

Annual IDD Mortality Report

2019



D·B·H·D·D

GEORGIA DEPARTMENT *of*

BEHAVIORAL HEALTH *and* DEVELOPMENTAL DISABILITIES

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EXECUTIVE SUMMARY

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

This report includes data and information concerning adults who died during calendar year 2019 while receiving intellectual and developmental disability (IDD) Medicaid waiver services from DBHDD and its contracted providers.

MAJOR FINDINGS

In calendar year 2019, DBHDD served 13,267 adults with intellectual and developmental disabilities in waiver services.¹ A total of 221 deaths occurred in 2019, resulting in a crude mortality rate of 16.7 deaths per 1,000 individuals.^{2,3} The respective mortality rates for 2017 and 2018 were 16.4 and 13.3 deaths per 1,000 individuals. The mortality rates do not differ significantly across any years.

Heart diseases were the leading cause of death in the general populations of the United States (U.S.; 2017) and Georgia (2018), as well as DBHDD's New Options Waivers and Comprehensive Supports Waivers (NOW/COMP) waiver population (2019). Six of the leading causes of death among DBHDD's IDD population were common to leading causes of death in the U.S. and Georgia: heart diseases, cancer, respiratory diseases, renal, pneumonia, and neurological conditions. Four of the leading causes of death for DBHDD's IDD population were not common to the top causes of death in the U.S. and Georgia: disability, sepsis, aspiration pneumonia, and gastrointestinal diseases. Results are similar for previous years of study.

¹ The total number of unduplicated IDD individuals with active NOW/COMP waivers in 2019 was 13,267; however, this analysis excluded individuals who had missing health risk data (n = 27).

² The mortality rate used in this report is a crude mortality rate, which is an unadjusted mortality rate. The mortality rate is a measure of how many people out of every thousand served by DBHDD died within the calendar year. It is determined by multiplying the number of people who died during the year by 1,000, then dividing by the total number of individuals served in the NOW/COMP waiver program during the same year. The crude mortality rate can be useful when comparing deaths across populations of varying sizes. For the purposes of the remainder of this report, crude mortality rate will be referred to as "mortality rate."

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

Several variables were analyzed to determine their association with mortality in 2019. These included age, gender, health risk, residential setting, and region. Major analytical findings from 2017 through 2018 show that increasing health risk and increasing age were most strongly associated with mortality, while gender, residential setting, region, and other variables were not related to mortality. In 2019, increasing health risk and increasing age were once again significantly related to mortality.

Community Mortality Review Committee (CMRC) has very few additional findings beyond the findings by internal DBHDD investigations. The most common provider deficiencies that required corrective action were linked to individual care and prevention (59.7% of all critical/high deficiencies). These deficiency areas included assessment and treatment plans, medical care needs, medication management, coordination of care, and failure to respond to an emergency or change in condition in a manner that would protect the welfare of the individual. The overlap among the areas above account for 74 of the 124 identified critical- or high-risk deficient practices. Though corrective action plans are intended to remediate deficient provider practices and mitigate further risk, the prevalence of the abovementioned common deficient practices may indicate additional areas for systemic improvement.

SCOPE OF THIS REPORT

The focus of the mortality review for this report includes adults with a primary IDD diagnosis who received services funded by NOW/COMP waivers during the 2019 calendar year. During 2019, data systems for individuals receiving waiver services were maintained separately from state-funded services, and data between these systems vary. This report used the NOW/COMP waiver data because it demonstrated the highest verifiable accuracy and reliability. A description of the chosen method and the analysis conducted in the report can be found in Appendix A. This report also includes data from the CMRC process from a subset of the deaths that occurred within this population during 2019.

Several considerations are provided for reading and interpreting the findings from this report. Although DBHDD looked closely at other states' reports, given the differences in waiver programs, obligations of the various state agencies, and other state-specific issues, it is difficult to compare mortality rates or conclusions between states. DBHDD has used caution when comparing mortality rates across unlike methods and populations. 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.

ABOUT DBHDD

DBHDD provides treatment and support services for people with mental health challenges and substance use disorders and assists individuals who live with intellectual and developmental disabilities.

VISION

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

MISSION

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

ABOUT DBHDD INTELLECTUAL AND DEVELOPMENTAL DISABILITY SERVICES

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

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

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

DBHDD SAMPLING PROCEDURE

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

DBHDD's sampling procedure proceeds in the following manner:

- First, when available, DBHDD utilizes data on the full population under study (e.g., all individuals who received services within a given period such as calendar or fiscal year).
- Second, if some individuals within the full population have missing data for variables being used for analysis, DBHDD considers widely-accepted procedures to address missing data. For example, individuals with missing data typically are excluded from analysis using listwise deletion,⁴ resulting in a subset of the full population. DBHDD may consider other theoretically-sound methods and procedures to understand or address missing data.⁵
- Third, in some cases, DBHDD utilizes some form of random sampling⁶ (e.g., a random subset of providers or events that occurred). For this approach to be valid, one must be able to define the entire population from which it is being drawn, and each unit (e.g., individual, situation, etc.) must have an equal chance of being included in the sample. This method is unbiased, and the resulting sample is representative of the full population under study.
- Fourth, DBHDD also occasionally makes use of purposive sampling, a non-probability sampling method. This method is typically reserved for specific instances (e.g., identifying when a situation occurred, selecting specific cases, identifying specific errors, etc.). Purposive sampling is a selective, non-probabilistic method, and purposive sampling is not representative of the full population under study; therefore, findings or

⁴ Listwise deletion is a method for handling missing data, whereby an entire record is excluded from analysis if any single value is missing.

⁵ Sensitivity analyses are conducted to evaluate the pattern of missing data, wherein missing data are determined to be either missing completely at random (MCAR) or missing at random (MAR). Data are determined to be MCAR when the probability of missing data on a variable is unrelated to any other measured variable and is unrelated to the variable with missing values itself. Data are determined to be MAR when the missingness can be explained by variables that do not contain missing values.

⁶ The leading component of simple random sampling is that every case (e.g., individuals or providers) has the same probability of being selected for inclusion in analysis.

results based on purposive sampling are not generalizable to the full population, rather only to the cases from which data were sampled.

- Fifth, a goal of inferential statistics is to make inferences about the population based on a sample smaller than the population. DBHDD considers sample sizes carefully and analytically to create empirical samples large enough to have sufficient statistical power to detect associations or differences and allow valid inferences to be drawn from and generalized about the population being studied.

PURPOSE

This is the sixth annual report on mortality, mortality trends, and related information pertaining to the health and care received by individuals on NOW/COMP waivers with IDD served by DBHDD. The report focuses on an analysis of mortality data and findings from DBHDD's mortality review process. Reports are scheduled for publication each year and cover the prior calendar year of January 1 through December 31.

CAUSES OF DEATH AMONG THE INTELLECTUAL AND DEVELOPMENTAL DISABILITY WAIVER POPULATION

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

Prior to the 2016 annual mortality report, DBHDD classified and determined primary cause of death based upon physician review and categorization of causes of death. In 2016, DBHDD began presenting an aggregate of all underlying causes of death listed on the death certificate following the methods outlined by the Centers for Disease Control and Prevention (CDC).⁷

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

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

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

⁷ (2017). Retrieved from https://www.cdc.gov/nchs/data/dvs/2a_2017.pdf. Accessed January 10, 2020.

A summary of the causes of death, as recorded within death certificates, follows (**Table 1**). The leading causes of death reported on death certificates among the intellectual and developmental disability waiver population for 2019 are heart diseases, respiratory diseases, disability, sepsis, and pneumonia. These causes of death also appeared as leading causes of death in 2018.

Table 1: Leading Causes of Death⁸

Rank	U.S. (2017)	Georgia (2018)	DBHDD (2019)
1	Heart Diseases (23.0)	Heart Diseases (29.6%)	Heart Diseases (21.7%)
2	Malignant Neoplasms (21.3%)	Malignant Neoplasms (20.4%)	Respiratory Diseases (17.0%)
3	Unintentional Injuries (6.0%)	Respiratory Diseases (10.6%)	Disability (10.5%)
4	Chronic Lower Respiratory Diseases (5.7%)	Nervous System Diseases (9.5%)	Sepsis (7.9%)
5	Cerebrovascular Diseases (5.2%)	External Causes (8.1%)	Pneumonia (5.2%)
6	Alzheimer's Disease (4.3%)	Endocrine, Nutritional, and Metabolic Diseases (4.6%)	Aspiration Pneumonia (4.5%)
7	Diabetes Mellitus (3.0%)	Digestive System Diseases (3.6%)	Cancer (3.9%)
8	Influenza and Pneumonia (2.0%)	Mental and Behavioral Disorders (3.3%)	Neurological Conditions (3.7%)
9	Renal (1.8%)	Reproductive and Urinary System Diseases (3.1%)	Renal (3.1%)
10	Suicide (1.7%)	Infectious and Parasitic Diseases (2.9%)	Gastrointestinal Disease (2.6%)

⁸ Data shown for the U.S. and Georgia include all ages, while the data shown for DBHDD's IDD population are limited to adults only. Percent is given for the overall cause of death, not subcategories within the cause of death. The information presented above is provided for descriptive purposes only. Due to the lack of consistency in categorizing the causes of death and expertise of those completing the death certificates, readers are strongly cautioned against drawing conclusions based on this information. In order to use this information to make conclusions or recommendations regarding system or practice changes, it is necessary to conduct further exploration into available information about individual cases or groups of cases. It is important to understand and consider information, such as the underlying causes of death, the circumstances of the death, the medical care provided prior to the death, co-morbid conditions, and potentially important early detection, screening, and preventive care practices. Data for U.S. mortality is from the CDC (https://www.cdc.gov/nchs/hus/contents2018.htm#Table_006). Data for Georgia mortality is from the Georgia Department of Public Health (<https://oasis.state.ga.us/oasis/webquery/grqMortality.aspx>).

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

At the time of writing this report, updated causes of death were not available for the U.S. and Georgia for 2019. Comparing the IDD population to U.S. mortality data (2017) and Georgia mortality data (2018), heart diseases were the leading cause of death in the general populations of U.S. and Georgia, and heart diseases were also the leading cause of death in 2019 for the IDD population. Chronic lower respiratory diseases were leading causes of death in U.S. and in Georgia. Respiratory diseases and pneumonia (including aspiration pneumonia) also were in the top leading causes of death in the IDD population in 2019. Therefore, as in past years, at least half of the top 10 leading causes of death in the U.S. and Georgia and the most prevalent causes of death in the IDD population in 2019 were similar.

Four of the leading causes of death among the IDD population in 2019 were not common to the top causes of death in the U.S. and Georgia during 2017 and 2018:

- Disability
- Sepsis
- Aspiration pneumonia
- Gastrointestinal disease

INTERPRETING STATISTICAL TESTS

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

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

MORTALITY DURING 2019

This section contains information on deaths reported to DBHDD among the IDD waiver population during calendar year 2019. Calendar years 2017 and 2018 are included for comparison purposes. Appendix A describes the method used to collect and analyze information and data contained in this section.

A search for peer-reviewed research for comparison data yielded data from four states.⁹ Compared to research¹⁰ that used data from Connecticut, Louisiana, Ohio, and New York, the combined crude mortality rate for these states was 14.96 deaths per 1,000 individuals in 2009, which is not significantly different from the 2019 intellectual and developmental disability mortality rate for DBHDD, 16.7 deaths per 1,000. The mortality rate for these states combined

⁹ As of March 2020, DBHDD searched for additional, more recent intellectual and developmental disability mortality reports and published scientific literature for comparison, to no avail.

¹⁰ Lauer, E & McCallion, P. (2015). Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data. *Journal of Applied Research in Developmental Disabilities*, 28, 394-405.

in 2011 was 9.37, which is significantly lower than the DBHDD 2019 mortality rate ($|z| = 7.970$; $p < 0.001$).

DBHDD also compared mortality findings from other states' mortality reports that were available. Tennessee reported mortality rates of 27.4 (fiscal year 2013) and 21.1 (fiscal year 2014) per 1,000.¹¹ Tennessee's 2013 rate was significantly higher than the 2019 DBHDD mortality rate ($|z| = 5.325$; $p < 0.001$), while the 2014 rate was statistically similar. Massachusetts reported a mortality rate of 18.0 deaths per 1,000 in 2015,¹² which was statistically similar to DBHDD's rate. The variability in ranges may reflect the differences in population and criteria of the study, as noted above.

As stated earlier: caution should be used in comparing mortality rates across populations that may differ in terms of inclusion criteria for study. States vary in the eligibility and enrollment criteria, yielding unlike populations, which may complicate meaningful comparisons of mortality rates. For example, Massachusetts¹³ included all individuals who were eligible for services in the study population, regardless of whether they were receiving services. Ohio, Connecticut, and Louisiana include individuals with an IQ above 70 who have functional support needs; however, some of these individuals were receiving only case coordination.¹⁴ DBHDD's report includes only those individuals who have an IQ below 70 and have the higher functional support needs required to receive more intensive services within the NOW/COMP waivers. Reports that include only individuals with a demonstrated, verified higher level of functional impairment (as does this report) may yield higher mortality rates than reports with a more expanded population that includes individuals with less severe functional or support needs. Because eligibility and enrollment criteria are not consistent across states, generalizations and comparisons may lead to insupportable conclusions.

AGE AND MORTALITY

The average ages of death in 2017 and 2018 were 53.48 years (SD = 15.18) and 54.35 (SD = 14.97), respectively. The average age of death in 2019 was 53.22 (SD = 16.77). The average age of death decreased by 1.13 years from 2018 to 2019; however, that change was not statistically significant. This means that individuals who died in 2019 lived about the same length of time as those who died in 2018. The reported average age of death falls within the 2009-2011 range for Connecticut, Louisiana, Ohio, and New York (combined), which was 50.4 to 58.7 years.

As in 2017 and 2018, mortality rates increased with increasing age (**Table 2, Figure 1**). In particular, the mortality rate for individuals between ages 45 and 54 exceeded the overall

¹¹ Tennessee Department of Intellectual and Developmental Disabilities. Annual Mortality Report, 2013-2014 Fiscal Year.

¹² Commonwealth of Massachusetts, Executive Office of Health & Human Services, Department of Developmental Services. 2015 Preliminary Mortality Report.

¹³ Commonwealth of Massachusetts, Executive Office of Health & Human Services, Department of Developmental Services. 2015 Preliminary Mortality Report.

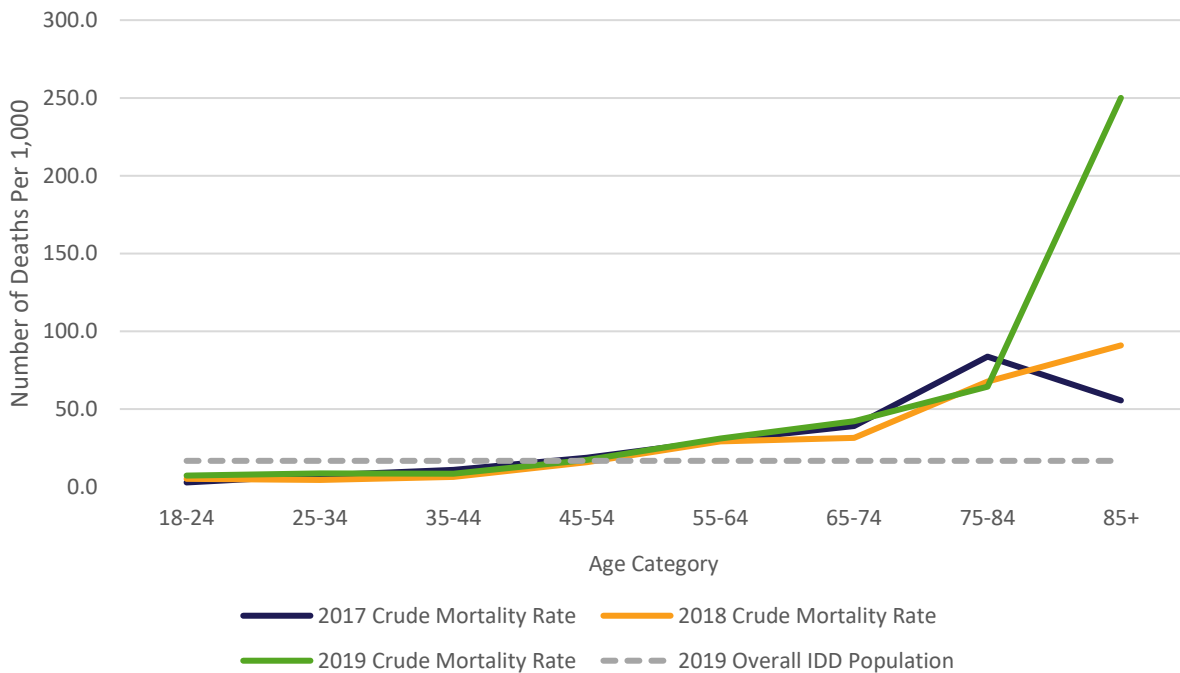
¹⁴ Lauer, E & McCallion, P. (2015). Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data. *Journal of Applied Research in Developmental Disabilities*, 28, 394-405.

mortality rate for the entire population. The same pattern was found in 2017 and 2018. This would imply that the mortality rate consistently rises above the population mortality group in the 45-54 age range.

Table 2: Mortality Rates Among the Adult IDD Waiver Population by Age Category, 2019

Age Category	Population	Deaths (#)	Deaths (%)	Crude Mortality Rate	Significance
18-24	1,247	9	4.1%	7.2	--
25-34	3,743	32	14.5%	8.5	NS
35-44	2,983	25	11.3%	8.4	NS
45-54	2,252	39	17.6%	17.3	z = 2.913; p = 0.004
55-64	1,933	60	27.1%	31.0	z = 2.912; p = 0.004
65-74	852	36	16.3%	42.3	NS
75-84	202	13	5.9%	64.4	NS
85+	28	7	3.2%	250.0	z = 3.267; p = 0.001
Total	13,240	221	100.0%	16.7	--

Figure 1: Mortality Rates by Age Category, 2017-2019¹⁵



The mortality rate for the age group 45-54 increased above the overall mortality rate for the population. From there, the mortality rate increased with age. This pattern did not occur for the 85+ group in 2017, but such a fluctuation is not abnormal for such a small subgroup.

Other research¹⁶ found that mortality rates tend to increase with increasing age, such that younger groups had lower mortality rates, and significant increases in mortality rates were found to begin at 45-54 and increased dramatically with increasing age. For the U.S. population, mortality rates also increase more rapidly with increasing years after about 55 years of age. The 2018 Georgia mortality rate for individuals aged 55-64 is 10.1 deaths per 1,000, and it increases in subsequent age categories.¹⁷

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

¹⁵ The horizontal gray line indicates the crude mortality rate (16.7 per 1,000) for the overall IDD population.

¹⁶ National Vital Statistics Report, Vol. 68 No. 9, June 24, 2019, p. 8.

https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_09-508.pdf, accessed March 13, 2020.

¹⁷ <https://oasis.state.ga.us/oasis/webquery/qryMortality.aspx>, accessed March 13, 2020.

HEALTH RISK AND MORTALITY

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

Table 3: HRST Health Care Levels

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

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

The average HCL for 2019 was 2.52 (SD = 1.52). In 2018, the average HCL was 2.45 (SD = 1.51), and, in 2017, the average HCL was 2.35 (SD = 1.48). The average HCLs across 2017-2017 were each statistically different from each other: 2018 to 2019 ($|t| = 3.736$, $df = 26,151$, $p < 0.001$) showed an increase and 2017 to 2019 ($|t| = 9.074$, $df = 25,695$, $p < 0.001$) also showed an increase. This means that, overall, there is a statistically significant increase in the amount of measured health risk in this population over time.

Similar to previous years, there was a statistical association between HCL and mortality rate in 2019. Individuals with lower HCLs (1-3) had a group mortality rate (7.6 deaths per 1,000) that was below the population mortality rate in 2019 (16.7 deaths per 1,000). Individuals with higher HCLs (4-6) had a group mortality rate (47.5 deaths per 1,000) that exceeded the overall population mortality rate (16.7 deaths per 1,000) by a large margin. The mortality rate for higher HCLs (4-6) was significantly higher than the mortality rate for the lower HCLs (1-3) ($|z| = 15.009$; $p < 0.001$).

Results from previous years have consistently indicated that a two-point increase in HCL is associated with a significant increase in mortality; therefore, attention should be given to a one-point increase in HCL to mitigate the increased risk of mortality associated with a two-point

increase in HCL. Analysis of 2019 data indicate that it is also important to consider a one-point change in health risk scores to address increasing mortality risk. For example, attention should be given to HCL 3 (in addition to HCLs 4, 5, and 6). HCL 4 is the health risk level that moves above the overall population mortality rate. An increase of one HCL above HCL 3 would move individuals into a level of risk more significantly associated with mortality (i.e., HCL 4-6).

Figure 2: Mortality Rates by HCL, 2017-2019¹⁸

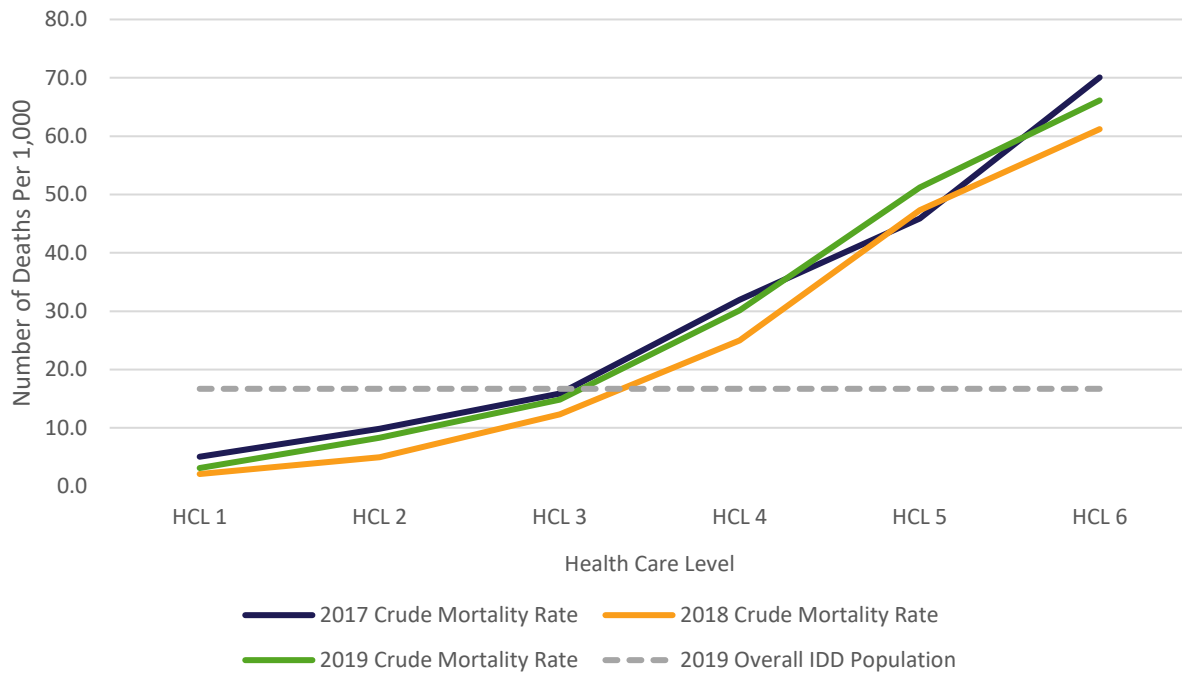


Table 4: Mortality Rates by HCL, 2019¹⁹

HCL	Population	Deaths (#)	Deaths (%)	Crude Mortality Rate	Significance
1	4,166	13	5.88%	3.1	--
2	3,836	32	14.48%	8.3	z = 3.120; p = 0.002
3	2,227	33	14.93%	14.8	NS
4	1,227	37	16.74%	30.2	z = 3.061; p = 0.002
5	801	41	18.55%	51.2	NS
6	983	65	29.41%	66.1	NS
Total	13,240	221	100.0%	16.7	--

¹⁸ The horizontal gray line indicates the crude mortality rate (16.7 per 1,000) for the overall IDD population.

¹⁹ "--" indicates that a statistical test was not conducted. "NS" indicates non-significance.

THE CENTRAL IMPORTANCE OF AGE AND HEALTH RISK²⁰

Health risk and age are important factors that need to be considered when investigating mortality. Within the IDD population, high-level risk tends to be present across all age categories, as well as varying degrees of lower-health risks across all age categories. The relationship between health risk and age is not uniform. HCLs are distributed similarly within each age group. Correlations between age (both as continuous and ordinal variables) indicate the association between HCL and age is weak (Pearson's $r = 0.07$, $p < 0.001$). Though this is statistically significant, the strength of the association between age and health risk is small, which indicates that, for this population, health risk and age are not necessarily meaningfully associated. Therefore, one would also expect that if health risk and age were related to mortality, these variables would have independent (not interactive) effects.

Data analysis to this point has examined variables as they individually relate to mortality. However, it also is important to consider all variables of interest at once to determine the individual effect of each variable on the occurrence of death, while controlling for the influence of other variables. Analyses considered if and how age, gender, region, intensity of residential setting, and health risk (using HCL) were associated with mortality to determine which variables may be of key importance. Such associations were examined using logistic regression.²¹

Non-significant variables were removed from the final model, leaving only age and HCL (**Table 5**). Gender, region, and intensity of residential setting were not significantly related to mortality in 2019. These logistic regression results align with reported results for 2013-2018.

Table 5: Odds Ratios for Final Logistic Regression Model of Mortality on Age and HCL, 2017-2019

Characteristic	2017	2018	2019
	Odds Ratio	Odds Ratio	Odds Ratio
Age	1.05	1.05	1.04
HCL	1.65	1.87	1.75
Pseudo R^2	0.13	0.17	0.14

In 2019, each one-year increase in age was associated with a four percent increase in the odds of dying. Similarly, in 2019, each one-unit increase in HCL was associated with a 75 percent increase in the odds of dying.

²⁰ Tables 5-7 display odds ratios (ORs). These tables report explained variance using pseudo R^2 , a statistical measure of fit that indicates how much variation of a dependent variable (e.g., mortality) is explained by the independent variables in a regression model (e.g., age and HCL). For example, a pseudo R^2 of 1.00 (or 100%) would mean that mortality is completely explained by the independent variables included in each model. Coefficients for Tables 5-7 are available on request.

²¹ Several advantages of using logistic regression exist. First, logistic regression allows one to determine the association of a variable without the influence of other variables. For example, logistic regression analysis about age pertains only to the effects of age and mortality without the effect of other variables. In this way, each variable is risk-adjusted so that the effects of other variables do not affect it. Another advantage is that logistic regression can be used to determine the importance of each variable and can be easily interpreted using odds ratios. An odds ratio is a measure of association between a variable and an outcome occurring. The odds ratio represents the odds of death occurring given a particular event or condition compared to the odds of death occurring in the absence of that variable.

These results are similar when treating HCL and age in a different manner (i.e., as categorical variables; **Tables 6-7**). For example, in 2019, individuals with HCLs of 2, 3, 4, 5, and 6 had greater odds of mortality, relative to individuals with an HCL of 1 (**Table 6**). Results are similar for 2017-2018, with the exception of HCL 2, which became statistically significant in 2019.

Table 6: Odds Ratios for Logistic Regression Model of Mortality on HCL, 2017-2019

HCL	2017	2018	2019
	Odds Ratio	Odds Ratio	Odds Ratio
1	1 [Reference]	1 [Reference]	1 [Reference]
2	1.96	2.43	2.69
3	3.18	5.97	4.81
4	6.49	12.31	9.93
5	9.45	23.78	17.23
6	14.81	31.24	22.62
Pseudo R²	0.08	0.12	0.10

In 2019, individuals in the following age categories had greater odds of mortality, relative to individuals aged 25-34: 45-54, 55-64, 65-74, 75-84, and 85+ (**Table 7**). Individuals aged 18-24 and 35-44 (as compared to those aged 25-34) had statistically equivalent odds of mortality. Results are similar for 2017-2018.

Table 7: Odds Ratios for Logistic Regression Model of Mortality on Age, 2017-2019

Age	2017	2018	2019
	Odds Ratio	Odds Ratio	Odds Ratio
18-24	0.30	1.16	0.84
25-34	1 [Reference]	1 [Reference]	1 [Reference]
35-44	1.53	1.44	0.98
45-54	2.42	3.69	2.04
55-64	3.52	6.84	3.72
65-74	4.21	7.39	5.12
75-84	8.04	16.53	7.98
85+	7.34	22.79	38.7
Pseudo R²	0.13	0.07	0.06

The sections above presented findings and observations based on a statistical analysis of all adults with a primary IDD diagnosis who received services funded by NOW/COMP waivers during the 2019 calendar year. Statistical analyses are useful for identifying variables and trends that are associated with mortality, which provide information for improvement of service quality. It is worth noting that, among the 2019 IDD population, death was a relatively rare outcome. Large increases in odds (such as with the upper values of HCL and age) do not necessarily mean that individuals with these attributes were in great danger of death; it only means that people in those groups were more likely than others to experience death. It is also worth noting that statistical

association does not indicate causation. (Please refer to the discussion about statistical analysis in the section titled “Interpreting Statistical Tests.”)

COMMUNITY MORTALITY REVIEW COMMITTEE AND DEFICIENT PRACTICE ANALYSIS

BACKGROUND

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

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

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

STATEWIDE ANALYSIS OF NUMBER AND TYPE OF CMRC-RELATED DEFICIENT PRACTICES

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

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

In 2019, there were 170 practices entered into CATS that were identified as moderate risk, defined as having the potential to result in no more than minimal physical, mental, or psychosocial discomfort. Providers were required to submit corrective action plans for these. One hundred sixty practices entered into CATS were identified as low risk. Providers were

requested to correct these deficiencies without submitting a formal corrective action plan to DBHDD. Recommendations made as the result of a CMRC review are also sent to the provider. DBHDD requests providers respond to or comment on recommendations identified as the result of CMRC reviews; however, no formal corrective action plan is required for recommendations.

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

CRITICAL RISK: STATEWIDE

Critical-risk deficient practices entered into CATS centered on individual care and prevention, performance monitoring report, and program planning and leadership (**Table 8**). As mentioned earlier, DBHDD requires providers to submit a corrective action plan to address critical-risk deficient practices.

Table 8: Statewide Critical-Risk Count, 2019

Critical Risk	26
Individual Care & Prevention	11
Assessments & Treatment Plans	1
Coordination of Care	4
Medical Care Needs	1
Medication Management	2
Response to Emergency/Change in Condition	3
Performance Monitoring Report	12
Compliance	12
Program Planning & Leadership	3
Human Resources & Training	3

HIGH RISK: STATEWIDE

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

Table 9: Statewide High-Risk Count, 2019

High Risk	98
Individual Care & Prevention	63
Assessments & Treatment Plans	25
Coordination of Care	4
Documentation	4
Medical Care Needs	1
Medication Management	25
Response to Emergency/Change in Condition	4
Performance Monitoring Report	8
Compliance	8
Physical Environment & Safety	2
Physical Hazards & Safety Issues	2
Program Planning & Leadership	25
Documentation	2
Financial Management	2
Human Resources & Training	12
Quality Improvement/Risk Management	4
Supervision & Oversight	5

REGIONAL ANALYSIS OF NUMBER AND TYPE OF CRITICAL AND HIGH DEFICIENT PRACTICES

Regions 3, 5, and 6 had the largest number of identified critical deficient practices and accounted for 84.6 percent of critical-risk deficient practices identified. Regions 2, 3, and 4 had the highest number of deficient practices that were identified as having high risk to individuals, accounting for 75.5 percent of the high-risk deficient practices.

Table 10: Regional Analysis of Number and Type of Deficient Practices, 2019²²

Region	Population	Critical-Risk Deficiencies (#)	Critical-Risk Deficiencies (%)	High-Risk Deficiencies (#)	High-Risk Deficiencies (%)
1	2,995	1	3.9%	2*	2.0%
2	2,293	1	3.9%	16	16.3%
3	3,347	4	15.4%	34	34.7%
4	1,406	2	7.7%	24*	24.5%
5	1,617	15*	57.7%	9	9.2%
6	1,813	3	11.5%	13	13.3%
Total	13,471	26	100.0%	98	100.0%

²² Asterisks indicate statistically significant differences in the number of deficient practices between individual regions and the overall state.

The main points concerning deficient practices identified in the course of CMRC reviews, when considering the 124-combined critical- and high-risk practices conjointly, one notices substantial overlap in one area: individual care and prevention, which constituted 59.7 percent of all critical- and high-risk deficient practices.

Though corrective action plans are intended to remediate deficient practices and mitigate further risk, the prevalence (59.7%) of the abovementioned common deficient practices may indicate additional areas for systemic improvement.

KEY FINDINGS

Below is a summary of the key findings identified in the 2019 Annual Mortality Report:

- The 2019 DBHDD NOW/COMP waiver mortality rate was 16.7 deaths per 1,000 individuals. The 2019 mortality rate did not differ significantly from the DBHDD NOW/COMP waiver mortality rates in 2017 and 2018.
- Increasing age was significantly associated with mortality.
- Increasing health risk was significantly associated with mortality.
- Mortality increased markedly for individuals in the 45-54 age group. Increased risk of mortality due to increasing age is also found in the general U.S. and Georgia populations.
- Life expectancy for the 2019 NOW/COMP waiver population (53.2 years) is comparable to the average age of death for intellectual and developmental disability populations as reported in other state mortality reports and in published, peer-reviewed research (50.4 to 58.7 years).
- Heart diseases were the leading cause of death in the general populations of U.S. (2017) and Georgia (2018), as well as DBHDD's NOW/COMP waiver population (2019). As in past years, most leading causes of death in the U.S. and Georgia and the most prevalent causes of death in the NOW/COMP waiver population in 2019 were similar: heart diseases, cancer, respiratory diseases, renal, pneumonia, and neurological conditions.
- Four of the leading causes of death for DBHDD's IDD population were not common to the top causes of death in the U.S. and Georgia: disability, sepsis, aspiration pneumonia, and gastrointestinal diseases.
- The most common critical- and high-risk deficient provider practices centered on individual care and prevention, including assessments and treatment plans, medical care needs, medication management, coordination of care, and failure to respond to an emergency or change in condition in a manner that would protect the welfare of the individual.
- Most providers had none or very few deficient practices (from CMRC reviews) that were identified to pose risk to individuals.

APPENDIX A: METHOD FOR MORTALITY REVIEW AND ANALYSIS

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

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

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

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

Individuals who moved between the NOW/COMP waiver during 2019 were categorized into the waiver in which they were last enrolled.

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

For these analyses, the following information was included:

- Region (WIS, IDD Connects)
- Medicaid number (WIS, IDD Connects)
- Date of birth (WIS, IDD Connects)
- Date of death (ROCI, Image)
- Residential setting (WIS, IDD Connects)
- Cause of death (if known) (death certificates)
- Whether death was referred for investigation (ROCI, Image)
- Whether a mortality review was completed (CMRC)

- Health risk scores (HCLs from Health Status Risk Screening Tool)
- Tracking of deficient practices and corrective action plans related to CMRC (CATS)

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

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

CRUDE MORTALITY RATE

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

Deaths were included, regardless of death category, for all population-eligible adults who died in 2019.

ANALYSIS AND MEASURES

Analyses were conducted using Stata version 15,²³ including tests of significance and logistic regression. In order to facilitate the interpretation of coefficients and odds ratios, variables were not transformed. The variables used for the logistic regression follow:

- **Death** (outcome): 0 = No death; 1 = Death
- **Age**: Continuous (ranging from 18 to 95; Table 5); Categorical (18-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+; Table 7)
- **Gender**: 0 = Female; 1 = Male
- **Region**: Categorical (Region 1, Region 2, Region 3, Region 4, Region 5, Region 6)
- **Health Risk (using HRST Health Care Level [HCL])**: Continuous (ranging from 1-6; Table 5); Categorical (HCL 1, HCL 2, HCL 3, HCL 4, HCL 5, HCL 6; Table 6)
- **Intensity of Residential Setting**: 0 = Lower Intensity (independent apartment/home; live with family/relative/caretaker/friend/other; other); 1 = Higher Intensity (personal care home; community living arrangement; host home)

All variables were entered into regression models individually, and the variables were examined for significant association with death. Variables that were indicated as not being significantly

²³ StataCorp. 2017. *Stata Statistical Software: Release 15*. College Station, TX: StataCorp LLC.

associated with death were removed, and the model was recomputed. Those variables that were indicated as significantly associated with death were retained in the model. This process continued until only significantly associated variables with death remained. Finally, the model was examined for meaningful relationships and interpretation.

The data for 2019 included a mix of records from WIS and IDD Connects. At the time of writing, only WIS data for intensity of residential setting were suitable for analysis. For this reason, a separate regression model was computed. Similar to previous years, intensity of residential setting was not significantly associated with mortality and was removed from the final model. The separate model for this analysis is not shown but is available by request.

APPENDIX B: NOW/COMP POPULATION DEMOGRAPHICS

CHARACTERISTICS OF THE INTELLECTUAL AND DEVELOPMENTAL DISABILITY WAIVER POPULATION

Below is a brief demographic description of the 2019 IDD waiver population:

- The total number of unduplicated IDD individuals with active NOW/COMP waivers in 2019 was 13,267; however, this analysis excluded individuals who had missing HCL data (n = 27), resulting in a final sample size of 13,240.
- These individuals were aged 18-95, with a mean age of 42.1.
- Of these, 59.2 percent were male and 40.9 percent were female.
- Region 3 (24.9%) was the most populous region, followed by Region 1 (22.3%), Region 2 (17.0%), Region 6 (13.5%), Region 5 (11.9%), and Region 4 (10.4%).
- Most of the population had COMP waivers (64.6%) as opposed to NOW waivers (35.4%).

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

Table 11: Characteristics of the Adult IDD Waiver Population, 2017-2019²⁴

Characteristic	2017		2018		2019	
	n	%	n	%	n	%
Age						
18-24	1,058	8.5	1,182	9.2	1,247	9.4
25-34	3,508	28.2	3,663	28.4	3,743	28.3
35-44	2,783	22.4	2,872	22.3	2,983	22.5
45-54	2,284	18.4	2,260	17.5	2,252	17.0
55-64	1,838	14.8	1,889	14.7	1,933	14.6
65-74	743	6.0	796	6.2	852	6.4
75-84	203	1.6	207	1.6	202	1.5
85+	18	0.1	22	0.2	28	0.2
Gender						
Male	7,318	58.9	7,622	59.1	7,832	59.2
Female	5,117	41.2	5,269	40.9	5,408	40.9
Region						
Region 1	2,612	21.0	2,758	21.4	2,950	22.3
Region 2	2,140	17.2	2,221	17.2	2,252	17.0
Region 3	3,148	25.3	3,251	25.2	3,290	24.9
Region 4	1,287	10.4	1,325	10.3	1,380	10.4
Region 5	1,519	12.2	1,562	12.1	1,581	11.9
Region 6	1,729	13.9	1,774	13.8	1,787	13.5
Waiver Type						
NOW	4,339	34.9	4,538	35.2	4,690	35.4
COMP	8,096	65.1	8,353	64.8	8,550	64.6
Residential Setting						
Lower Intensity	8,110	65.2	8,461	65.6	--	--
Higher Intensity	4,325	34.8	4,430	34.4	--	--
Total	12,435	100.0	12,891	100.0	13,240	100.0

²⁴ Shown for each characteristic are totals and percentages. Total percentages may not total to 100.0 because of rounding. Residential setting was not available for all waiver participants in 2019.