Annual IDD Mortality Report 2020

GEORGIA DEPARTMENT *of*

BEHAVIORAL HEALTH *and* DEVELOPMENTAL DISABILITIES

Office of Performance Analysis

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EXECUTIVE SUMMARY

This report includes data and information concerning adults who died during calendar year 2020 (CY20) while receiving intellectual and developmental disability (IDD) Medicaid waiver services from the Georgia Department of Behavioral Health and Developmental Disabilities ("DBHDD" or "the department") and its contracted providers.

An analysis of individual deaths and trends in mortality is a component of health and safety oversight and is part of DBHDD's quality management and improvement system. This is the seventh annual mortality report released by DBHDD. The purpose of this report is to provide CY20 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.

MAJOR FINDINGS

In calendar year 2020, DBHDD served 13,362 adults with intellectual and developmental disabilities in waiver services.[1] A total of 217 deaths occurred in 2020, resulting in a crude mortality rate of 16.2 deaths per 1,000 individuals.[2, 3] The respective mortality rates for 2018 and 2019 were 13.3 and 16.7 deaths per 1,000 individuals. The mortality rates do not differ significantly across the last three years.

As in previous years, most of the 10 leading causes of death for general populations of the United States or Georgia were also common with leading causes of death in the IDD population. Common causes of death for general and IDD populations included the following six:

- Heart diseases
- Respiratory diseases
- COVID-19
- Cancer
- Renal diseases

[1] The total number of unduplicated IDD individuals with active NOW/COMP waivers in 2020 was 13,370; however, this analysis excluded individuals who had missing health risk data (n = 8).

[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.

- Pneumonia.

Four of the 10 leading causes of IDD deaths in 2020, as in previous years were not common to the general population:

- Sepsis
- Disability
- Aspiration pneumonia
- Seizures.

Several variables were analyzed to determine their association with mortality in 2020. These included age, gender, health risk, residential setting, and region. Major analytical findings from 2020 mirror those from 2018 through 2019: increasing health risk and increasing age were most strongly associated with mortality, while gender, residential setting, region, COVID-19, and other variables were not related to mortality.

Statistical analyses of the NOW/COMP 2020 population in this Annual Mortality Report indicated COVID-19 was not significantly related to mortality in 2020 for DBHDD individuals. A limitation to the lack of association between COVID-19 and mortality in the Annual IDD Mortality Report is the low number of deaths in the target population that occurred due to COVID-19. Oftentimes, it is difficult to reach definitive associations with low numbers of events; consequently, this finding is tentative. Therefore, DBHDD conducted additional analyses to understand better the relationship between COVID-19 and the population we served, which revealed that the crude, overall mortality rate of the IDD population that includes COVID-19 deaths does not differ significantly from the COVID-19 crude mortality rate which removes the deaths due to COVID-19 from the analyses. Sentinel research about COVID-19's impact on the IDD population is beginning to emerge, and DBHDD will continue to follow the research while also continuing to contribute to the knowledgebase and advance the sophistication of how we understand and apply what is known about mortality trends for people with IDD, as well as the impact of COVID-19 (and other variables).

DBHDD's Community Mortality Review Committee (CMRC) uses a standardized, systematic process to conduct mortality reviews to identify opportunities to reduce morbidity, mortality, and identify opportunities to improve the quality of services. CMRC data review identified low-, moderate-, high-, and critical-risk provider deficient practices, defined below:

- Low-risk provider deficient practice: an issue, regardless of frequency, that has little to no impact or a unique issue that resulted in or had the potential to result in mild/moderate impact.
- Moderate-risk provider deficient practice: a repeated issue that resulted in or had the potential to result in mild/moderate impact.
- High-risk provider deficient practice: an issue, regardless of frequency, that resulted in or had the potential to result in significant harm.
- Critical-risk provider deficient practice: a situation that has caused or is likely to cause serious injury, harm, impairment, or death.

Most providers had no or very few deficient practices that were identified as posing risk to individuals based on Community Mortality Review Committee (CMRC) findings. The most common provider deficiencies that required corrective action were linked to individual care and prevention (80.1% of all critical/high deficiencies). This category of deficiency includes citations related to 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. These provider deficiency types account for 285 of the 352 identified high- or critical-risk deficient practices.

PURPOSE AND SCOPE OF THIS REPORT

This is the seventh annual report on mortality, mortality trends, and related information pertaining to individuals on NOW/COMP waivers served by DBHDD during calendar year 2020. The report focuses on an analysis of mortality data and findings from DBHDD's mortality review process. Reports are scheduled for publication in August of each year and cover the prior calendar year of January 1 through December 31. A description of the chosen method and the analysis conducted in the report can be found in Appendix A.

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.

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

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

consider other theoretically-sound methods and procedures to understand or address missing data.[5]

- Third, in some cases, DBHDD utilizes some form of random sampling[6] (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 results based on purposive sampling are not generalizable to the full population, rather only to the cases from which data were sampled.

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. When the entire population is not used in the analyses, DBHDD relies upon practical application of scientific, statistical, and theory-based techniques and procedures to yield inferences about the population based on a sample smaller than the population that increases the chances that the sample has sufficient size and power to identify and draw valid conclusions from the data and generalize to the larger system.

[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.

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 individual's family.

Prior to the 2016 annual mortality report, DBHDD classified and determined primary causes of death based upon physician review and categorization of causes of death. Starting with the 2016 annual mortality report, 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.

A summary of the causes of death, as recorded within death certificates follows (**Table 1**). Additional analysis of COVID-19 deaths is presented later in this report.

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

Table 1: Leading Causes of Death[8]

Rank	U.S. (2020) provisional[9]	Georgia (2019)	DBHDD (2020)
1	Heart Diseases (20.6%)	Heart Diseases (30.0%)	Heart Diseases (19.0%)
2	Malignant Neoplasms (17.8%)	Malignant Neoplasms (20.6%)	Respiratory Diseases (16.8%)
3	COVID-19 (10.3%)	Respiratory Diseases (9.7%)	COVID-19 (9.0%)
4	Unintentional Injuries (5.7%)	Nervous System Diseases (9.5%)	Sepsis (8.0%)
5	Respiratory Diseases (4.5%)	External Causes (8.2%)	Disability (6.7%)
6	Alzheimer's Disease (4.0%)	Endocrine, Nutritional, and Metabolic Diseases (4.6%)	Pneumonia (5.9%)
7	Diabetes Mellitus (3.0%)	Digestive System Diseases (3.7%)	Aspiration Pneumonia (4.1%)
8	Influenza and Pneumonia (1.6%)	Reproductive and Urinary System Diseases (3.1%)	Cancer (3.1%)
9	Renal (1.6%)	Mental and Behavioral Disorders (3.1%)	Seizures (2.8%)
10	Suicide (1.3%)	Infectious and Parasitic Diseases (2.9%)	Renal (2.3%)

At the time of writing this report, updated causes of death were not available for Georgia for 2020. On March 31, 2021, the CDC released preliminary causes of death information for 2020 in the United States.[9]

[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 typically from the CDC (https://www.cdc.gov/nchs/hus/contents2018.htm#Table_006). This year, provisional data were used (reference below) to include COVID-19 analysis.
Department of Health and Human Services/Centers for Disease Control and Prevention. Data for Georgia mortality is from the Georgia Department of Public Health (https://oasis.state.ga.us/oasis/webquery/qryMortality.aspx).
Farida B. Ahmad, MPH; Robert N. Anderson, PhD (2021) The Leading Causes of Death in the US for 2020

[9] Ahmad, F. B., Cisewski, J. A., Minino, A. & Anderson, R. N. (2021) "Provisional Mortality Data—United States, 2020." *Morbidity and Mortality Weekly Report, 70, 4*, pp. 519-522: Department of Health and Human Services/Centers for Disease Control and Prevention. https://www.cdc.gov/mmwr/volumes/70/wr/pdfs/mm7014e1-H.pdf, accessed April 15, 2021.

As in previous years, most of the 10 leading causes of death for general populations of the United States or Georgia were also common with leading causes of death in the IDD population. Common causes of death for general and IDD populations included the following six:

- Heart diseases
- Respiratory diseases
- COVID-19
- Cancer
- Renal diseases
- Pneumonia.

Four of the 10 leading causes of IDD deaths in 2020, as in previous years were not common to the general population:

- Sepsis
- Disability
- Aspiration pneumonia
- Seizures.

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.

IDD MORTALITY DURING CY2020

This section contains information on deaths reported to DBHDD among the IDD waiver population during calendar year 2020. Calendar years 2018 and 2019 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 seven states.[10] Compared to research[11] 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 2020 intellectual and developmental disability mortality rate for DBHDD, 16.2 deaths per 1,000. The mortality rate for these states combined in 2011 was 9.37, which is significantly lower than the DBHDD 2020 mortality rate ($|z| = 7.092$; $p < 0.001$).

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.[12] Tennessee's 2013 rate was significantly higher than the 2020 DBHDD mortality rate ($|z| = 5.473$; $p < 0.001$), while the 2014 rate was statistically similar. Massachusetts reported a mortality rate of 18.0 deaths per 1,000 in 2015,[13] which was statistically similar to DBHDD's rate. Virginia DBHDS reported a mortality rate of 20.4 deaths per 1,000 in fiscal year 2017,[14] 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, Massachusetts[14] 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.[15] DBHDD's report includes only those individuals who have an IQ below 70 and have the higher functional support needs required to receive 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

[10] 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.

[11] 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.

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

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

[14] Results of analyses of deaths in FY17 of service recipients of Virginia Department of Behavioral Health & Developmental Services (DBHDS).

[15] 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.

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 2018 and 2019 were 54.35 (SD = 14.97) and 53.22 (SD = 16.77), respectively. The average age of death in 2020 was 54.40 (SD = 15.21). The average age of death increased from 2019 to 2020; however, that change was not statistically significant. This means that individuals who died in 2020 lived about the same length of time as those who died in 2019.

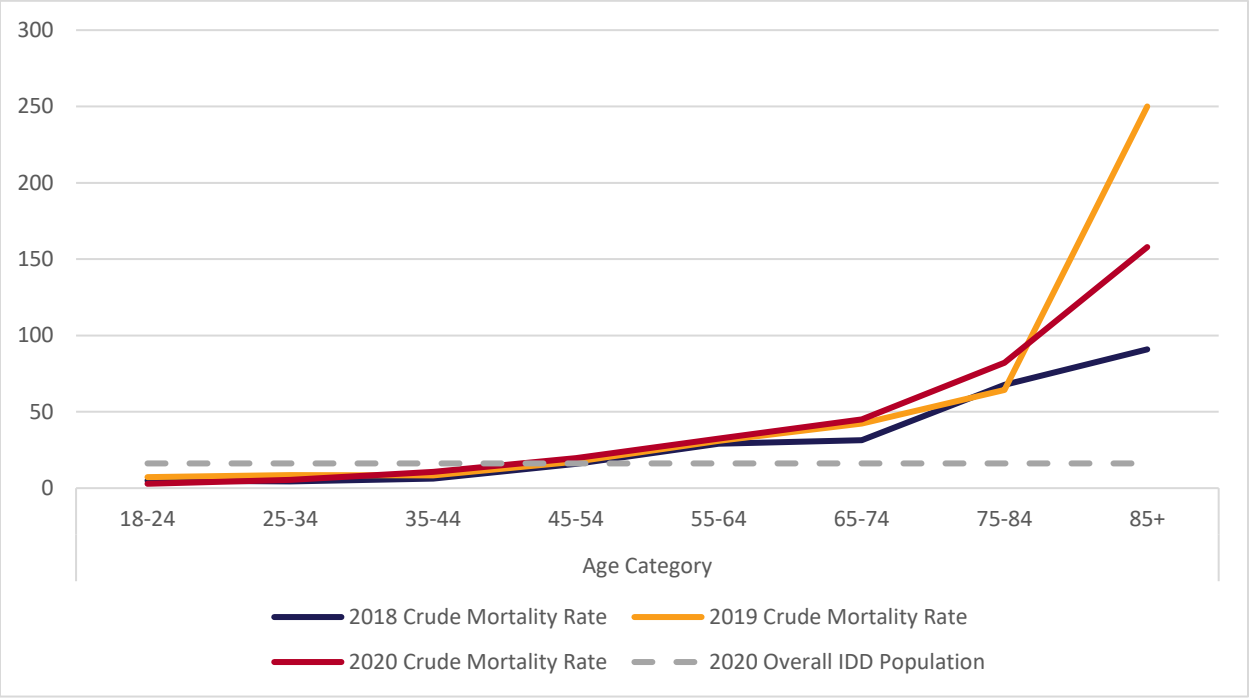
As in 2018 and 2019, mortality rates increased with increasing age (**Table 2, Figure 1**). In particular, the mortality rate for individuals between ages 45 and 54 exceeded the overall mortality rate for the entire population. A different pattern emerged in 2020: no significant increases between age groups emerged until 45-54, which increased significantly; then, 55-64 age group increased significantly over the 45-54. No significant differences existed between any other consecutive age groups. This would imply that the mortality rate consistently rises above the population mortality group in the combined 45-64 age range.

Table 2: Mortality Rates Among the Adult IDD Waiver Population by Age Category, 2020[16]

Age Category	Population	Deaths (#)	Deaths (%)	Crude Mortality Rate	Significance
18-24	1,398	4	1.8%	2.9	--
25-34	3,855	21	9.7%	5.4	NS
35-44	2,998	32	14.7%	10.7	NS
45-54	2,192	43	19.8%	19.6	$\|z\| = 2.667$; $p = 0.004$
55-64	1,882	61	28.1%	32.4	$\|z\| = 2.582$; $p = 0.005$
65-74	823	37	17.1%	45.0	NS
75-84	195	16	7.4%	82.1	NS
85+	19	3	1.4%	157.9	NS
Total	**13,362**	**217**	100.0%	16.2	--

[16] "--" indicates that a statistical test was not conducted. "NS" indicates non-significance.

Figure 1: Mortality Rates by Age Category, 2018-2020[17]



The mortality rate for the age group 45-54 increased above the overall mortality rate for the population. One can see from the graphic, mortality rates increased with age across the entire age range, and visually at least, the mortality rates began increasing more dramatically after ages 45-54.

This report's findings were supported by other research[18] which 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. For 2019, Georgia's mortality rate for individuals aged 55-64 is 10.1 deaths per 1,000, and it increases in subsequent age categories.[19]

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.

[17] The horizontal gray line indicates the crude mortality rate (16.7 per 1,000) for the overall IDD population.
[18] 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.
[19] 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. 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 2020 was 2.59 (SD = 1.54). In 2019, the average HCL was 2.52 (SD = 1.52), and, in 2018, the average HCL was 2.45 (SD = 1.51). The average HCLs across 2018-2020 were each statistically different from each other: 2019 to 2020 ($|t| = 3.689$, df = 25,998, $p = < 0.001$) showed an increase and 2018 to 2020 ($|t| = 7.401$, df = 25,723, $p < 0.001$) also showed an increase. This means that, overall, there is a statistically significant increase in the amount of measured health risk in the IDD population over time.

Similar to previous years, there was a statistical association between HCL and mortality rate in 2020. Individuals with lower HCLs (1-3) had a group mortality rate (8.7 deaths per 1,000) that was below the population mortality rate in 2020 (16.2 deaths per 1,000). Individuals with higher HCLs (4-6) had a group mortality rate (39.5 deaths per 1,000) that exceeded the overall population mortality rate (16.2 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) ($|t| = 371.445$, df = 13,360, $p < 0.001$).

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. The data also reflected this in 2020.

Figure 2: Crude Mortality Rates by HCL, 2018-2020[20]

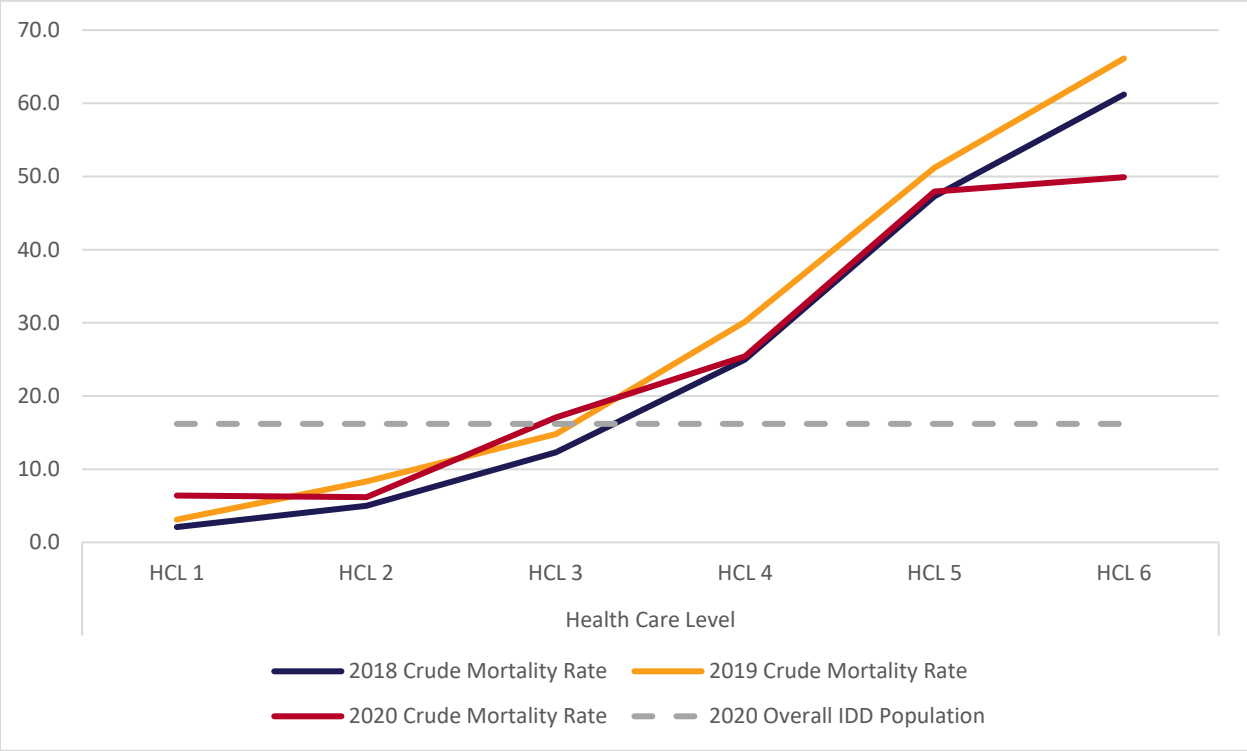


Table 4: Mortality Rates by HCL, 2020[21]

HCL	Population	Deaths (#)	Deaths (%)	Crude Mortality Rate	Significance
1	3,903	25	11.5%	6.4	--
2	3,881	24	11.1%	6.2	$\|z\| = 4.129$; $p = 0.000$
3	2,341	40	18.4%	17.1	NS
4	1,298	33	15.2%	25.4	$\|z\| = 2.836$; $p = 0.002$
5	897	43	19.8%	47.9	NS
6	1,042	52	24.0%	49.9	NS
Total	**13,362**	**217**	**100.0%**	**16.2**	**--**

[20] The horizontal gray line indicates the crude mortality rate (16.7 per 1,000) for the overall IDD population.
[21] "--"indicates that a statistical test was not conducted. "NS" indicates non-significance.

THE CENTRAL IMPORTANCE OF AGE AND HEALTH RISK[22]

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 = 0.05, $p < 0.001$). 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, having a COVID-19 diagnosis, 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.[23]

Non-significant variables were removed from the final model, leaving only age and HCL (**Table 5**). Gender, region, intensity of residential setting, and a COVID-19 diagnosis were not significantly related to mortality in 2020. These logistic regression results align with reported results for 2018-2019. (The lack of association between COVID-19 and mortality in this year's annual mortality report is discussed in a later section of this report.)

Table 5: Odds Ratios for Final Logistic Regression Model of Mortality on Age and HCL, 2018-2020

Characteristic	2018	2019	2020
	Odds Ratio	Odds Ratio	Odds Ratio
Age	1.05	1.04	1.05
HCL	1.87	1.75	1.59
Pseudo R^2	**0.17**	**0.14**	**0.13**

[22] 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.

[23] 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.

In 2020, each one-year increase in age was associated with a five percent increase in the odds of dying. Similarly, in 2020, each one-unit increase in HCL was associated with a 59 percent increase in the odds of dying. These results are similar when treating HCL and age in a different manner (i.e., as categorical variables; **Tables 6-7**). For example, in 2020, individuals with HCLs of 3, 4, 5, and 6 had greater odds of mortality, relative to individuals with an HCL of 1 (Table 6).

Results are similar for 2018-2019, with the exception of the odds ratio for HCL = 2, which became statistically significant at a lower value in 2020. The exception of the association of HCL = 2 is possibly due to attenuation by all HCL levels being at risk for COVID-19.

Table 6: Odds Ratios for Logistic Regression Model of Mortality on HCL, 2018-2020

HCL	2018	2019	2020
	Odds Ratio	Odds Ratio	Odds Ratio
1	1 [Reference]	1 [Reference]	1 [Reference]
2	2.43	2.69	0.97
3	5.97	4.81	2.70
4	12.31	9.93	4.05
5	23.78	17.23	7.81
6	31.24	22.62	8.15
Pseudo R^2	**0.12**	**0.10**	**0.07**

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**). In 2020, individuals in the following age categories had greater odds of mortality, relative to individuals aged 35-44: 45-54, 55-64, 65-74, 75-84, and 85+ (**Table 7**). Individuals aged 18-24 (as compared to those aged 25-34) had statistically equivalent odds of mortality. Results are similar for 2018-2019.

Table 7: Odds Ratios for Logistic Regression Model of Mortality on Age, 2018-2020

Age	2018	2019	2020
	Odds Ratio	Odds Ratio	Odds Ratio
18-24	1.16	0.84	0.52
25-34	1 [Reference]	1 [Reference]	1 [Reference]
35-44	1.44	0.98	1.97
45-54	3.69	2.04	3.65
55-64	6.84	3.72	6.12
65-74	7.39	5.12	8.59
75-84	16.53	7.98	16.32
85+	22.79	38.7	34.23
Pseudo R^2	**0.07**	**0.06**	**0.07**

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 2020 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 2020 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.

EXCESS MORTALITY DUE TO COVID-19

COVID-19 was the third leading cause of death in the United States in 2020 (based on preliminary data), and COVID-19 was the third leading cause of death in the NOW/COMP IDD population in 2020. COVID-19 was reported as the underlying cause of death or a contributing cause of death for an estimated 377,883 (10.3%) of the 3,358,814 deaths occurred in the United States.[24] Results from the same study of 64,858,460 individuals (including 128,074 with IDD) across 547 healthcare organizations, showed that individuals with intellectual disabilities were 2.5 times more likely to contract COVID-19.[25]

Within the DBHDD NOW/COMP IDD population in 2020, COVID-19 was reported as the underlying cause of death for 35 (9.0%) of the 217 deaths that occurred in the NOW/COMP IDD population in 2020. Statistical analyses of the NOW/COMP 2020 population in this Annual Mortality Report indicated, however, COVID-19 was not significantly related to mortality in 2020 for DBHDD individuals. A limitation to the lack of association between COVID-19 and mortality in the Annual IDD Mortality Report is the low number of deaths that occurred due to COVID-19. Oftentimes, it is difficult to reach definitive associations with low numbers of events; therefore, this finding is tentative. Therefore, DBHDD sought to understand the impact of COVID-19 on the IDD population we serve by comparing the overall crude mortality rate to the mortality rate that adjusts for COVID-19 (COVID-19-adjusted mortality rate) to provide additional information.

One way to understand the impact of COVID-19 on this population is to compare the crude mortality rate with the COVID-19-adjusted mortality rate, which is the mortality rate without the deaths due to COVID-19. To adjust the 2020 mortality rate, the count of COVID-19 deaths is removed from the numerator and denominator. The COVID-19-adjusted mortality rate would be 182 non-COVID-19 deaths (217 total deaths – 35 COVID-19 deaths = 182 non-COVID-19 deaths) and 13,327 COVID-19-adjusted population (13,362 population– 35 COVID-19 deaths = 13,327 COVID-19-adjusted population). The COVID-19-adjusted mortality rate would be 13.7 deaths per 1,000. The COVID-19-adjusted 2020 mortality rate 13.7 deaths per 1,000 is significantly lower than the crude mortality rate of 16.2 deaths per 1,000 (which includes COVID-19). Therefore, even with the statistically significant mortality due to COVID-19 in 2020, the 2020 crude mortality rate did not differ significantly from the 2019 crude mortality rate.

[24] Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. (2021). "The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States," *New England Journal of Medicine Catalyst*, March 5: 10. Published online 2021 Mar 5. doi: 10.1056/CAT.21.0051. Accessed April 16, 2021.

Our current point-in-time, relatively small sample size, and lack of tested models limit further conclusive and data-based conclusions. DBHDD will continue to follow the research, continuing to contribute to the knowledgebase and advance the sophistication of how we understand and apply what is known about mortality trends for people with IDD, as well as the impact of COVID-19 (and other variables).

COMMUNITY MORTALITY REVIEW COMMITTEE RELATED DEFICIENT PRACTICE ANALYSIS

BACKGROUND

DBHDD's Community Mortality Review Committee (CMRC) uses a standard process to conduct interdisciplinary 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 harm, which include moderate-, high-, and critical-risk practices.

Deficiencies are tracked in DBHDD's Corrective Action Tracking System (CATS). This database maintains information about deficient practices, entities cited, and categorization of the deficiencies (e.g., low, moderate, high, or critical risk). 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.[25]

STATEWIDE ANALYSIS OF NUMBER AND TYPE OF CMRC RELATED DEFICIENT PRACTICES[26]

The analysis of deficient practices and deficiency tracking presented below is based on deficient practices entered into CATS that were related to deaths that were reviewed by CMRC. Not all deaths are reviewed by the CMRC; the CMRC reviews unexpected deaths, suicides, and expected deaths at the discretion of the investigations director or medical director.

In 2020, 560 deficient practices entered into CATS were identified as low risk, defined as an issue, regardless of frequency, that has little to no impact or a unique issue that resulted in or had the potential to result in mild/moderate impact. Recommendations made are also sent to the provider. For low-risk deficient practices, DBHDD requests providers respond to or comment on identified recommendations; however, no formal corrective action plan is required for recommendations.

[25] Internal and External Reviews and Corrective Action Plans, 13-101

[26] Due to small sample sizes, statistical analysis is not advisable. The reader is cautioned from generalizing findings and observations from the analyses below to the DBHDD intellectual and developmental disability population.

There were 1,401 practices entered into CATS that were identified as moderate risk, defined as a repeated issue that resulted in or had the potential to result in mild/moderate impact. Providers were required to develop internal corrective action plans for moderate-, high-, and critical-risk deficient practices.

The next part of this section focuses on providing analysis of high- and critical-risk deficient practices—the ones with the most potential for adverse outcomes. High risk is defined as an issue, regardless of frequency, that resulted in or had the potential to result in significant harm. Critical risk is defined as a situation that has caused or is likely to cause serious injury, harm, impairment, or death.

HIGH-RISK: STATEWIDE

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 provider deficient practice area, specifically, attending to assessment and treatment plans (**Table 8**).

Table 8: Statewide High-Risk Count, 2020

High Risk	**279**
Client Rights	**4**
Alleged Abuse, Neglect, Exploitation	4
Individual Care & Prevention	**224**
Assessments & Treatment Plans	99
Coordination of Care	18
Documentation	21
Medical Care Needs	31
Medication Management	47
Response to Emergency/Change in Condition	8
Program Planning & Leadership	**51**
Human Resources & Training	30
Policy, Procedure & Protocol Development	5
Program Requirements	1
Quality Improvement/Risk Management	7
Supervision & Oversight	8

Comparing 2019 and 2020 high-risk deficient practices, one notices the number of deficient practices increased significantly. The increase should not be attributed to the providers actually having more deficient practices. Instead, the identification increased because of the change to RNs completing the death investigations.

CRITICAL-RISK

Critical-risk deficient practices entered into CATS centered on client rights; individual care and prevention; physical environment and safety; and program planning and leadership (**Table 9**). As mentioned earlier, DBHDD requires providers to submit a corrective action plan to address critical-risk deficient practices.

Table 9: Statewide Critical-Risk Count, 2020

Critical-Risk	**73**
Client Rights	**4**
Alleged Abuse, Neglect, Exploitation	4
Individual Care & Prevention	**61**
Assessments & Treatment Plans	18
Coordination of Care	1
Documentation	2
Medical Care Needs	12
Medication Management	3
Response to Emergency/Change in Condition	25
Physical Environment and Safety	**2**
Physical Hazards & Safety Issues	2
Program Planning & Leadership	**6**
Human Resources & Training	4
Policy, Procedure & Protocol Development	1
Supervision & Oversight	1

The most common provider deficiencies that required corrective action were linked to individual care and prevention (80.1% of all high/critical 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. These deficiency types account for 285 of the 352 identified high- or critical-risk deficient practices.

KEY FINDINGS

Below is a summary of the key findings identified in the 2020 Mortality Report:

- The 2020 DBHDD NOW/COMP waiver mortality rate was 16.2 deaths per 1,000 individuals.
- The 2020 mortality rate did not differ significantly from the DBHDD NOW/COMP waiver mortality rates in 2018 and 2019.
- Increasing age was significantly associated with mortality.
- Increasing health risk was significantly associated with mortality.
- Mortality increased markedly for individuals in the 45-54 and 55-64 age groups. Increased risk of mortality due to increasing age is also found in the general U.S. and Georgia populations.
- Life expectancy for the 2020 NOW/COMP waiver population (54.4 years) is comparable to 55-64 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).
- Six of the 10 leading causes of death in the IDD population was also present in the 10 leading causes of death in the U.S. and Georgia: heart diseases, respiratory diseases, COVID-19, cancer, pneumonia, and renal diseases.
- 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: sepsis, disability, aspiration pneumonia, and seizures.
- Statistical analyses did not show an association between COVID-19 and mortality in this year's Annual IDD Mortality Report; this finding is tentative due to the small number of deaths analyzed. The overall crude mortality rate (that includes COVID-19 deaths) does not differ statistically from the COVID-19-adjusted mortality rate which removes COVID-19 deaths.
- The most common provider deficiencies that required corrective action were linked to individual care and prevention (80.1% 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.
- Most providers had none or very few deficient practices (from CMRC reviews).

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 2020 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 IDD Connects and Image. IDD Connects data also included identifying, demographic, and payer information, as well as residential setting. Health risk information was extracted from HSRT and IDD Connects. Death and incident data were extracted from Image.

For these analyses, the following information was included:

- Region (IDD Connects)
- Medicaid number (IDD Connects)
- Date of birth (IDD Connects)
- Date of death (Image)
- Residential setting (IDD Connects)
- Cause of death (if known) (death certificates)
- Whether death was referred for investigation (Image)
- Whether a mortality review was completed (CMRC)
- Health risk scores (HCLs from Health Status Risk Screening Tool and IDD Connects).
- 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 in 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 2020.

ANALYSIS AND MEASURES

Analyses were conducted using R,[27] 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 96; **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 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.

[27] R is a programming language and free software environment for statistical computing and graphics supported by the R Foundation for Statistical Computing.

APPENDIX B: NOW/COMP POPULATION DEMOGRAPHICS

CHARACTERISTICS OF THE INTELLECTUAL AND DEVELOPMENTAL DISABILITY WAIVER POPULATION

Below is a brief demographic description of the 2020 IDD waiver population:

- The total number of unduplicated IDD individuals with active NOW/COMP waivers in 2020 was 13,370; however, this analysis excluded individuals who had missing HCL data (n = 8), resulting in a final sample size of 13,362.
- These individuals were aged 18-96, with a mean age of 41.6.
- Of these, 59.7 percent were male, and 40.3 percent were female.
- Region 3 (24.8%) was the most populous region, followed by Region 1 (22.2%), Region 2 (17.0%), Region 6 (13.4%), Region 5 (12.0%), and Region 4 (10.4%).
- Most of the population had COMP waivers (61.1%) as opposed to NOW waivers (38.9%).

More information about the characteristics of the population can be found on the following page (**Table 10**).

Table 10: Characteristics of the Adult IDD Waiver Population, 2018-2020[28]

Characteristic	2018		2019		2020	
	n	%	n	%	n	%
Age						
18-24	1,182	9.2	1,247	9.4	1,398	10.5
25-34	3,663	28.4	3,743	28.3	3,855	28.9
35-44	2,872	22.3	2,983	22.5	2,998	22.4
45-54	2,260	17.5	2,252	17	2,192	16.4
55-64	1,889	14.7	1,933	14.6	1,882	14.1
65-74	796	6.2	852	6.4	823	6.2
75-84	207	1.6	202	1.5	195	1.5
85+	22	0.2	28	0.2	19	0.1
Gender						
Male	7,622	59.1	7,832	59.2	7,979	59.7
Female	5,269	40.9	5,408	40.9	5,381	40.3
Unknown					2	0.0
Region						
Region 1	2,758	21.4	2,950	22.3	3,189	23.9
Region 2	2,221	17.2	2,252	17	2,270	17.0
Region 3	3,251	25.2	3,290	24.9	3,286	24.6
Region 4	1,325	10.3	1,380	10.4	1,374	10.3
Region 5	1,562	12.1	1,581	11.9	1,600	12.0
Region 6	1,774	13.8	1,787	13.5	1,643	12.3
Waiver Type						
NOW	4,538	35.2	4,690	35.4	5,198	38.9
COMP	8,353	64.8	8,550	64.6	8,164	61.1
Residential Setting						
Lower Intensity	8,461	65.6	7713	58.3	8,924	66.8
Higher Intensity	4,430	34.4	5527	41.7	4,438	33.2
Total	12,891	100	13,240	100	13,362	100

[28] Shown for each characteristic are totals and percentages. Total percentages may not total to 100% because of rounding. Residential setting was not available for all waiver participants in 2020.