014, data systems for individuals receiving IDD waiver services were maintained separately from state-funded services, and the data between these systems varies. DBHDD focused on the data that demonstrated the highest verifiable accuracy and reliability for this report, which was the IDD waiver data. A description of the analysis conducted in the report can be found in Appendix B.

This report does not include data for children under the age of 18. Seven deaths of children were reported to DBHDD in 2013, and eight deaths were reported in 2014. Deaths for children are analyzed on a case-by-case basis and not included in these statistical analyses due to potential differences between the populations and small sample size.

Though not included in the analysis within this report, Appendix C provides a descriptive overview of the 45 deaths reported to DBHDD for those adults with a primary IDD diagnosis receiving state-funded (i.e., not receiving NOW or COMP waivers) services in 2013 and2014.

Several considerations are provided for reading and interpreting the findings from this report. Caution should be taken when comparing this report’s findings with other mortality reviews and reports’ findings that included all eligible individuals or analyzed data from different populations. Although Georgia’s DBHDD has looked closely at other states’ reports, given the differences in waiver programs, obligations of the various state agencies (oversight of Nursing Homes in some states), and other state specific issues, it is difficult to compare mortality rates or conclusions between states. DBHDD has also used caution not to compare 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 2013 and 2014 are presented in the first section below, followed by a description of the analysis of information known about causes of death during 2013 and 2014. 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 pairs relate to mortality rates. Finally, the data analysis section considers all variables of interest at once to determine the individual impact of each variable on the occurrence of death.

Mortality Reviews

Mortality Reviews promote a culture of safety through seeking to understand systems that are working well and those that need improvement. The DBHDD Community Mortality Review Committee (CMRC) reviews and determines whether necessary and reasonable measures were taken to provide for the health, safety, and welfare of the individual receiving services by a DBHDD provider and to identify and mitigate future risks that could affect the health, safety and welfare of other individuals receiving supports and services from DBHDD community providers. In developing the CMRC, the Department reviewed the United States Government Accountability Report which identified six basic, but critical, components of a mortality review system.[4] See Appendix D, *The DBHDD Community Mortality Review Committee (CMRC)* for further information on the ways in which the DBHDD mortality review process aligns with the six recommended components.

During 2013, the CMRC met five times and reviewed 54 deaths and in 2014, the CMRC met nine times and reviewed 87 deaths. It should be noted that the number of deaths reviewed each year is different than the number of deaths reported for the year due to two primary reasons. First, the CMRC reviews a specific subset of deaths that are reported to DBHDD. This category of deaths includes all unexpected deaths, death of an individual receiving residential services or receiving 24/7 community living support; deaths occurring on site of a community provide or occurring in the company of staff of a community provider; or the death of an individual absent without leave from residential services. Unexpected death is defined as a death in which the cause of the death is not attributed to a terminal diagnosis or a diagnosed disease process where the reasonable expectation of the outcome is death. See Appendix E, *Community Mortality Review Process* for a description of the types of deaths as identified in the Community Incident Management Policy and reported to the Department.

---

[4] http://www.gao.gov/assets/280/275743.pdf

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 DBHHDD 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, the death has been reviewed by the external reviewer, when applicable, and the autopsy report has been received, if an autopsy has been ordered. While unlikely, the number of reviews may coincide with the number of deaths in a given year; however, the two sets will never be identical.

Recommendations made by the CMRC during 2013 and 2014 for DBHDD and providers include:

- The Department's Office of Incident Management and Investigations (OIMI) should use feedback from the CMRC to strengthen and improve staffs' investigative skills;
- Ensure that individuals who transition into the community from the hospital have a new medical provider identified prior to discharge;
- Provide information on trends and patterns to the Executive Quality Council;
- Specific recommendations for provider actions such as providing additional staff training and submitting additional corrective action plans;
- Making referrals to professional licensing boards when appropriate.

In addition to the CMRC reviews, the Department entered into a contract in FY15 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 utilizes physicians and nurses with experience in IDD to perform mortality reviews for class members, including reviews of those occurring in FY15 and earlier. 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. A summary of Columbus recommendations and how they are incorporated into the Department's quality improvement initiatives will be provided in the 2016 Mortality Report.

At the conclusion of each review, Columbus provides recommendations to the Department for any systemic changes for providers and the Department. These reports are reviewed by the CMRC to identify any issues that were not identified by DBHDD Investigators (for learning purposes) and, as applicable, sent to providers for implementation of recommendations and corrective action plans as appropriate.

Mortality Review Process Enhancement Recommendations

In addition to implementing recommendations from mortality reviews, the Department continuously works to improve its mortality review process. The below are examples of actions DBHDD will undertake to enhance the process:

- The Department has engaged the services of expert consultants from RPA, Ltd. led by Lyn Rucker to review and make recommendations for system improvements;
- Screen Category 2 or 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;
- Increase membership of the CMRC to include additional representatives with medical expertise and representatives of external organizations and stakeholders;
- Provide training for all new CMRC members to ensure that all members understand the goals of the CMRC, the review process, and his/her role in the process and as part of the committee;
- Continue to evaluate the Department's Mortality Review system utilizing the standards checklist "Evaluation of State MR/DD Mortality Review Systems: Criteria and Standards"[5];
- Utilize a database that is being developed to track the identification of deficient practices and the corresponding recommendations and corrective actions that are described in quality reviews, audit reports, and reports concerning providers' performance including compliance with contractual, regulatory, and programmatic requirements; CMRC and external mortality review recommendations will be included this database;
- Identify other actions that could be taken to reduce potential risk and inform provider training through continued work with the Division of Developmental Disabilities and the Office of Learning and Organizational Development;
- Provide feedback to the CMRC regarding the status of their recommendations until resolution has been verified;
- Revise the community incident management policy to provide a system whereby information is gathered and analyzed for each reported death to determine whether an immediate response is needed to ensure the health and safety of other individuals receiving services by the provider.

---

[5] 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 the cause and manner 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 on the Death Certificate is varied. 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 from one of the following means: from the autopsy report, if an autopsy has been conducted; from the death certificate issued by the Department of Public Health Division of Vital Statistics; from 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 the Department's Reporting of Critical Incidents (ROCI) database follows. Note that some individuals had multiple causes of death listed; therefore, the count of causes of death exceeds the number of individuals.

Table 1: Causes of Death of NOW and COMP Waiver Recipients for CY 2013 and 2014 (Totals)

Causes of Death	2013	Rank	Percent	2014	Rank	Percent
Pulmonary	(50)	1	38.2%	(42)	1	32.8%
a. Pneumonia b. Aspiration Pneumonia c. Respiratory Disease d. Choking	13 6 30 1			9 4 27 2		
Cardiovascular Disease	(33)	2	25.2%	(40)	2	31.3%
a. Heart Disease b. Peripheral Vascular Disease	27 6			34 6		
Infections	(20)	3	15.3%	(12)	4	9.4%
a. Sepsis/Septic Shock b. Other Infections	20			10 2		
Nervous System	(20)	3	15.3%	(20)	3	15.6%
a. Cerebrovascular Disease b. Complications of Cerebral Palsy c. Epilepsy d. Other	4 5 9 2			3 4 11 2		
Cancer	12	5	9.2%	10	5	7.8%
Gastrointestinal System	11	6	8.4%	10	5	7.8%
Other	9	7	6.9%	8	7	6.3%
Renal	(8)	8	6.1%	(6)	8	4.7%
a. Metabolic Disorders b. Structural	1 7			1 5		
Natural Causes	1	9	0.8%	6	8	4.7%
Hematologic	1	9	0.8%	1	10	0.8%

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, and readers are strongly cautioned against drawing conclusions based on this information due to the lack of consistency in categorizing the causes of death and expertise of those completing the Death Certificates. In order to utilize 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. Therefore, going forward the Department will undertake the following improvements:

- Utilize the expertise and experience of the Medical Director and members of the CMRC to determine whether there is opportunity for intervention at the system or provider levels;
- Clearly identify the most common conditions that elevate risk for death and for which there are specific techniques to reduce the risk of their occurrence (aspiration pneumonia, bowel obstruction, status epilepticus, sepsis, dehydration, and GERD) to determine opportunities for improvement and/or early detection and intervention;
- Consider other data collection systems and elements to allow for more uniform identifying, recording, and analyzing causes of death;
- Continue to analyze the data in different ways to identify opportunities to reduce risk and actions that may effectuate positive changes in care, e.g. use a group of cases to determine if an "alert" should be sent to all providers).

Analyses 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 single variables. Following that, analyses of pairs of variables that are associated with mortality are presented. Finally, all variables of interest are analyzed at once to report how key variables are associated with mortality.

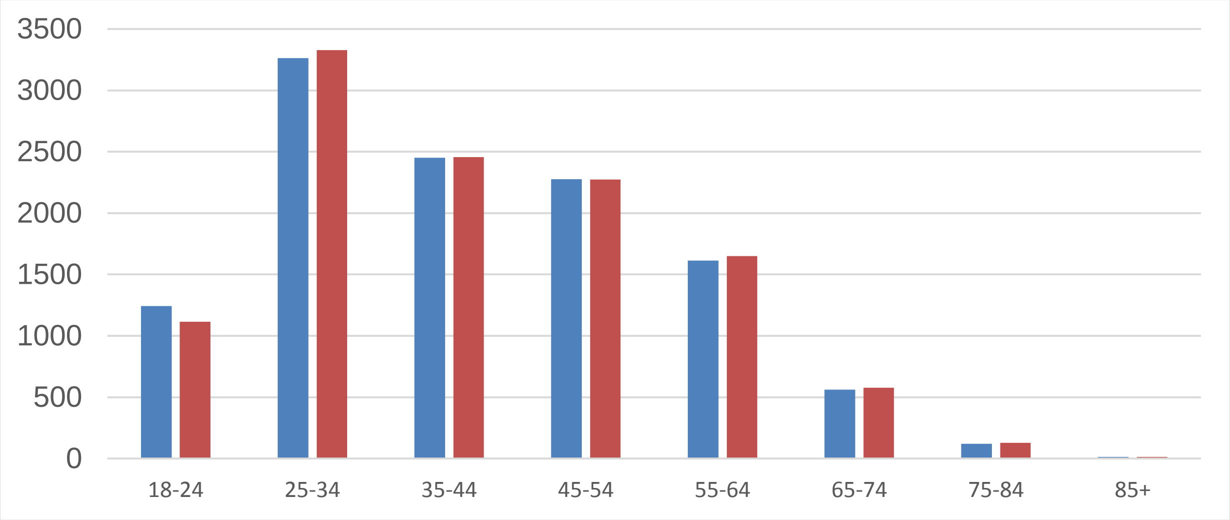
Age

The age distribution of the adult IDD waiver population for 2013 and 2014 are very similar (t = 0.0001, p = 0.999, df = 1). In 2013, the average age of the adult IDD waiver population was 41.3 years (median = 39; SD = 14.0). In 2014, the average age of the adult IDD waiver populations was 41.6 years (median = 40; SD = 14.1). Table 2 and Figure 1 present the distribution for the IDD population by 10-year age groups. For both years, half of the population is between the ages of 25-44 years old. In both years, the largest population group was 25-34 year old individuals; there is a gradual decrease in the percent of individuals across the following three 10-year categories. The percent of individuals in the last three 10-year age groups decreases drastically.

Table 2: Age Distribution of the Adult IDD Waiver Population, 2013 and 2014

Age	2013		2014	
	Individuals	Percent	Individuals	Percent
18-24	1243	10.8	1116	9.7
25-34	3263	28.3	3327	28.8
35-44	2450	21.2	2456	21.3
45-54	2275	19.7	2273	19.7
55-64	1614	14.0	1651	14.3
65-74	563	4.9	577	5.0
75-84	121	1.0	128	1.1
85+	15	.1	14	.1
Totals	11544	100.0	11542	100.0

Figure 1: Age Distribution of the Adult IDD Waiver Population, 2013 and 2014



Note: 2013 data represented by blue bars.

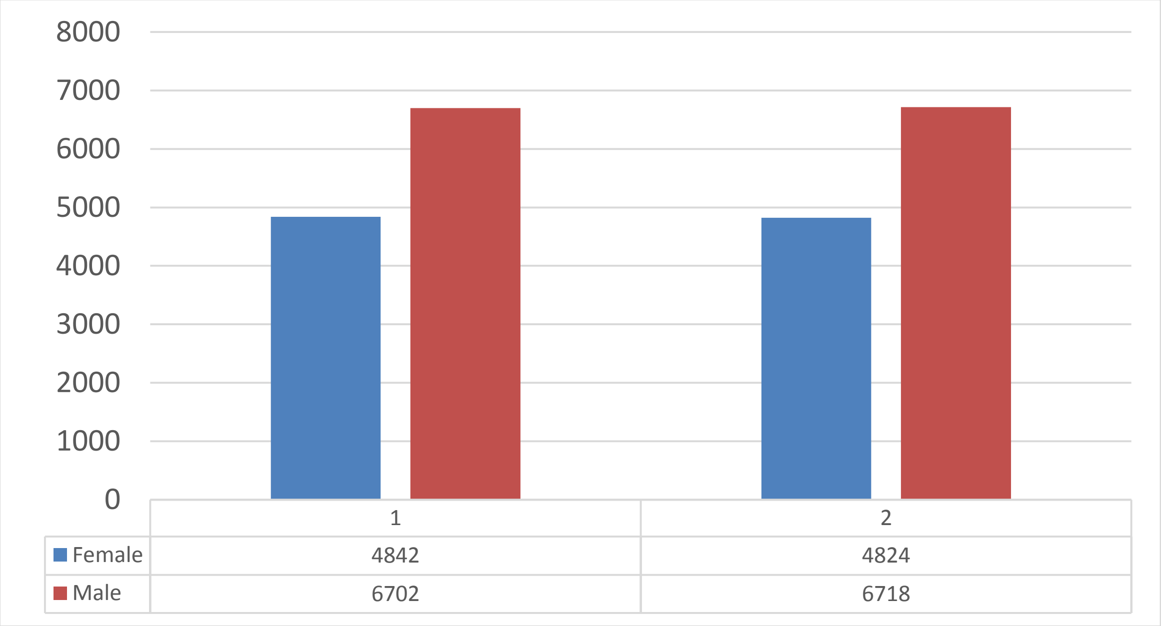
Gender

The distribution of gender across adults receiving IDD waivers in 2013 and 2014 is similar. About 42 percent of the adult IDD waiver recipients were female in both years; about 58 percent were males. The proportion of females between 2013 and 2014 was not statistically significant (z = -0.229, p = 0.82, NS); the proportion of males between 2013 and 2014 also was not statistically significant (z = 0.229, p = 0.82, NS).

Table 3: Gender Distribution of the IDD Waiver Population, 2013 and 2014

	2013		**2014**	
	Individuals	Percent	Individuals	Percent
Female	4842	41.9	4824	41.8
Male	6702	58.1	6718	58.2
Total	11544	100.0	11542	100.0

Figure 2: Gender Distribution of the IDD Waiver Population, 2013 and 2014



Note: 2013 data represented by blue bars.

Region

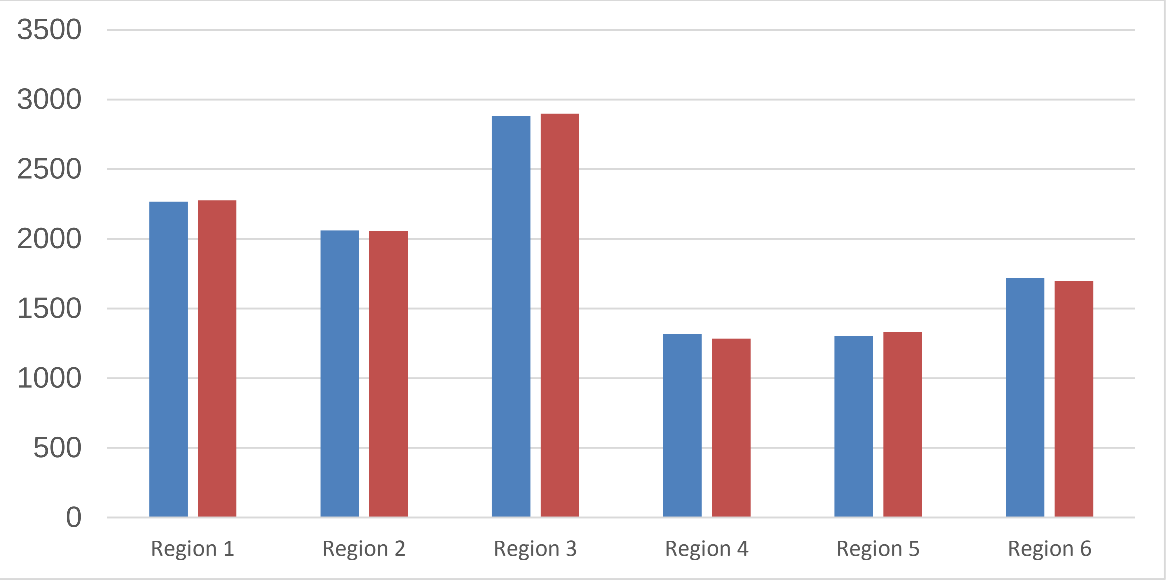
DBHDD serves individuals throughout the state in six geographic regions through a network of contracted providers. See Appendix A for a description of the Regions.

Table 4 and Figure 3 show the regional distribution of adults receiving IDD waivers in 2013 and 2014. The number and percent of individuals receiving IDD waivers across the regions was stable between 2013 and 2014; the largest percent change was in a decrease of 0.4 percent in Region 5.

Table 4: The Distribution of Adults Receiving IDD Waivers, 2013 and 2014

Region	2013		2014	
	Individuals	Percent	Individuals	Percent
Region 1	2266	19.6	2275	19.7
Region 2	2060	17.8	2055	17.8
Region 3	2880	24.9	2899	25.1
Region 4	1317	11.4	1284	11.1
Region 5	1302	11.3	1331	11.5
Region 6	1719	14.9	1698	14.7
Total	11544	100.0	11542	100.0

Figure 3: Adult IDD Waiver Population by Region, 2013 and 2014



Note: 2013 is represented by the blue bars.

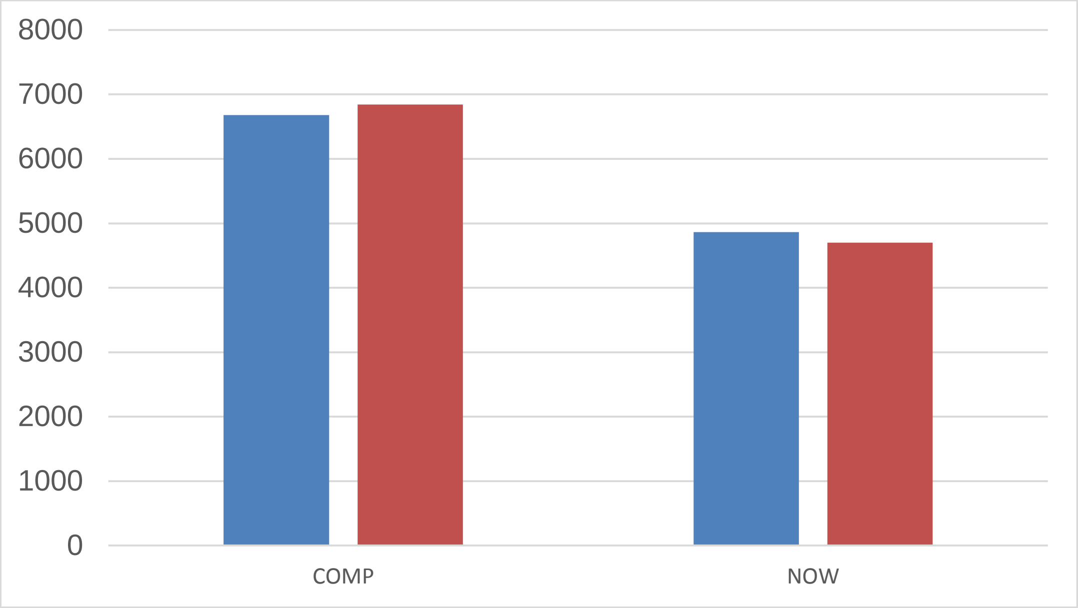
Type of Medicaid Waiver

The number of COMP waivers increased from 6,679 in 2013 to 6,841 in 2014, which was a 2.4 percent increase. This was not a statistically significant increase in COMP waivers (z = 2.18, p = 0.029). The number of NOW waivers decreased from 4,865 in 2013 to 4,701 in 2014, which was a 3.4 percent decrease, which was not a statistically significant decrease (z = 2.18, p = 0.029).

Table 5: Distribution of Adult NOW and COMP Waiver Population, 2013 and 2014

Type of Waiver	2013		2014	
	Individuals	Percent	Individuals	Percent
COMP	6679	57.9	6841	59.3
NOW	4865	42.1	4701	40.7
Total	11544	100.0	11542	100.0

Figure 4: Distribution of Adult NOW and COMP Waiver Population, 2013 and 2014



Note: 2013 data are represented by blue bars.

Residential Setting

Individuals who receive IDD services from the DBHDD live in a variety of settings. Many individuals live independently or with family members, friends or caretakers. 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 and includes the individual with the disability in household routines, providing training and supervision.
- Community Living Arrangement (CLA): Agencies providing this community residential setting option must hold a Community Living Arrangement License from the Department of Community Health's Healthcare Facilities Regulation Division.
- Personal Care Home (PCH): Agencies providing this community residential service must hold a Georgia Personal Care Home Permit/License from the Department of Community Health's Healthcare Facilities Regulation Division.

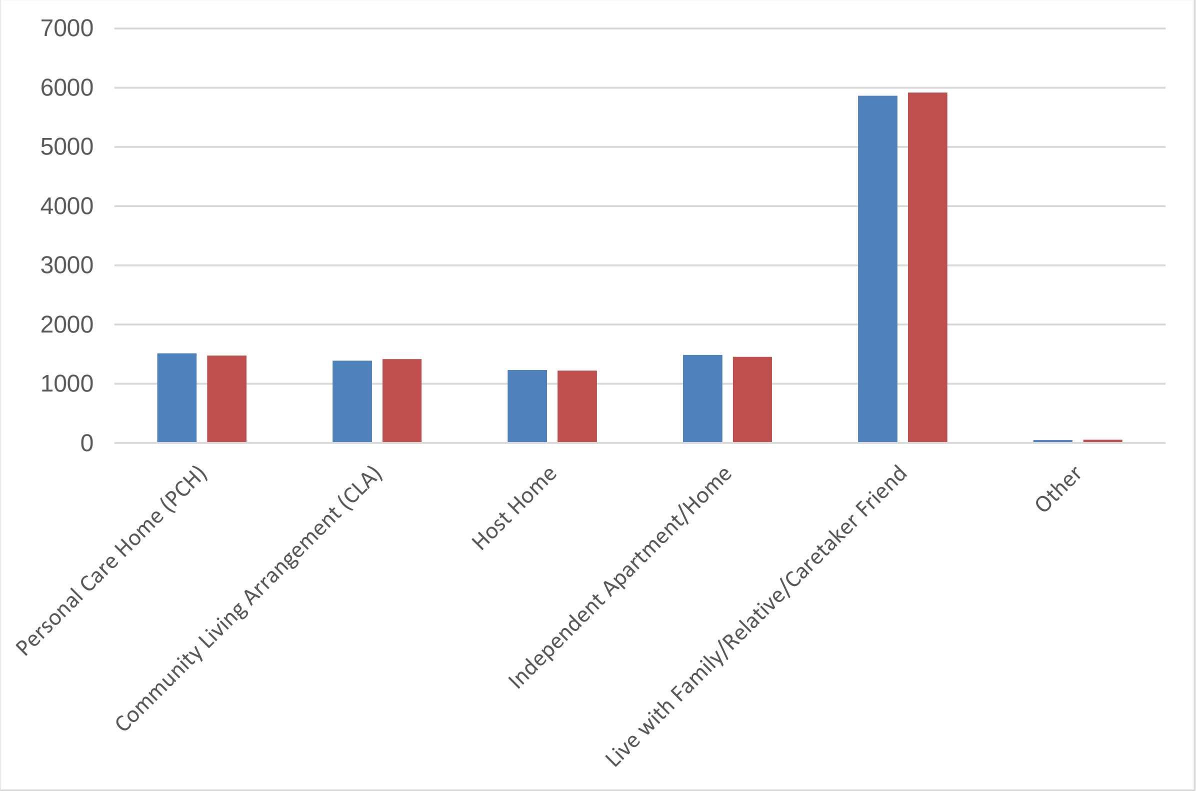
Personal Care Homes (PCHs), Community Living Arrangements (CLAs), and Host Homes are residential settings that can provide more intensive services and supports. Generally, individuals with greater support needs tend to reside in PCHs, CLAs, and host homes, though individuals and families may choose these 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 from 2013 to 2014. Just over half of all adults that received IDD waiver services in 2013 and 2014 lived with family, relatives, caretakers, or friends. Almost 64 percent of individuals lived independently or with a family/relative/caretaker/friend in 2013 and 2014. Approximately 36 percent of the adult IDD waiver recipients in 2013 and 2014 resided in settings that receive more intensive services. Twenty-nine individuals' residential setting was coded as "Other" due to their residential setting being coded as "Other"; 13 individuals' residential setting was included in one of the other categories listed above; and eight individuals were coded as "Other" due to missing data.

Table 6: Distribution of Adults in Residential Settings in IDD Waivers, 2013 and 2014

	2013		2014	
Residential Setting	Individuals	Percent	Individuals	Percent
Personal Care Home (PCH)	1517	13.1	1475	12.8
Community Living Arrangement (CLA)	1392	12.1	1420	12.3
Host Home	1233	10.7	1223	10.6
Independent Apartment/Home	1487	12.9	1454	12.6
Live with Family/Relative/ Caretaker/Friend	5865	50.8	5915	51.2
Other	50	0.4	55	0.5
Total	11544	100	11542	100

Figure 5: Distribution of Adults in Residential Settings in IDD Waivers, 2013 and 2014



Note: 2013 data are represented by blue bars.

Health Risk

The HRST (Health Risk Screening Tool[6]) is a standardized tool used to determine an individual's vulnerability in terms of potential health risks and needed supports to enable the early identification of individuals with deteriorating health. HRST measures health risk using a distinct rating scale related to functional status, behavior, physiological condition and safety, not the individual's disability. The HRST is a functional document, to be incorporated into the ongoing health care surveillance process. By policy, it is completed in order for an individual to be approved to receive community developmental disability services, annually thereafter and whenever an individual experiences significant health events or changes in health, functional or behavioral status. A functional outcome of the HRST is to provide the provider/support team with guidance in determining the individual's need for further assessment and evaluation and needed modifications to the individual's service plan to address identified health risks. It will also guide the team in determining the need for professional services.

The HRST assigns point scores to rating items. The resulting numerical totals are assigned Health Care Levels associated with degrees of health risk. Table 7 below

---

[6] Health Risk Screening, Inc., Karen Green McGowan, http://hrstonline.com/.

shows the risk level designations and points associated with each of the 6 Health Care Levels used as a part of the HRST.

Table 7: Distribution of Adults in Residential Settings in IDD Waivers, 2013 and 2014

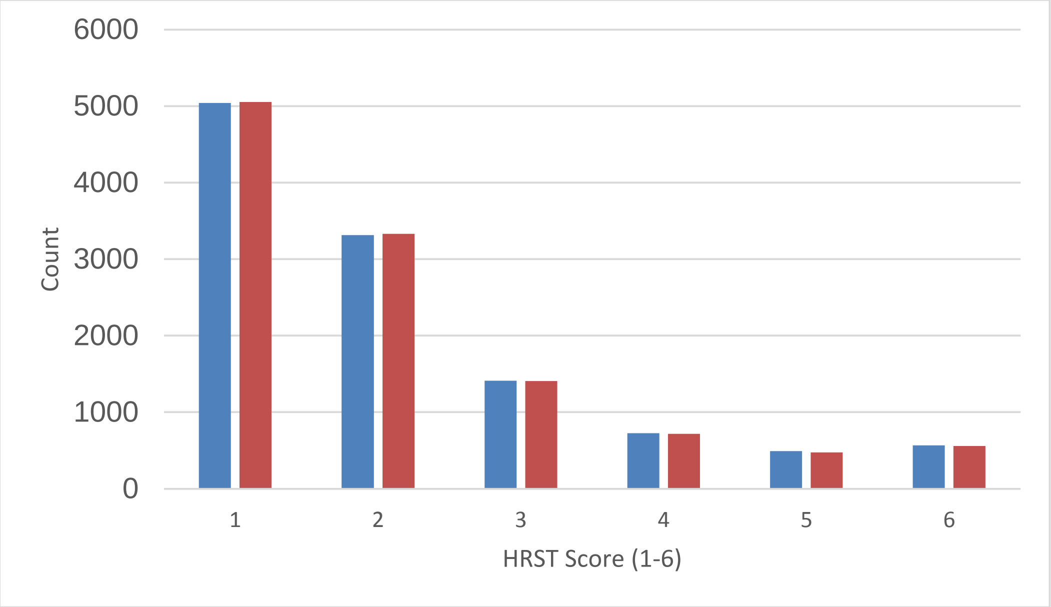
HRST: Health Care Levels		
Level #1:	*(Low Risk)*	*0 to 12 Points*
Level #2:	*(Low Risk)*	*13 to 25 Points*
Level #3:	*(Moderate Risk)*	*26 to 38 Points*
Level #4:	*(High Moderate Risk)*	*39 to 53 Points*
Level #5:	*(High Risk)*	*54 to 68 Points*
Level #6:	*(Highest Risk)*	*69 or greater*

In an effort to understand the contributing factor of health risk on mortality, the analysis for this report includes the most current HRST score for each individual. 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. Almost 85 percent of this population had a low health-risk score for 2013 and 2014. About 15 percent of the population in both 2013 and 2014 had a high-HRST score of four, five, or six. The proportion of individuals between 2013 and 2014 with each score was not statistically significantly different.

Table 8: Distribution of HRST Scores for Adults Receiving IDD Waivers, 2013 and 2014

	Count		Percent of Population	
HRST	2013	2014	2013	2014
1	5039	5053	43.7%	43.8%
2	3313	3332	28.7%	28.9%
3	1411	1405	12.2%	12.2%
4	725	719	6.3%	6.2%
5	490	476	4.2%	4.1%
6	566	557	4.9%	4.8%
Total	11544	11542	100.0%	100.0%

Figure 6: Distribution of HRST Scores for Adults Receiving IDD Waivers, 2013 and 2014



Note: 2013 data indicated by blue bars.

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 at once and their association to mortality.

Health Risk and Residential Setting

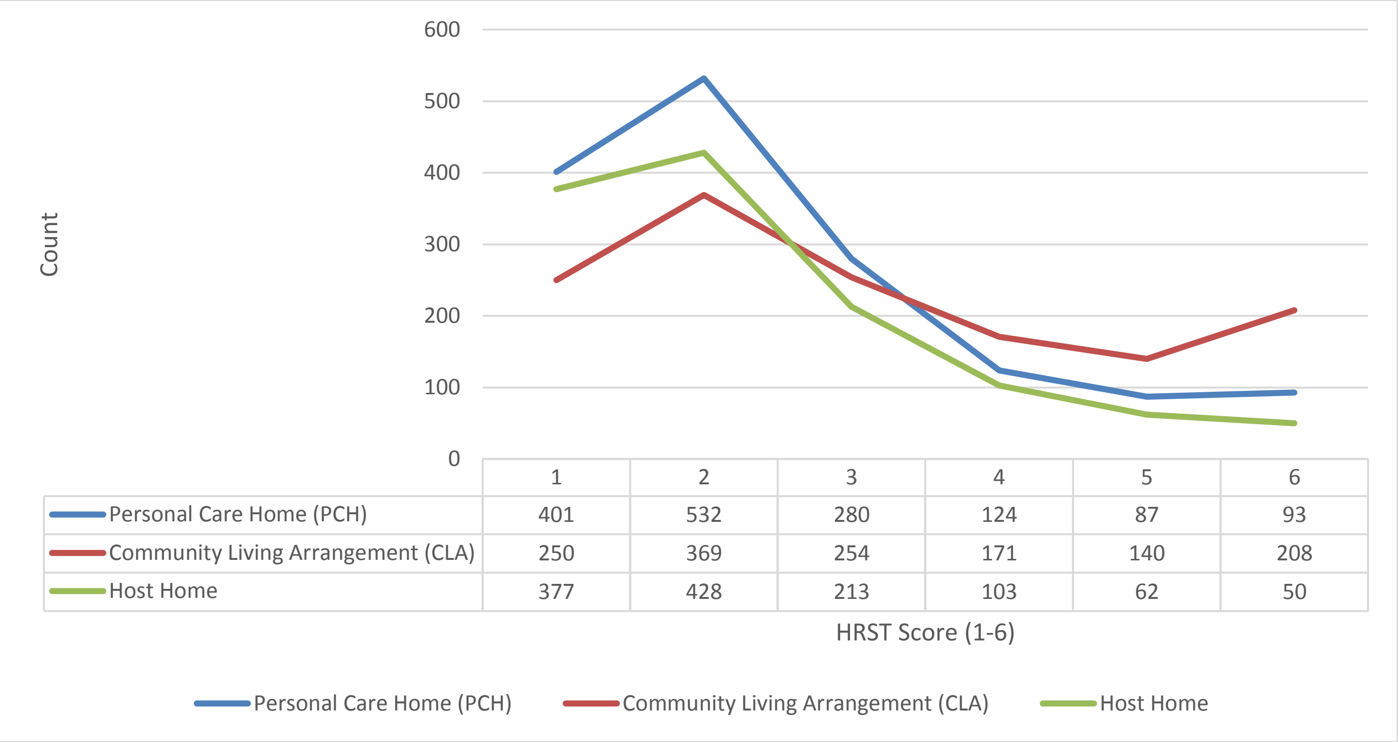
It also is instructive to consider health risk across residential settings. In 2013, 67.7 percent of individuals with a low-risk HRST score resided in independent living arrangements or with friends, caregivers, or relatives; this was 67.8 percent in 2014. This indicates that most individuals with a low health-risk score live in settings that receive IDD waiver services that are less intensive than other residential settings.

In 2013 and 2014, the majority of individuals with higher-risk scores resided in more intensive residential settings. In fact, about 58 percent in both 2013 and 2014 of the indviduals that live in higher-intensive residential settings characterized by higher needs have high-level HRST scores.

Table 9: Residential Setting by HRST Score, 2013

	Count by HRST							Percent by HRST						
Residential Setting	1	2	3	4	5	6	Total	1	2	3	4	5	6	Total
Personal Care Home (PCH)	401	532	280	124	87	93	1517	8.0%	16.1%	19.8%	17.1%	17.8%	16.4%	13.1%
Community Living Arrangement (CLA)	250	369	254	171	140	208	1392	5.0%	11.1%	18.0%	23.6%	28.6%	36.7%	12.1%
Host Home	377	428	213	103	62	50	1233	7.5%	12.9%	15.1%	14.2%	12.7%	8.8%	10.7%
Independent Apartment/Home	725	429	151	79	51	52	1487	14.4%	12.9%	10.7%	10.9%	10.4%	9.2%	12.9%
Live with Family/Relative/Caretaker Friend	3265	1542	502	245	149	162	5865	64.8%	46.5%	35.6%	33.8%	30.4%	28.6%	50.8%
Other	21	13	11	3	1	1	50	0.4%	0.4%	0.8%	0.4%	0.2%	0.2%	0.4%
Total	5039	3313	1411	725	490	566	11544	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

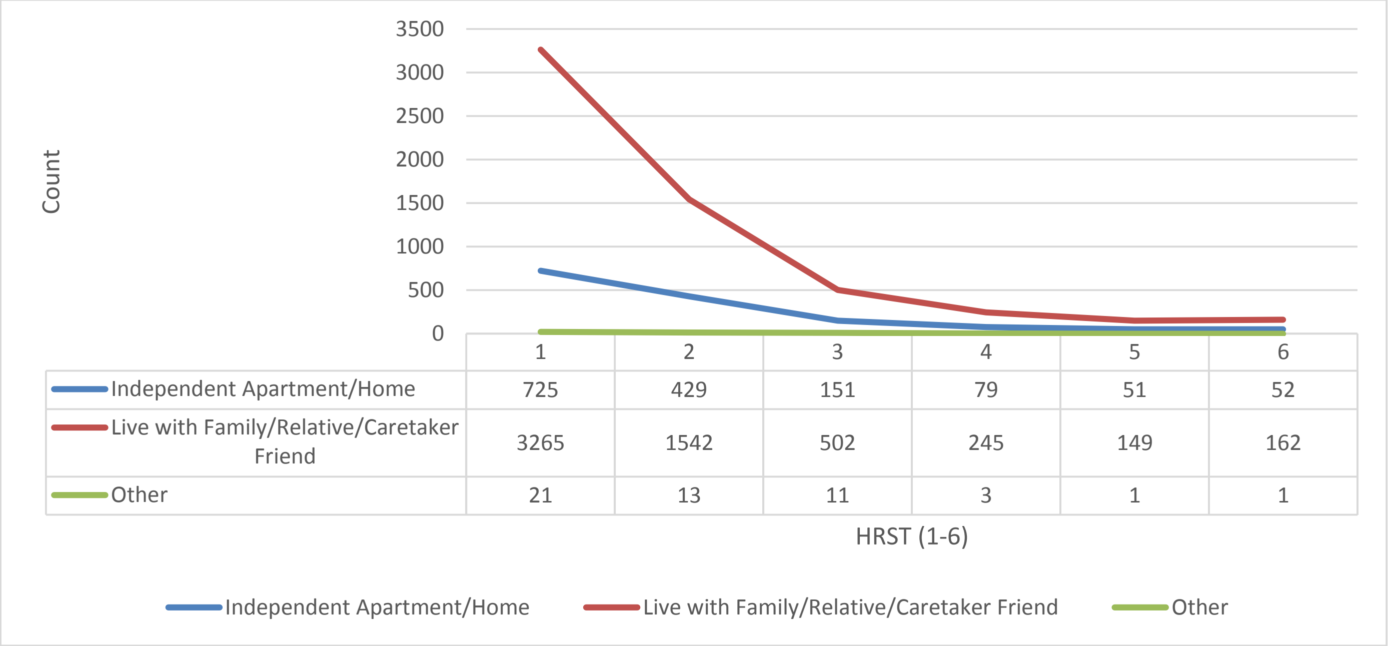
Figure 7: PCH, CLA, Host Home Residential Setting by HRST Score, 2013



	1	2	3	4	5	6
Personal Care Home (PCH)	401	532	280	124	87	93
Community Living Arrangement (CLA)	250	369	254	171	140	208
Host Home	377	428	213	103	62	50

Note: The count axis is in increments of 100.

Figure 8: Independent, Live with Family/Relative/Caregiver/Friend and Other Residential Setting by HRST Score, 2013



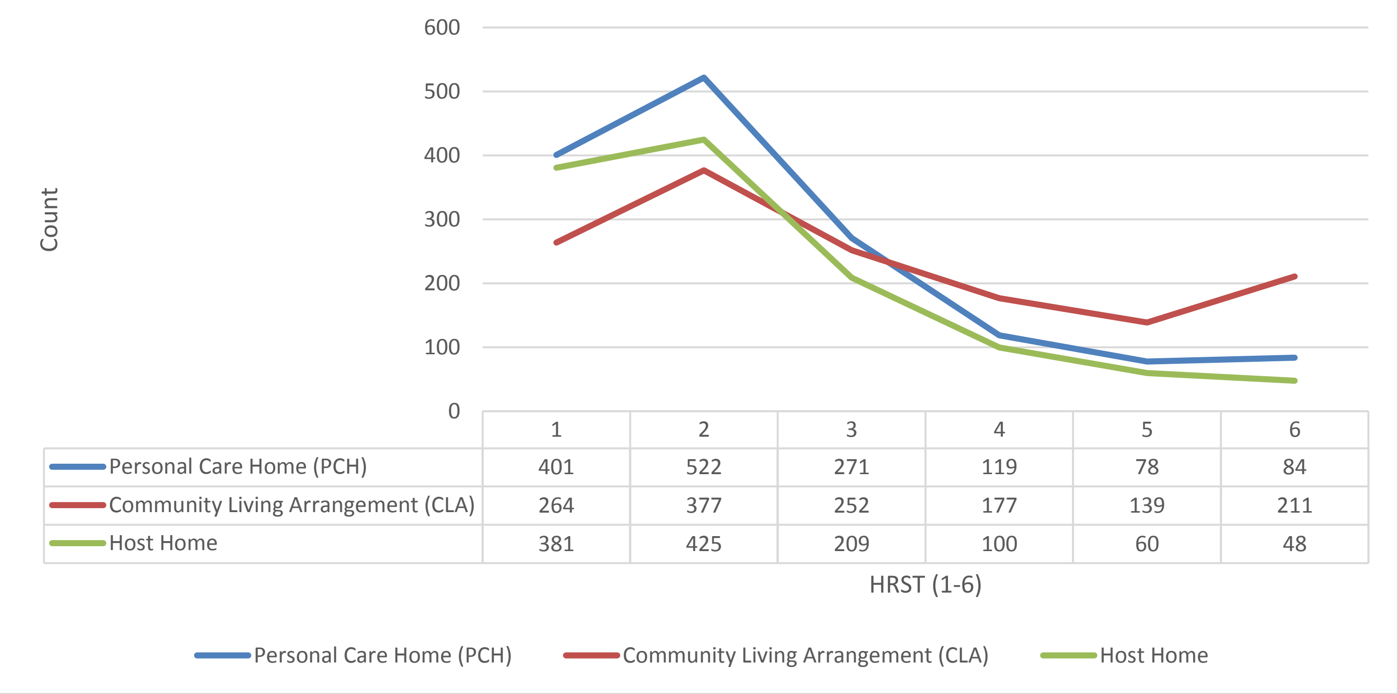
	1	2	3	4	5	6
Independent Apartment/Home	725	429	151	79	51	52
Live with Family/Relative/Caretaker Friend	3265	1542	502	245	149	162
Other	21	13	11	3	1	1

Note: The count axis is in increments of 500.

Table 10: Residential Setting by HRST Score, 2014

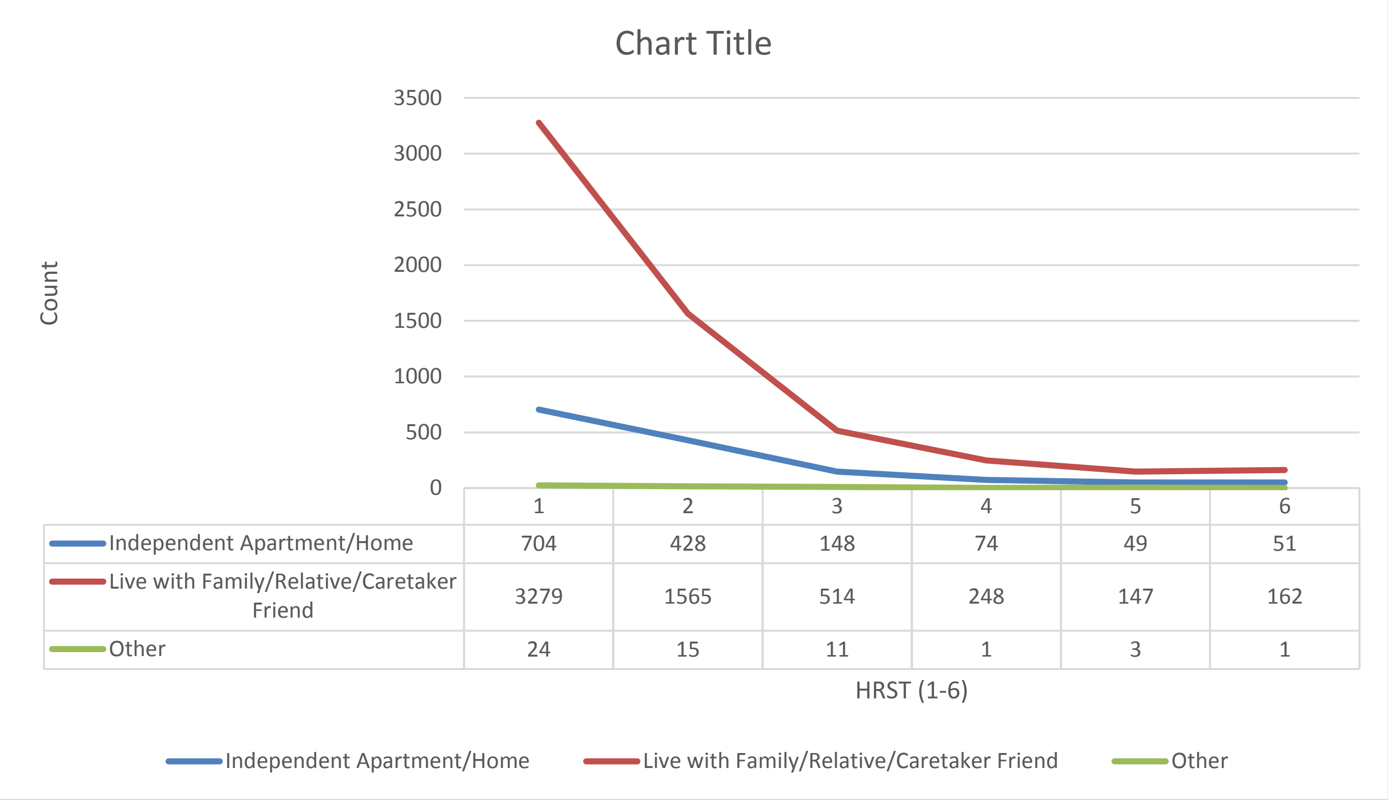
	Count by HRST						Total	Percent by HRST						Total
	1	2	3	4	5	6		1	2	3	4	5	6	
Personal Care Home (PCH)	401	522	271	119	78	84	1475	7.9%	15.7%	19.3%	16.6%	16.4%	15.1%	12.8%
Community Living Arrangement (CLA)	264	377	252	177	139	211	1420	5.2%	11.3%	17.9%	24.6%	29.2%	37.9%	12.3%
Host Home	381	425	209	100	60	48	1223	7.5%	12.8%	14.9%	13.9%	12.6%	8.6%	10.6%
Independent Apartment/Home	704	428	148	74	49	51	1454	13.9%	12.8%	10.5%	10.3%	10.3%	9.2%	12.6%
Live with Family/Relative/Caretaker Friend	3279	1565	514	248	147	162	5915	64.9%	47.0%	36.6%	34.5%	30.9%	29.1%	51.2%
Other	24	15	11	1	3	1	55	0.5%	0.5%	0.8%	0.1%	0.6%	0.2%	0.5%
Total	5053	3332	1405	719	476	557	11542	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Figure 9: PCH, CLA Host Home Residential Setting by HRST Score, 2014



Note: The count axis is in increments of 100.

Figure 10: Independent, Live with Family/Relative/Caregiver and Other Residential Setting by HRST Score, 2014



	1	2	3	4	5	6
Independent Apartment/Home	704	428	148	74	49	51
Live with Family/Relative/Caretaker Friend	3279	1565	514	248	147	162
Other	24	15	11	1	3	1

Note: The count axis is in increments of 500.

Though individuals with lower health risk scores tend to live in lower-intensive residential settings and individuals with higher health risk scores tend to live in higher-intensive residential settings, each type of residential setting has individuals with the full range of HRST scores—individuals with a low risk score reside in each type of residential setting, and individuals with a high-level health risk score reside in each type of residential setting.

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-level health risks varying across all age categories; the relationship is not uniform across the entire age range. HRST scores are distributed similarly in the entire distribution of HRST scores across the first four age groups younger than 54. Starting with the 55-64 age groups, 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.

Mortality During 2013 and 2014

This section contains information on the deaths reported to DBHDD of the IDD waiver population during 2013 and 2014. Appendix B describes the method used to collect and analyze information and data contained in this section.

A total of 131 deaths of adults receiving IDD waiver services were reported to DBHDD in 2013; the resulting mortality rate was 11.3 deaths per thousand. In 2014, 128 deaths of adults receiving IDD waiver services were reported to DBHDD; the resulting mortality rate was 11.1 deaths per thousand. The mortality rate for this population was not statistically significantly different between 2013 and 2014 overall (z = -0.1861, p = 0.85).

Age and Mortality

The average age of death in 2013 was 50.7 years (median = 52.0); the average age of death in 2014 was 51.7 years (median = 55.0).[7] The mortality rate increases with increasing age (Figure 11). In particular, in the age range of 45-54 in both 2013 and 2014, the mortality rate exceeded the overall mortality rate for the entire population for each year, which was about 11 deaths per one thousand people. Statistical comparisons between corresponding mortality rates for each age category between 2013 and 2014 were not statistically significant. The trends in Figure 11 are visually striking due to the absolute difference between mortality rates for the 85+ age category which was 85 deaths per 1000. The difference in proportions, however, was not statistically significant due to the small numbers of individuals for that 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.

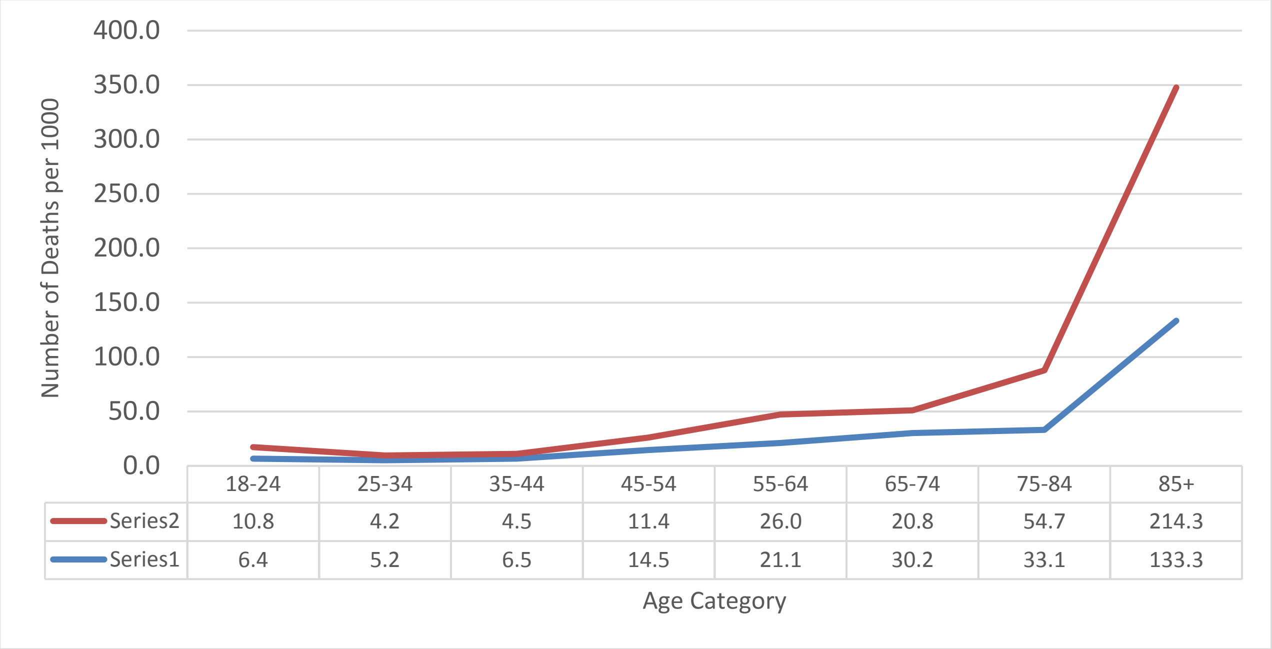
Table 11: Mortality Rate by Age Category, 2013-2014

	2013				2014				Statistical difference	
	Adult Waiver Population	No. Deaths	Percent of Deaths	Crude Mortality Rate	Adult Waiver Population	No. Deaths	Percent of Deaths	Crude Mortality Rate	z score	p =
18-24	1243	8	9.2	6.4	1116	12	10.2	10.8	1.1417	0.23
25-34	3263	17	11.5	5.2	3327	14	12.6	4.2	0.5943	0.56
35-44	2450	16	11.5	6.5	2456	11	9.4	4.5	-0.9713	0.33
45-54	2275	33	20.4	14.5	2273	26	18.1	11.4	-0.9139	0.36
55-64	1614	34	31.2	21.1	1651	43	33.1	26.0	0.9374	0.35
65-74	563	17	9.6	30.2	577	12	7.9	20.8	-1.0076	0.16
75-84	121	4	4.6	33.1	128	7	5.5	54.7	-0.8302	0.41
85+	15	2	1.9	133.3	14	3	3.1	214.3	0.5767	0.56
Total	11544	131	100.0	11.3	11542	128	100.0	11.1	-0.1861	0.85

---

[7] The original Mortality Report posted in August 2015 reported the average age of death in 2013 was 41.3 and 41.6 years in 2014. The above numbers were corrected and submitted for reposting in November 2015.

Figure 11: Mortality Rate by Age Category, 2013-2014



Gender and Mortality

Although males are a proportionately larger subset of the adult IDD waiver population, gender is otherwise not found to be an explanatory variable for mortality in 2013 and 2014. The average age of death is between 50 and 52 years of age. In 2013, the mortality rate between females (9.7 deaths per 1000 individuals) and males (12.5 deaths per 1000 individuals) was not significantly statistically different (z = -1.415, p = 0.08); in 2014 the mortality rate between females (12.2 deaths per 1000) and males (10.3 deaths per 1000) also was not statistically significantly different (z = 0.9915, p = 0.16). The proportion of deaths in females and males across 2013 and 2014 also remained stable (females: z = -1.1913, p = 0.12; males: z = 1.2345, p = 0.11).

Table 12: Number of Deaths, Average Age at Death and Mortality Rate by Gender, 2013-2014

	2013					2014				
Gender	Adult Waiver Population	No. Deaths	Percent of Deaths	Average Age at Death	Crude Mortality Rate	Adult Waiver Population	No. Deaths	Percent of Deaths	Average Age at Death	Crude Mortality Rate
Female	4842	47	35.9%	51.9	9.7	4824	59	46.1%	51.9	12.2
Male	6702	84	64.1%	50.0	12.5	6718	69	53.9%	51.4	10.3

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 the health status of the population that reside in each setting. The rate of mortality is higher in residential settings typically characterized by higher-intensity of services to meet the higher levels of support needs. This may have been found since increased health risk is associated with risk of mortality.

In 2013, the average age at death ranged between 54.5 years old and 58.7 years of age for all residential settings below, except for those individuals that lived with their families/relatives/caretakers/friends, whose average age of death was 39.8 years. The average age of death in 2013 for individuals that lived in higher-intensive residential settings was 57.1 years (SD = 12.1). The average age of death for those living in lower-intensive residential settings was 42.7 years (SD = 15.4). The difference between the average age of death for these two groups is statistically significantly different (unequal variances t = -5.087, df = 106.9, p < 0.001).

In 2014, the average age at death ranged between 43.8 and 58.9 years for all residential settings. The average age of death in 2014 for individuals that lived in higher-intensive residential settings was 55.4 years (SD = 14.9). The average age of death in 2014 for individuals that in lived lower-intensive residential settings was 46.0 (SD = 17.2). The difference between the average age of death for these two groups is statistically significantly different (unequal variances t = -3.212, df = 96.6, p = 0.002).

That the average age of death in 2013 and 2014 is significantly lower for individuals residing in lower-intensive services (though the mortality rate is also lower for this group) merits additional analysis and research. The findings that lowest average age of death for both years was for individuals living with their families/relatives/caretakers/friends will also be researched further. DBHDD is planning follow-up analysis and investigation to understand this finding more completely and to respond accordingly if needed.

Individuals living in personal care homes, community living arrangements, and host homes have mortality rates that range between 14.6 to 19.4 deaths per 1000 individuals. The mortality rate for these three higher-intensity residential settings combined is 17.1 deaths per 1000 individuals. The mortality rates for individuals that live independently (6.7 deaths per 1000) and with families/relatives/caretakers/friends (8.2 deaths per 1000) was lower.

In 2013, the mortality rate for these two lower-intensity residential settings combined was 7.9 deaths per 1000 people. The mortality rate for the low-intensity residential service setting is significantly lower than the higher-intensity residential setting (z = 4.5209, p <0.001). It should be noted that the mortality rate for “Other” (which includes 6 missing) is the highest of all (40.0 deaths per 1000); however, this represents two deaths, which is much less than the other categories, but proportionately larger due to the small numbers and cannot be interpreted with meaningfulness. (See Table13.)

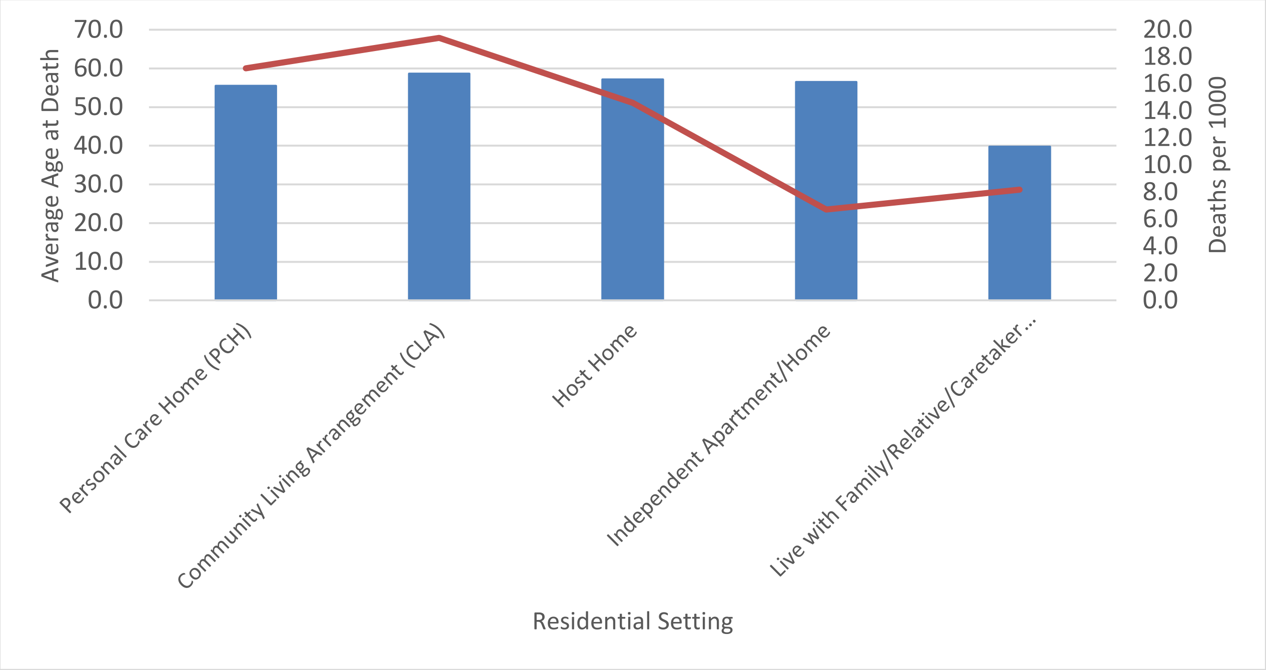
Similar to 2013, in 2014, the mortality rate was higher for those who resided in higher-intensive residential settings. The number of deaths per 1000 people for personal care home residents was 19.7, community living arrangements was 17.6, and host homes was 17.2. The mortality rate for the combined residential settings that received higher-intensity services was 18.7 deaths per 1000.

In contrast, the number of deaths per 1000 individuals was lower for those that lived in less-intensive residential settings. The mortality rate for independent apartment/home was 11.0 deaths per 1000, and the mortality rate for individuals who lived with family/relative/caretaker/friend was 5.9. The mortality rate for the combined residential settings that receive lower-intensity services was 6.9 deaths per 1000. In 2014, the mortality rate for the low-intensity residential setting is statistically significantly lower than the higher-intensity residential setting (z = 5.7667, p <0.001). It should be noted that unlike 2013, there were no deaths for individuals whose residential setting was categorized as "Other," including eight that were missing. (See Table 14.)

Table 13: Average Age at Death and Mortality Rate by Residential Setting, 2013

Residential Setting	Adult Population	Percent	% of Population 65+ yrs	No. Deaths	Average Age at Death	Crude Mortality Rate
Personal Care Home (PCH)	1517	13.1	23.2	26	55.5	17.1
Community Living Arrangement (CLA)	1392	12.1	20.0	27	58.7	19.4
Host Home	1233	10.7	17.0	18	57.2	14.6
Independent Apartment/Home	1487	12.9	18.9	10	56.5	6.7
Live with Family/Relative/ Caretaker/Friend	5865	50.8	20.3	48	39.8	8.2
Other (Includes 6 missing)	50	.4	0.6	2	54.5	40.0
Total	11544	100.0	100.0	131	50.7	11.3

Figure 12: Average Age at Death and Mortality Rate by Residential Setting, 2013

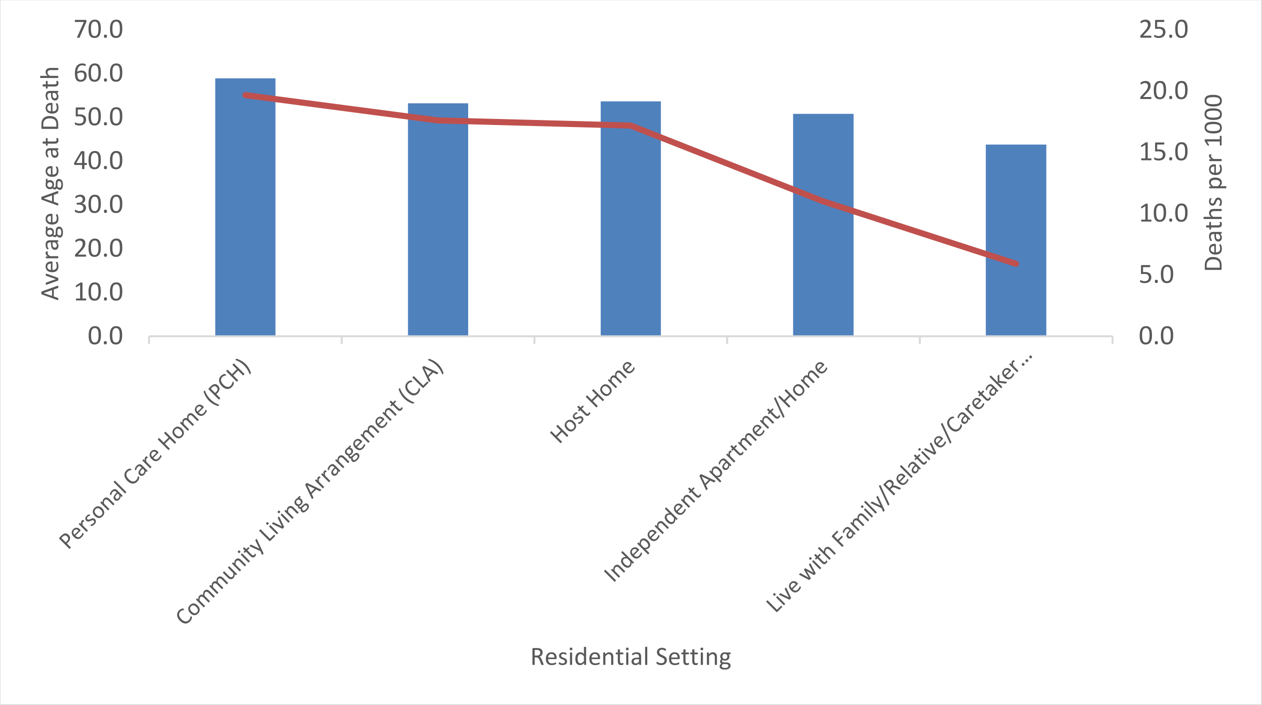


Note: Bars represent average age at death; the line indicates the mortality rate.

Table 14: Average Age at Death and Mortality Rate by Residential Setting, 2014

Residential Setting	Adult Population	Percent	% of Population 65+ yrs	No. Deaths	Average Age at Death	Crude Mortality Rate
Personal Care Home (PCH)	1475	12.8	22.7	29	58.9	19.7
Community Living Arrangement (CLA)	1420	12.3	20.2	27	53.2	17.6
Host Home	1223	10.6	16.8	21	53.6	17.2
Independent Apartment/Home	1454	12.6	19.1	16	50.8	11.0
Live with Family/Relative/Caretaker Friend	5915	51.2	20.6	35	43.8	5.9
Other (Includes 8 missing)	55	0.5	0.7	0	N/A	N/A
Total	11542	100	100.0	128	51.7	11.1

Figure 13: Average Age at Death and Mortality Rate by Residential Setting, 2014



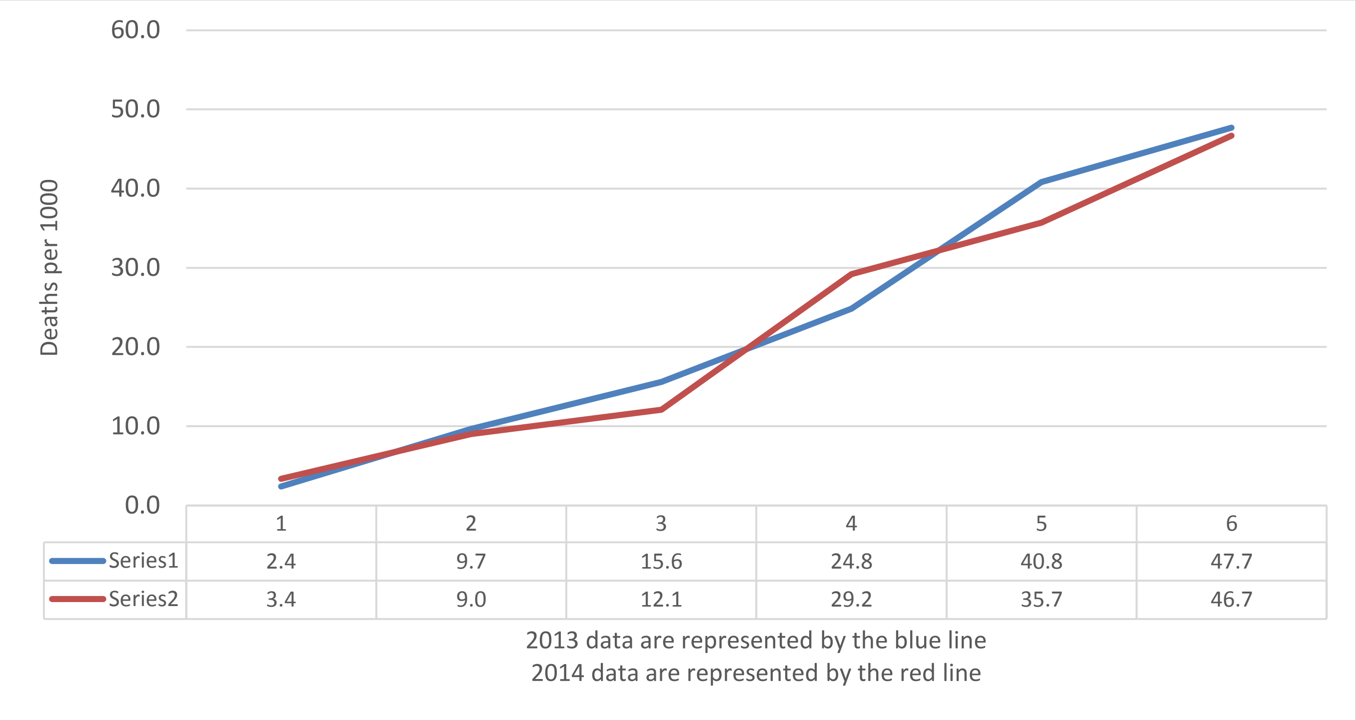
Health Risk and Mortality

A linear relationship exists between HRST scores and mortality rates. Lower HRST scores (1-2) have mortality rates that are below the population mortality rates in 2013 and 2014. The mortality rates associated with an HRST score of 3 or higher exceed the overall population mortality rates, and the mortality rates increase as HRST scores increase.

The associated increase in mortality rate with each unit increase in HRST score is not necessarily statistically significant. In fact, across 2013 and 2014, the difference between the mortality rates associated with a one- point increase of HRST score is significant only three out of 10 times. Therefore, the difference in associated mortality with an increase of one HRST level may not be a significant indicator of risk of death.

It should be noted, however, there is a statistically significant increase in mortality rate with any two-point increase in HRST in both years. This suggests a recommendation of more frequent reassessment of risk with an increase of one point in HRST scores to identify service needs that could potentially reduce increased risk of mortality associated with a two-point increase in HRST scores.

Figure 14: Mortality Rate by HRST Score, 2013 and 2014



2013 data are represented by the blue line
2014 data are represented by the red line

Table 15: Mortality Rate by HRST Score, 2013 and 2014

HRST Score	2013					2014				
	Adult Waiver Population	No. Deaths	Percent of Deaths	Crude Mortality Rate	Stat sig between HRST Scores	Adult Waiver Population	No. Deaths	Percent of Deaths	Crude Death Rate	Stat sig between HRST Scores
1	5039	12	9.2%	2.4		5053	17	13.3%	3.4	
2	3313	32	24.4%	9.7	z = 4.4945, p = 0.002	3332	30	23.4%	9.0	z = 3.3847, p < 0.001
3	1411	22	16.8%	15.6	ns	1405	17	13.3%	12.1	ns
4	725	18	13.7%	24.8	ns	719	21	16.4%	29.2	z = 2.8146, p = 0.005
5	490	20	15.3%	40.8	ns	476	17	13.3%	35.7	ns
6	566	27	20.6%	47.7	ns	557	26	20.3%	46.7	ns
Total	11544	131	100.0%	11.3		11542	128	100.0%	11.1	

The Importance of Age and Health Risk

The data analyses to this point have examined the relationship of age, gender, residential setting, and health risk as they have individually or in pairs relate to mortality rates. Examining the contribution of one variable or a pair of variables at a time and how mortality rates are affected is instructive; it also is instructive to consider all variables of interest at once to determine the individual impact of each variable on the occurrence of death while controlling for the influence of all other variables. This report now turns to considering how age, gender, residential setting, and health risk all at once are associated with mortality to determine which variables may be of key importance in understanding the occurrence of death.

Age, gender, residential setting, and HRST score were analyzed using logistic regression analysis to predict if a death occurred in 2013. Only age and HRST scores were significantly associated with the occurrence of a death. Inspection of the individual coefficients indicated that gender and residential setting were not significantly related to the occurrence of a death in 2013.

Table 16: Final Logistic Regression Model with Death as Outcome, 2013

Variable	B	S.E.	Wald	df	Sig.	Exp(B)
Age	.035	.006	36.878	1	.000	1.036
HRST	.500	.049	102.855	1	.000	1.648
Constant	-7.487	.334	502.433	1	.000	.001

The same approach was taken to model the 2014 data, and very similar results were found. Age, gender, residential setting, and HRST score were analyzed using logistic regression analysis to predict if a death occurred in 2014. Like 2013, only age and HRST scores were significantly associated with the occurrence of death in 2014. Gender and residential setting were not significantly related to the occurrence of a death in 2014.

Table 17: Final Logistic Regression Model with Death as Outcome, 2014

Variable	B	S.E.	Wald	df	Sig.	Exp(B)
Age	.040	.006	45.523	1	.000	1.041
HRST	.478	.050	92.241	1	.000	1.614
Constant	-7.653	.343	496.780	1	.000	.000

An advantage of using logistic regression to determine the importance of each variable is the information from the model can be used to calculate the odds ratio (OR) of an event occurring given the impact of one or more variables. An OR is a measure of association between one variable and an outcome occurring, such as death in these analysis. The OR represents the odds that death occurred given a particular event or condition occurred compared to the odds of the death occurred in the absence of that variable. OR estimates of 1 indicate that the variable of interest does not affect the odds of death occurring; OR estimates > 1 indicate that variable is associated with higher odds of death occurring; OR estimates < 1 indicate that the variable is associated with lower odds of death occurring.

The analyses demonstrate a clear association between HRST scores and the odds of dying. Each one-point increase in HRST score is associated with an increase in OR for both 2013 and 2014. At the baseline score of HRST = 1, the odds of death occurring is low, just over 1; the odds of death occurring is almost or more than 10 times higher at HRST = 6. (See Table 18.)

Table 18: Odds Ratio (OR) for HRST Scores, 2013-2014

HRST	OR 2013	OR 2014
1	1.65	1.61
2	2.72	2.60
3	4.48	4.20
4	7.39	6.77
5	12.18	10.91
6	20.09	17.60

One can also see the clear association between age and the odds of dying. In fact, the odds of dying more than double every 20 years; the odds of dying at age 80 is about 10 times as high as dying at age 20. (See Table 19.)

Table 19: Odds Ratios (OR) for 10-Year Ages Difference, 2013-2014

Age	OR 2013	OR 2014
20	2.01	2.23
30	2.86	3.32
40	4.06	4.95
50	5.75	7.39
60	8.17	11.02
70	11.59	16.44
80	16.44	24.53
85	19.59	29.96

The primary results of these analyses indicate two main points. First, models for 2013 and 2014 were very similar in that (1) age and health risk scores were the two variables that were significant predictors of death (and not gender and residential setting). Second, the model indicates possible opportunities to identify risk of death associated with age and HRST scores and identify if additional services or supports are needed.

Implications of Analysis

The results are reviewed in this section, and implications of findings are highlighted. These findings suggest that particular attention should be given to assessing health risk needs regularly for those individuals who may be at risk for an adverse health event. Clearly, that age has the strongest association with the odds of death occurring, consideration should be given to assessing health risk more frequently with increasing age. Recall, that mortality rates increased above the population level for age groups 45-54 and over. (See Figure Table 11 and Figure 11.) This would suggest that more frequent assessment of health risks should occur when the risk of mortality increases for this population, specifically by age 45, regardless of residential setting, gender, HRST, or region.

These analyses also highlight the importance of assessing health risk more frequently as health status and risk changes. DBHDD already specifies that HRST reassessment should occur when a potentially negative change in health status, health risk, adverse event, etc. occurs. These analyses suggest further consideration should be given to assessing HRST more frequently for a period of time for someone who has experienced an increase in HRST status until the individualized plan of care has been evaluated, implemented, and assessed to be addressing needs. Recall that analysis indicated a significant increase in mortality rates associated with a two-point increase in HRST scores, which would indicate that reassessment should occur more often in the time after an individual's HRST score increases even one point. This recommendation includes all individuals regardless of service intensity of residential setting, gender, age, or region.

Discussion and Review of Mortality Report Findings

The purpose of this report was to provide information about what DBHDD has learned about deaths, to identify trends or patterns and 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. To accomplish this purpose, this mortality review analyzed information and data from causes of death, the mortality review process, and data analysis of mortality factors for the IDD waiver population in 2013 and 2014. Each section brought to light a number of findings, recommendations, or plans that can assist with improving services to the IDD population. These are reviewed below.

Key Findings, Recommendations, Plans: Mortality Reviews

Mortality reviews conducted by the Department's CMRC have resulted in several recommendations and plans for system improvements and improvements:

- The Department's Office of Incident Management and Investigations (OIMI) should use feedback from the CMRC to strengthen and improve staffs' investigative skills;
- Ensure that individuals who transition into the community from the hospital have a new medical provider identified prior to discharge;
- Provide information on trends and patterns to the Executive Quality Council.

In addition to implementing recommendations from mortality reviews, the Department continuously works to improve the mortality review process. The below are examples of actions DBHDD will undertake to enhance the process:

- The Department has engaged the services of expert consultants from RPA, Ltd. led by Lyn Rucker and Eva Kutas to review and make recommendations for system improvements;
- Screen Category 2 or 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;
- Increase membership of the CMRC to include additional representatives with medical expertise and representatives of external organizations and stakeholders;
- Provide training for all new CMRC members to ensure that all members understand the goals of the CMRC, the review process, and his/her role in the process and as part of the committee;
- Continue to evaluate the Department's Mortality Review system utilizing the standards checklist "Evaluation of State MR/DD Mortality Review Systems: Criteria and Standards";
- Utilize a database that is being developed to track the identification of deficient practices and the corresponding recommendations and corrective actions that

are described in quality reviews, audit reports, and reports concerning providers' performance including compliance with contractual, regulatory, and programmatic requirements; CMRC and external mortality review recommendations will be included this database;
- Identify other actions that could be taken to reduce potential risk and inform provider training through continued work with the Division of Developmental Disabilities and the Office of Learning and Organizational Development;
- Provide feedback to the CMRC regarding the status of their recommendations until resolution has been verified;
- Revise the community incident management policy to provide a system whereby information is gathered and analyzed for each reported death to determine whether an immediate response is needed to ensure the health and safety of other individuals receiving services by the provider.

Key Findings, Recommendations, Plans: Causes of Death

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. Cause of death findings assist in identifying strategies for monitoring incidents related to risk and serve as an indicator to review, revise or establish additional procedures to reduce risk of illness and death. To this end, this information will:

- Utilize the expertise and experience of the Medical Director and members of the CMRC to determine whether there is opportunity for intervention at the system or provider levels;
- Clearly identify the most common conditions that elevate risk for death and for which there are specific techniques to reduce the risk of their occurrence (aspiration pneumonia, bowel obstruction, status epilepticus, sepsis, dehydration, and gastrointestinal conditions) to determine opportunities for improvement or early detection and intervention;
- Consider other data collection systems and elements to allow for more uniform methods of identifying, recording, and analyzing causes of death;
- Continue to analyze the data in different ways to identify opportunities to reduce risk and actions that may effectuate positive changes in care, e.g., use a group of cases to determine if an "alert" should be sent to all providers.

Key Findings, Recommendations, Plans: Data Analysis

DBHDD has made and continues to make significant improvements in data tracking systems for all individuals, regardless of payer source, diagnosis, disability category, residential setting, etc. The disparate data systems that existed in 2013 and 2014 presented barriers to identifying and matching data for individuals across categories for this report. Future mortality review reports will include more comprehensive data across payer sources, diagnosis, disability category, residential setting, etc. based on data available as a result of these improvements. DBHDD plans to have a fully-integrated data system in place that will track these data by 2016.

That the average age of death in 2013 and 2014 is significantly lower for individuals residing in lower-intensive services (though the mortality rate is also lower for this group) merits additional analysis and research. The findings that the lowest average age of death for both years was for individuals living with their families/relatives/caretakers/friends will be researched further to determine if and what response may indicated.

Increasing age is most strongly associated with mortality. These findings suggested that particular attention should be given to assessing health risk needs regularly for those individuals who may be at risk for an adverse health event. Data analysis indicated that more frequent assessment of health risks should occur when the risk of mortality increases for this population at age 45, regardless of residential setting, gender, HRST, or region.

Analyses also highlighted the importance of assessing health risk more frequently as health status and risk change. These analyses suggest further consideration should be given to assessing HRST more frequently when HRST score increases one point or more for a period of time for someone who has experienced an increase in HRST status until the individualized care of plan has been evaluated, implemented, and assessed to be addressing needs. This recommendation includes all individuals regardless of service intensity of residential setting, gender, age, or region. Increased frequency of reassessing HRST indicates a trigger for reassessment of an individual’s needs, evaluation of the individualized plan of service and care, and monitoring the effectiveness of care more closely.

This report provided information about what DBHDD has learned about deaths, identified trends and patterns as well as indicators that will assist DBHDD in the development of polices, processes, and trainings to improve care related to certain illnesses that may lead to deaths. Whether it involves systemic or programmatic change, DBHDD is committed to its continued review of all available data to know what is working and what needs improvement. The Mortality Report scheduled for 2015 will certainly benefit from the initial efforts and findings reported here.

Appendix A: Regions of DBHDD

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

- Communicating and implementing Department policy at the regional level;
- Developing annual regional plans in conjunction with the Regional Planning Board;
- Managing allocated funds and contracting with providers for provision of mental health, addictive disease, and intellectual and developmental disability services for individuals eligible to receive 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 Planning Board members, and other social service agencies; and
- Investigating and resolving complaints and conducting special investigations as needed.

Region Descriptions: (see map)

Region 1- Region One covers 31 predominantly rural counties of Northwest and Northeast Georgia with a total population of over 2.5 million people.

Region 2- Region Two covers 33 counties of East and Central Georgia with a total population of 1.27 million people.

Region 3- Region 3 covers 6 counties, which includes the capital city of Atlanta. The six counties have a total population of 2.9 million people.

Region 4- Region 4 consists of 24 predominantly rural counties in the far Southwest corner of Georgia with a total population of 611,590 people.

Region 5- Region 5 covers 34 counties of Southeast Georgia, with a total population of 1.1 million people.

Region 6- Region 6 covers 31 counties in West-Central Georgia, with a population of 1.37 million. Two-thirds of the region is rural.

Figure 15: DBHDD Regional Map with State Hospital Locations

Appendix B: Method for Mortality Review and Analysis

This mortality report analyzes information on all deaths that were 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)

The data used to calculate mortality rates per 1000 people by age group and type of residence was supplied by the WIS Medicaid information system and ROCI. WIS Medicaid information was the primary source for identifying, demographic, payer information, and 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 on 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 $\alpha = 0.01$ to compensate that significance is found due to increased chances afforded by multiple comparisons.

Crude mortality rates were calculated for the NOW and COMP Medicaid Waiver population, age category, gender, and residence type. The specific methodology employed by this report to calculate mortality rates per 1000 people throughout this report is as follows:

$$\text{Crude Mortality Rate} = \frac{\text{(Number of people who died in calendar year x 1000)}}{\text{(Number of people that received waiver service during the calendar year)}}$$

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 that are receiving services may have produce upwardly biased mortality rates relative to including all that are eligible for services. Due to data limitations mentioned earlier, it was not possible to investigate this possible bias. The integrated medical record and data tracking system that DBHDD is creating and implementing fully in 2016 will allow any bias to be investigated as well as allow for including those individuals receiving funds from disparate payer sources. The data tracking system will also allow DBHDD to include those that are eligible for services in future reports.

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

Analyses were conducted using SPSS© version 23, 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 for 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 the most parsimonious model of significant predictor variables of death remained. Finally, the model was examined for meaningful relationships and interpretation. Models were built separately for 2013 and 2014, compared, and then interpreted.

Appendix C: Description of Non-Waiver Adult Deaths Reported to DBHDD in 2013 and 2014

In 2013, 18 deaths were reported to DBHDD of adults that were not receiving NOW or COMP Medicaid waiver services. Eight of these deaths (44.4%) were females; 10 deaths (55.6%) were males. The average age of death for the entire group was 49.0 years (SD = 15.4).

If these deaths were included in the 2013 mortality rate, the resulting 2013 mortality rate would be 12.9 deaths per 1000. It should be noted that these deaths are being added to the numerator of the mortality rate equation without including the population count from which they were drawn (receiving non-Medicaid waiver supports, such as State-funded services). Therefore, 12.9 deaths per 1000 is an upwardly biased estimate of mortality.

In 2014, 27 deaths were reported to DBHDD of adults that were not receiving NOW or COMP Medicaid wiaver services. Fifteen of these deaths (56%) were females; 12 deaths (44%) were males. The average age of death for the entire group was 52.0 years (SD = 16.7).

If these death were included in the 2014 mortality rate, the resulting 2014 mortality rate would be 13.4 deaths per 1000. It should be noted that these deaths were added to the numerator of the mortality rate without including the population count from which they were drawn (receiving non-Medicaid waiver supports, such as State-funded services). Therefore, 13.4 deaths per 1000 is an upwardly biased estimate of mortality.

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 that are receiving services may have produce upwardly biased mortality rates relative to including all that are eligible for services. Due to data limitations mentioned earlier, it was not possible to investigate this possible bias. The integrated medical record and data tracking system that DBHDD is creating and implementing fully in 2016 will allow any bias to be investigated as well as allow for including those individuals receiving funds from disparate payer sources. The data tracking system will also allow DBHDD to include those that are eligible for services in future reports.

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

Causes of Death

In 2013, the primary cause of death was related to cardiovascular disease (11 deaths – nine involving heart disease and two regarding peripheral vascular disease). The second most frequently occurring cause of death was related to pulmonary disease (nine deaths – eight with respiratory disease and one with pneumonia). There were two deaths related to renal disease and infections (sepsis and other). Cancer, seizures, and natural causes accounted for one death each. There were eight other causes of death identified. Note: an individual may have more than one cause of death; therefore, the total number of causes exceeds the number of deaths.

In 2014, the cause of death for one of the 27 individuals receiving state-funded services at the time of his/her death was unknown. Of the remaining individuals, the primary cause of death was related to cardiovascular disease (14 deaths – 13 involving heart disease and one regarding peripheral vascular disease). The second most frequently occurring cause of death was related to pulmonary disease (eight deaths – one involving pneumonia, two related to aspiration pneumonia and five with respiratory disease) and nervous system diseases (eight deaths – four related to cerebrovascular disease, one with complications of Cerebral Palsy, and three with epilepsy. There were six deaths related to infections, four pertaining to sepsis and two other; three deaths related to cancer; three deaths related to the gastrointestinal system; two to renal disease; and five others. Again, the total number of causes of deaths exceeds the number of deaths.

Appendix D: Community Mortality Review Process

APPLICABILITY

All DBHDD Community Providers

POLICY

DBHDD conducts thorough reviews of all Category I, Category II and, upon request, Category III mortalities of individuals receiving services by or through DBHDD community providers. All such reviews are conducted using the systematic interdisciplinary procedures described in this policy. The systematic review of mortality described in this policy does not replace investigations conducted by investigative staff.

The goals of this policy, procedures and related materials include the following:

- To conduct mortality reviews utilizing a systematic interdisciplinary review of all deaths,
- To review the provision of services to the individual,
- To identify factors that may have contributed to the death and/or indicate possible gaps in services,
- To recommend and/or implement corrective actions to improve the performance of staff and systems,
- To monitor support systems and programmatic operations to ensure reasonable medical, educational, legal, social, or psychological interventions were being provided prior to deaths; and
- To ensure that all community providers have a system in place for the identification of risk factors for mortality and the development of prevention strategies.

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: For the purposes of this policy, the term Provider includes any person or organization that provides services that are financially supported in whole or in part by funds authorized through DBHDD.

Corrective Action Plan: A document 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.

Licensed Clinical Disciplines: For the purposes of this policy, licensed clinical disciplines includes services which require a professional license or qualification according to the practice acts of the state of Georgia, including the following: medicine, nursing, optometry, podiatry, physical therapy, speech pathology and audiology, occupational therapy, dentistry, dietician, psychology, addiction counseling, professional counseling, social work and/or marriage and family therapy.

Reasonable intervention: An intervention that would have been possible given known circumstances or circumstances they should have known and resources available.

Senior Executive Manager: The individual authorized by the agency to review for accuracy and completeness incident reports, investigative reports and corrective action plans prior to submission to DBHDD.

PROCEDURES

A. Mortality Review Committee

1. The DBHDD Community Mortality Review Committee (CMRC) is established to ascertain whether all necessary and reasonable interventions were taken to provide for the health, safety, and welfare of the individual receiving services by a DBHDD provider and to identify and mitigate any preventable findings that could affect the health, safety and welfare of other individuals receiving supports and services from DBHDD community providers.
2. Members of the CMRC are appointed by the DBHDD Medical Director.
3. Membership of the CMRC may include but shall not be limited to representatives of the following:
    a. DBHDD Medical Director
    b. DBHDD Physician
    c. DBHDD Suicide Risk Prevention Coordinator
    d. A community physician who is experienced and understanding of the needs of individuals who are receiving services through DBHDD
    e. A Registered Nurse who is experienced and understanding of the needs of individuals who are receiving services through DBHDD
    f. DBHDD Director of Quality Management
    g. DBHDD Director of DD Quality Management
    h. DBHDD Division of Addictive Diseases (AD) Representative
    i. DBHDD Division of Mental Health (MH) Representative
    j. DBHDD Director of the Office of Incident Management and Investigations (OIMI)

    4. There must be a minimum of five committee members present, three or at least 51% of which must come from one of the licensed clinical disciplines (as defined in this policy) and one of which must be a physician.
    5. The CMRC may establish subcommittees of clinical members as necessary to accomplish its purposes.
    6. The CMRC will meet at least quarterly.

B. Process

1. Community providers report all deaths to DBHDD, follow all procedures for notification of appropriate persons and agencies, and investigate the death in accordance with Reporting and Investigating Deaths and Critical Incidents in Community Services, 04-106.
2. Community provider submits documentation requested for review by the CMRC.
3. The community provider shall respond to any additional requests for information made by the DBHDD CMRC within five business days of the provider's receipt of a request or more quickly if an expedited request is made.
4. Upon completion of the investigation by the provider or by OIMI, as applicable, the deaths will be reviewed by the CMRC.
5. The committee shall, at a minimum, review the following documents:
    a. The provider's investigative report;
    b. OIMI's investigative report;
    c. The death certificate, if available;
    d. The autopsy report, if available; and
    e. Any available reports from physicians, hospitals, agencies, consultants, or others providing services.
6. If a subcommittee has been created, then the process is as follows:
    a. The subcommittee, at a minimum, reviews the documents.
    b. Any reviews that result in a concern or require a higher level of scrutiny will be directed to the full CMRC.
7. The committee shall identify:
    a. Conclusions regarding clinically suspected cause(s) of death and classification of death (expected or not expected);
    b. Conclusions regarding gaps in staff/provider performance;
    c. Conclusions regarding performance improvement opportunities;
    d. Recommendations regarding corrective actions needed;
    e. Unanswered issues needing further clarification, if any;
    f. Recommendations regarding the need for further review and the recommended focus of that review.

8. The committee may make recommendations regarding the investigation and request follow-up or other actions deemed necessary.

C. Recommendations

   1. Within 10 calendar days of notification of the CRMC’s request for a corrective action plan, the provider must submit a corrective action plan to include the following:
      a. The plan for correcting the specific gaps in performance or systems. The plan should address the processes that lead to the gap in performance or system;
      b. The procedure for implementing the acceptable plan of correction;
      c. The date certain by which the corrections will be made;
      d. The monitoring procedure to ensure that the provider has corrected the identified problems in performance ;
      e. The title of the person responsible for implementing the acceptable plan of correction.

   2. The CAP must be signed and dated by the Senior Executive Manager who is also responsible for implementing the CAP.

D. Other Procedures

   1. If the CMRC determines that further action is needed, they may request such action from the community provider.

   2. When the CMRC determines that no further action is needed, the mortality review is closed.

   3. If additional information not originally considered in the review of the individual’s death is received, the CMRC may re-convene to review the death and all related information:

   4. Provider practices, where appropriate, will be reviewed at a systems level and be the subject of community provider performance improvement projects as applicable.

Appendix E: The DBHDD Community Mortality Review Committee (CMRC)

The DBHDD mortality review process was implemented on October 1, 2012, for review of the death of anyone for whom DBHDD had direct or oversight responsibility. The direct or oversight responsibilities are outlined in the definitions of death in Reporting and Investigating Deaths and Critical Incidents in Community Services, Policy 04-106. Types of deaths identified in policy include:

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.

As noted above, a Category III Death is the death of an individual enrolled and actively receiving DBHDD funded services; however, unless the death occurred on the site of a community provider or in the company of staff of a community provider, DBHDD has no direct or oversight responsibility for these individuals. Individuals for whom DBHDD has direct or oversight responsibility include those who are receiving residential services, those who are on site of a community provider at the time of death or those who are in the company of staff of a community provider at the time of death (Category I and II above).

To illustrate, a person may live with his/her family and attend a DBHDD funded day program for four hours two days per week. He/she may also receive transportation services to/from the day program. If the individual died while at the day program or while en route to or from the day program, the death would be reportable as a Category I or II death. However, if the person was picked up from the day program by his/her relative and died away from the day program site, the death would be reportable as a Category III death, denoting no direct or oversight responsibility.

Compliance with Recommended Components

In establishing a Mortality Review process, the Department reviewed the May 2008 United States Government Accountability Office (GAO) Report to the Ranking Member, Committee on Finance, U.S. Senate on Medicaid Home and Community-Based Waivers.[8] The GAO report identified six basic components of developmental disabilities agency mortality reviews for individuals with developmental disabilities. The GAO identified that reviewing the deaths of individuals with developmental disabilities as critical incidents in the Medicaid HCBS waiver program is one of several mechanisms states can use to ensure that this vulnerable population is protected from harm and to address quality-of-care concerns.[9,10] The DBHDD process complies with the six components recommended by the GAO as follows:

1. *Component: Screen individual deaths with standard information.*
   DBHDD requires the submission of standard information when reporting deaths. The same information is routinely collected for each death. The information is screened; and all Category I and Category II deaths are investigated. Depending on the circumstances, a Category III may be investigated.

2. *Component: Review unexpected deaths, at a minimum.*
   DBHDD reviews all unexpected deaths as defined by the community incident management policy. These may include deaths that were accidental, that resulted from an undiagnosed condition, or those that were suspicious for possible abuse or neglect.

3. *Component: Routinely include medical professionals in mortality reviews.*
   DBHDD's CMRC regularly included at least one physician, at least one nurse as well as other health care providers.

4. *Component: Document mortality review process, findings or recommendations.*
   DBHDD routinely documented recommendations of the CMRC for each mortality review committee meeting.

5. *Component: Use mortality information to address quality of care.*
   DBHDD identified improvements in statewide practices. See Mortality Review Section in the body of this report.

6. *Component: Aggregate mortality data over time to identify trends.*
   DBHDD's current mortality report represents the fulfillment of this component.

---

[8] http://www.gao.gov/assets/280/275743.pdf

[9] http://www.gao.gov/assets/280/275743.pdf

[10] The Mortality Report posted in August 2015 did not provide the reference in footnote 9. The Mortality Report was corrected and resubmitted for posting in November 2015.