Annual IDD Mortality Report CY2021

GEORGIA DEPARTMENT *of*

BEHAVIORAL HEALTH *and* DEVELOPMENTAL DISABILITIES

Office of Performance Analysis and Quality Improvement

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EXECUTIVE SUMMARY

This report includes data and information concerning adults who died during calendar year 2021 (CY2021) while receiving intellectual and developmental disability (IDD) Medicaid waiver services authorized by the Georgia Department of Behavioral Health and Developmental Disabilities ("DBHDD" or "the department") and rendered by 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 eighth annual mortality report released by DBHDD. The purpose of this report is to provide CY2021 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 CY2021, DBHDD served 13,841 adults with intellectual and developmental disabilities in waiver services. A total of 297 deaths occurred in CY2021, resulting in a crude mortality rate of 21.5 deaths per 1,000 individuals.[1, 2] This increase from the CY2020 rate of 18.2 deaths per thousand[3] is statistically insignificant.

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

- Heart diseases
- Respiratory diseases
- COVID
- Cancer

[1] The mortality rate used in this report is a crude mortality rate, which is an unadjusted mortality rate. The mortality rate is a measure of how many people out of every thousand served by DBHDD died within the calendar year. It is determined by multiplying the number of people who died during the year 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."

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

[3] In reviewing our procedures for creating the CY 2021 mortality report, we discovered a discrepancy in the CY 2020 data in the CY 2020 mortality report, which inadvertently omitted 171 individuals (1.26%) in the IDD NOW/COMP waiver population. This omission was due to an error in how our report data for 2020 was extracted, which has now been corrected. We have validated our findings, and updated CY 2020 data are reflected in this report. None of the findings in the CY 2020 mortality report were significantly impacted by this data correction, so we are not reissuing the CY 2020 mortality report.

- Renal diseases

Five of the 10 leading causes of IDD deaths in CY2021 were not common to the general population:

- Sepsis
- Pneumonia
- Disability
- Aspiration pneumonia
- Seizures

Several variables were analyzed to determine their association with mortality in CY2021. These included age, gender, health risk, residential setting, race and region. Major analytical findings from CY2021 mirror those from CY2019 through CY2020: increasing health risk and increasing age were most strongly associated with mortality, while gender, residential setting, race, region, COVID, and other variables were not significantly related to mortality.

Statistical analyses of the NOW/COMP CY2021 population in this Annual Mortality Report indicated COVID was not significantly related to mortality in CY2021 for individuals receiving DBHDD waiver services. A limitation to the lack of association between COVID and mortality in the Annual IDD Mortality Report is the low number of deaths in the target population that occurred due to COVID. 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 and the population we served. This review revealed that the crude, overall mortality rate of the IDD population that includes COVID deaths does not differ significantly from the COVID crude mortality rate which removes the deaths due to COVID from the analyses. In other words, deaths with COVID as an underlying cause did not add significantly to the overall death rate. DBHDD will 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 (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: an issue, regardless of frequency, that resulted in or had the potential to result in moderate impact on individual(s) served
- High-risk provider deficient practice: an issue, regardless of frequency, that resulted in or had the potential to result in significant harm to individual(s) served

- Critical-risk provider deficient practice: a situation that has caused or is likely to cause serious injury, harm, impairment, or death to an individual served

The most common provider deficiencies that required corrective action were linked to individual care and prevention (67.5% of all high/critical deficiencies). These deficiency areas included assessments and treatment plans, medical care needs, medication management, coordination of care, documentation, 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 208 of the 308 identified high- and critical-risk deficient practices.

PURPOSE AND SCOPE OF THIS REPORT

This is the eighth annual report on mortality, mortality trends, and related information pertaining to individuals on NOW/COMP waivers. The report focuses on an analysis of mortality data and findings from DBHDD's mortality review process for calendar year 2021. During CY2021, there were 297 deaths reported for the 13,841 waiver population served. This is a mortality rate of 21.5 deaths per thousand, which is explored in further detail in the pages that follow.

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 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 considered the inclusion of other states' findings, given the differences in waiver programs, obligations of the various state agencies, stale data (most recent from 2017) and other state-specific issues, it is difficult to compare mortality rates or draw conclusions between states. Therefore, this report going forward will only present findings for individuals on Georgia NOW/COMP waivers.

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).[4]

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 deaths is presented later in this report.

[4] (2017). Retrieved from https://www.cdc.gov/nchs/data/dvs/2a_2017.pdf. Accessed January 10, 2020.

Table 1: Leading Causes of Death[5]

Rank	U.S. (CY2021) provisional[6]	Georgia (CY2020)[7]	DBHDD (CY2021)
1	Heart Diseases (20.0%)	Heart Diseases (28.0%)	Heart Diseases (16.4%)
2	Malignant Neoplasms (17.5%)	Malignant Neoplasms (17.9%)	Respiratory Diseases (15.7%)
3	COVID (12.0%)	Infectious and Parasitic Diseases (12.1%)	COVID (9.4%)
4	Unintentional Injuries (6.3%)	Nervous System Diseases (9.5%)	Sepsis (7.6%)
5	Cerebrovascular Diseases (stroke) (4.7%)	Respiratory Diseases (9.2%)	Pneumonia (7.0%)
6	Respiratory diseases (4.1%)	Unintentional Injuries (8.2%)	Disability (6.7%)
7	Alzheimer's Disease (3.4%)	Endocrine, Nutritional, and Metabolic (4.9%)	Aspiration Pneumonia (3.9%)
8	Diabetes Mellitus (3.0%)	Digestive System Diseases (3.6%)	Renal (3.5%)
9	Chronic Liver Disease (1.6%)	Mental and Behavioral Disorders (3.1%)	Cancer (3.3%)
10	Renal (1.6%)	Reproductive and Urinary System Diseases (2.9%)	Seizures (2.9%)

At the time of writing this report, updated causes of death were not available for Georgia for CY2021. On April 12, 2022, the CDC released preliminary causes of death information for CY2021 in the United States.

[5] 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.

[6] Ahmad, F. B., Cisewski, J. A., Minino, A. & Anderson, R. N. (2021) "Provisional Mortality Data—United States, 2021." *Morbidity and Mortality Weekly Report* 2022;71:597-600: Department of Health and Human Services/Centers for Disease Control and Prevention. https://www.cdc.gov/mmwr/volumes/71/wr/mm7117e1.htm#T1_down, accessed April 11, 2022.

[7] Data for Georgia mortality is from the Georgia Department of Public Health (https://oasis.state.ga.us/oasis/webquery/qryMortality.aspx).

As in previous years, several of the 10 leading causes of death for general populations of the United States or Georgia were also found to be leading causes of death in the IDD population. Common causes of death for general and IDD populations included the following five:

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

Five of the 10 leading causes of IDD deaths in CY2021 were not common to the general population:

- Sepsis
- Disability
- Aspiration pneumonia
- Seizures
- Pneumonia

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 CY2021

This section contains information on deaths reported to DBHDD among the IDD waiver population during CY2021. 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 failed to yield any new comparison data other than that which has been provided in previous versions of this report. The most recent data available was for 2017. Additionally, as has been noted in previous versions of this report, eligibility and enrollment criteria are not consistent across states, and generalizations and comparisons may lead to insupportable conclusions. Considering these caveats, this report will consider DBHDD's data.

AGE AND MORTALITY

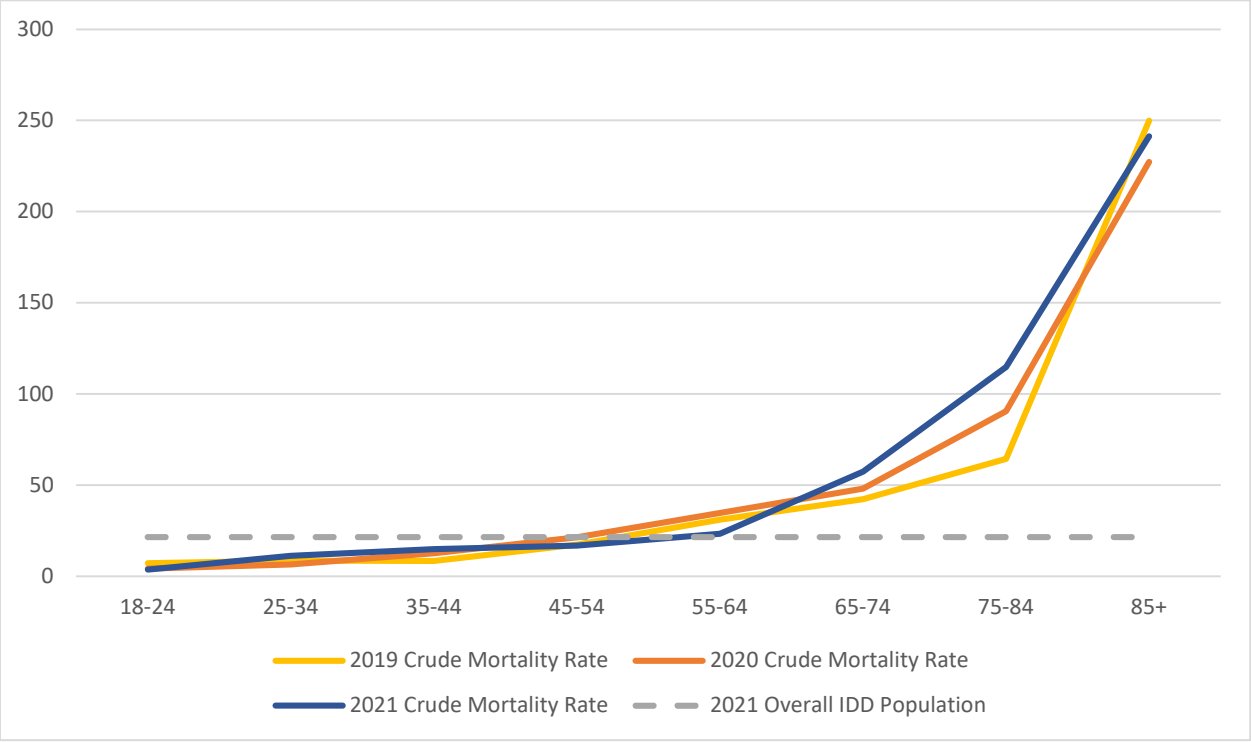
The average ages of death in CY2019 and CY2020 were 53.22 (SD = 16.77) and 54.20 (SD = 15.88), respectively. The average age of death in CY2021 was 54.60 (SD = 16.82). The average age of death remained almost constant between CY2020 and CY2021.

As in CY2019 and CY2020, mortality rates increased with increasing age (**Table 2, Figure 1**). In CY2020, the mortality rate for individuals exceeded the overall mortality rate for the entire population between ages 45-54. This same pattern emerged in CY2021, with significant increases between age groups beginning in age group 45-54. One can see from the graphic that mortality rates increased with age across the entire age range, and visually at least, the mortality rates began increasing more dramatically after ages 55-64.

Table 2: Mortality Rates Among the Adult IDD Waiver Population by Age Category, CY2021[8]

Age Category	Population	Deaths (#)	Deaths (%)	Crude Mortality Rate	Significance
18-24	1,186	11	3.70%	9.3	--
25-34	3,968	33	11.10%	8.3	NS
35-44	3,215	44	14.80%	13.7	NS
45-54	2,270	50	16.80%	22.0	|z|=2.3442; p=.00964
55-64	1,969	69	23.20%	35.0	|z|=2.5589; p=.00523
65-74	960	55	18.50%	57.3	|z|=2.807; p=.00248
75-84	244	28	9.40%	114.8	|z|=3.1636; p=.00079
85+	29	7	2.40%	241.4	NS
Total	**13,841**	**297**	**100.00%**	**21.5**	--

Figure 1: Mortality Rates by Age Category, CY2019-CY2021



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

This report's findings were supported by other research[9] 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 typically 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.

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 assist in 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. Please see Appendix D for more information about the HRST domains.

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.

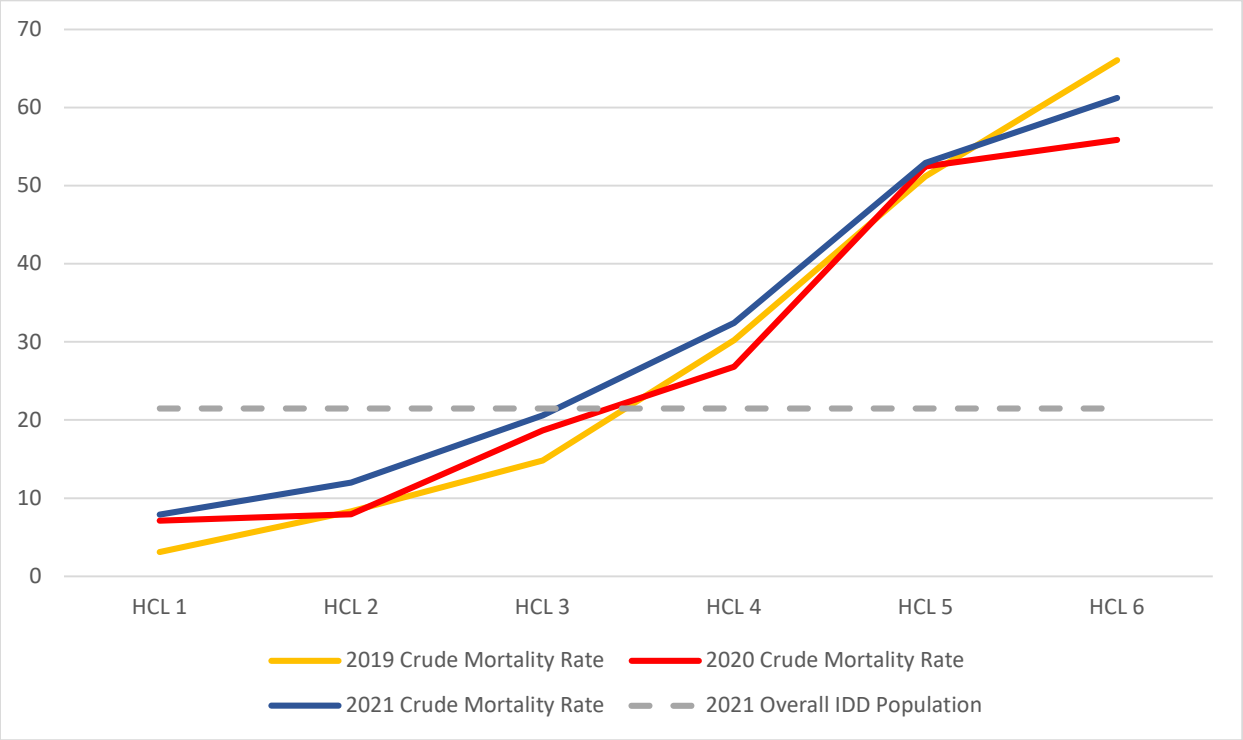
The average HCL for CY2021 was 2.65 (SD = 1.55). In CY2020, the average HCL was 2.59 (SD = 1.54), and, in CY2019, the average HCL was 2.52 (SD = 1.52). This means that, overall, there is a statistically significant increase in the amount of measured health risk in the IDD population over time.

Similar to previous years, there was a statistical association between HCL and mortality rate in CY2021. Individuals with lower HCLs (1-3) had a group mortality rate (12.6 deaths per 1,000) that was below the population mortality rate in CY2021 (21.5 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 (21.5 deaths per 1,000) by a wide margin.

[9] National Vital Statistics Report, Vol. 68 No. 9, June 24, CY2019, p. 8. https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_09-508.pdf, accessed March 13, 2020.

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 CY2021.

Figure 2: Crude Mortality Rates by HCL, CY2019-CY2021[10]



[10] The horizontal gray line indicates the crude mortality rate (21.5 per 1,000) for the overall IDD population.

Table 4: Mortality Rates by HCL, CY2021[11]

HCL	Population	Deaths (#)	Deaths (%)	Crude Mortality Rate	Significance
1	3,797	30	10.10%	7.9	--
2	4,005	48	16.20%	12.0	NS
3	2,525	52	17.50%	20.6	|z|=2.27589; p=.00289
4	1,388	45	15.20%	32.4	NS
5	983	52	17.50%	52.9	|z|=2.48; p=.00657
6	1,143	70	23.60%	61.2	NS
Total	**13,841**	**297**	**100.00%**	**21.5**	**--**

As one can see from Table 4, HCLs one and two are not statistically significant from one another. HCL 3 shows a marked increase from HCL 2, and HCLs 3 and 4 are not significantly different from one another. Another marked increase at HCL 5 shows a significant increase, and once again, HCL 6 is not vastly different from HCL 5.

THE CENTRAL IMPORTANCE OF AGE AND HEALTH RISK[12]

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 = 0.056, $p < .00001$). Though this is 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, waiver type (NOW vs.

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

[12] 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.

COMP), current living situation, intensity of residential setting, having a COVID 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.[13]

While some areas of the differing variables demonstrated more significance than others, all 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 diagnosis were not significantly related to mortality in CY2021. These logistic regression results have remained consistent over time. (The lack of association between COVID and mortality in this year's annual mortality report is discussed in a later section of this report.)

Table 5: Odds Ratios for Logistic Regression Model of Mortality on Age and HCL; CY2021

Characteristic	2021 Odds Ratio
Age	1.05
HCL	1.54
Pseudo R^2	**0.16**

Table 6: Odds Ratio for Logistic Regression Model of Mortality on HCL; CY2021

HCL Category	2021 Odds Ratio
1	**1 [Reference]**
2	1.52
3	2.64
4	4.21
5	7.01
6	8.19
Pseudo R^2	**0.01**

[13] 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.

Table 7: Odds Ratio for Logistic Regression Model of Mortality on Age; CY2021

Age Category	2021 Odds Ratio
18-24	1.12
25-34	1 [Reference]
35-44	1.65
45-54	2.69
55-64	4.33
65-74	7.25
75-84	15.46
85+	37.94
Pseudo R^2	**0.02**

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 CY2021. 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 CY2021 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

As noted above, preliminary data indicates that COVID was the third leading cause of death in the United States in CY2021; it was also the third leading cause of death in the NOW/COMP IDD population in CY2021. COVID was reported as the underlying cause of death for an estimated 460,513 (13.3%) of the 3,458,697, deaths that occurred in the United States in CY2021.

Within the DBHDD NOW/COMP IDD population in CY2021, COVID was reported as an underlying cause of death for 40 (13.5%) of the 297 deaths that occurred in the NOW/COMP IDD population in CY2021, closely mirroring that of the overall United States population. Statistical analyses of the NOW/COMP CY2021 population in this Annual Mortality Report indicated, however, COVID was not significantly related to mortality in CY2021 for DBHDD individuals. A limitation to the lack of association between COVID and mortality in the Annual IDD Mortality Report is the low number of deaths that occurred among individuals with a COVID diagnosis. Oftentimes, it is difficult to reach definitive associations with low numbers of events; therefore, this finding is tentative. As a next step, DBHDD sought to understand the impact of COVID on the IDD population we serve by comparing the overall crude mortality rate to the mortality rate that adjusts for COVID (COVID-adjusted mortality rate) to provide additional information.

One way to understand the impact of COVID on this population is to compare the crude mortality rate with the COVID-adjusted mortality rate, which is the mortality rate without the deaths due to COVID. The COVID-adjusted CY2021 mortality rate of 18.6 deaths per 1,000 is not significantly lower than the crude mortality rate of 21.5 deaths per 1,000 (which includes COVID). To adjust the CY2021 mortality rate, the count of COVID deaths is removed from the numerator and denominator before being calculated.

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 (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.[14]

STATEWIDE ANALYSIS OF NUMBER AND TYPE OF DEFICIENT PRACTICES[15]

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 CY2021, 65 deficient practices entered into CATS were identified as low risk, defined as an issue, regardless of frequency, that has little to no impact on individual(s) served. For low-risk deficient practices, providers are required to develop an internal corrective action plan, which is maintained on file and may be requested/reviewed by DBHDD to determine compliance at any time.

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

[15] 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 251 deficient practices entered into CATS that were identified as moderate risk. Moderate risk is defined as an issue, regardless of frequency, that resulted in or had the potential to result in moderate impact on individual(s) served. For these, providers are required to develop an internal corrective action plan, which is maintained on file and may be requested/reviewed by DBHDD to determine compliance at any time.

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 to individual(s) served. Critical risk is defined as a situation that has caused or is likely to cause serious injury, harm, impairment, or death to an individual served. Both high- and critical-risk deficient practices require a corrective action plan to be submitted to DBHDD, and evidence of implementation of the corrective action plan.

HIGH-RISK: STATEWIDE

A closer examination of the 240 high-risk deficient practices in 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 assessments and treatment plans (**Table 8**).

Table 8: Statewide High-Risk Count, CY2021

High Risk	240
Client Rights	**3**
Alleged Abuse, Neglect, Exploitation	1
Rights and Privacy	2
Individual Care & Prevention	**161**
Assessments & Treatment Plans	57
Coordination of Care	17
Documentation	23
Medical Care Needs	16
Medication Management	39
Response to Emergency/Change in Condition	9
Program Planning & Leadership	**68**
Documentation	7
Emergency Planning	1
Human Resources & Training	35
Policy, Procedure & Protocol Development	3
Program Requirements	4
Quality Improvement/Risk Management	1
Supervision & Oversight	17
Miscellaneous	**6**
Miscellaneous	6

Physical Environment & Safety	2
Cleaning, Infection Control & Hygiene Practices	1
Physical Hazards & Safety Issues	1

CRITICAL-RISK

The 68 critical-risk deficient practices in 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, CY2021

Critical-Risk	68
Client Rights	**8**
Alleged Abuse, Neglect, Exploitation	7
Rights and Privacy	1
Individual Care & Prevention	**47**
Assessments & Treatment Plans	5
Coordination of Care	7
Documentation	4
Medical Care Needs	6
Medication Management	7
Response to Emergency/Change in Condition	18
Physical Environment and Safety	**1**
Physical Hazards & Safety Issues	1
Program Planning & Leadership	**11**
Documentation	2
Human Resources & Training	4
Supervision & Oversight	5
Miscellaneous	**1**
Miscellaneous	1

The most common provider deficiencies that required corrective action were linked to individual care and prevention (208 of 308 (67.5%) of all high/critical deficiencies). These deficiency areas included assessments and treatment plans, medical care needs, medication management, coordination of care, documentation, and failure to respond to an emergency or change in condition in a manner that would protect the welfare of the individual.

DBHDD requires providers to take actions to correct deficient practices identified in investigations. For low- and moderate-risk deficient practices, providers are required to develop an internal corrective action plan, which is maintained on file and may be requested/reviewed by DBHDD to determine compliance at any time. Both high- and critical-risk deficient practices require an acceptable corrective action plan to be submitted to DBHDD, and evidence of implementation of the corrective action plan. Evidence may be requested for review, or an onsite visit may be conducted to determine compliance. In CY2021, DBHDD established five new positions for CAP Analysts to focus on provider compliance following an investigation.

KEY FINDINGS

Below is a summary of the key findings identified in the CY2021 Mortality Report:

- The CY2021 DBHDD NOW/COMP waiver mortality rate was 21.5 deaths per 1,000 individuals.
- The CY2021 mortality rate was not significantly higher than the DBHDD NOW/COMP waiver mortality rate in CY2020.
- 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.
- Five of the 10 leading causes of death in the IDD population were also present in the 10 leading causes of death in the U.S. and Georgia: heart diseases, respiratory diseases, COVID, cancer and renal diseases.
- Five 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, pneumonia, and seizures.
- Statistical analyses did not show an association between COVID 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 deaths) does not differ statistically from the COVID-adjusted mortality rate which removes COVID deaths.
- The most common provider deficiencies that required corrective action were linked to individual care and prevention (67.5% of all critical/high deficiencies). These deficiency areas included assessment and treatment plans, medical care needs, medication management, coordination of care, documentation, and failure to respond to an emergency or change in condition in a manner that would protect the welfare of the individual.

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.

Individuals who moved between the NOW/COMP waiver during CY2021 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 HRST 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 and IDD Connects)
- 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 (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.

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 CY2021.

ANALYSIS AND MEASURES

Analyses were conducted using XLSTAT, a statistical add on toolkit for Microsoft Excel, 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 93; **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.

APPENDIX B: NOW/COMP POPULATION DEMOGRAPHICS

CHARACTERISTICS OF THE INTELLECTUAL AND DEVELOPMENTAL DISABILITY WAIVER POPULATION

Below is a brief demographic description of the CY2021 IDD waiver population:

- The total number of unduplicated IDD individuals with active NOW/COMP waivers in CY2021 was 13,841;
- These individuals were aged 18-93, with a mean age of 42.3.
- Of these, 59.9 percent were male, and 40.1 percent were female.
- Region 3 (24.7%) was the most populous region, followed by Region 1 (23.3%), Region 2 (16.9%), Region 6 (13.2%), Region 5 (11.8%), and Region 4 (9.8%).
- Most of the population had COMP waivers (66.2%) as opposed to NOW waivers (33.8%).

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, CY2019-CY2021[16]

Characteristic	2019		2020		2021	
	n	%	n	%	n	%
Age						
18-24	1,247	9.4	1,406	10.4	1,186	8.6
25-34	3,743	28.3	3,881	28.8	3,968	28.7
35-44	2,983	22.5	3,019	22.4	3,215	23.2
45-54	2,252	17	2,204	16.4	2,270	16.4
55-64	1,933	14.6	1,902	14.1	1,969	14.2
65-74	852	6.4	834	6.2	960	6.9
75-84	202	1.5	199	1.5	244	1.8
85+	28	0.2	22	0.2	29	0.2
Gender						
Male	7,832	59.2	8,032	59.6	8,293	59.9
Female	5,408	40.9	5,433	40.3	5,544	40.1
Unknown			2	0.0	4	0.0
Region						
Region 1	2,950	22.3	3,215	23.9	3,231	23.3
Region 2	2,252	17	2,286	17.0	2,344	16.9
Region 3	3,290	24.9	3,309	24.6	3,417	24.7
Region 4	1,380	10.4	1,389	10.3	1,363	9.8
Region 5	1,581	11.9	1,612	12.0	1,637	11.8
Region 6	1,787	13.5	1,656	12.3	1,822	13.2
Region 99					27	0.2
Waiver Type						
NOW	4,690	35.4	5,242	38.9	4,680	33.8
COMP	8,550	64.6	8,225	61.1	9,161	66.2
Residential Setting						
Lower Intensity	7713	58.3	8,999	66.8	9,419	68.1
Higher Intensity	5527	41.7	4,468	33.2	4,422	31.9
Race						
American Indian/Alaskan Native					3	0.0
Asian					97	0.7
Black/African American					6,004	43.4
Multiracial					90	0.7
Native Hawaiian/Other Pacific Islander					12	0.1
Other Single Race					290	2.1
Unknown/Refused					502	3.6
White/Caucasian					6,843	49.4
Total	13,240	100	13,467	100	13,841	100

[16] Shown for each characteristic are totals and percentages. Total percentages may not total to 100% because of rounding.

APPENDIX C: 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,[17] resulting in a subset of the full population. DBHDD may consider other theoretically-sound methods and procedures to understand or address missing data.[18]
- Third, in some cases, DBHDD utilizes some form of random sampling[19] (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

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

[18] 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.

[19] 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.

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.

APPENDIX D: HRST DOMAINS

Risk Dimension	Item Letter (A-V)	Item Topic
Functional status	A	Eating
	B	Ambulation
	C	Transfer
	D	Toileting
	E	Clinical issues affecting daily life
Behaviors	F	Self-abuse
	G	Aggression towards others and property
	H	Use of physical restraints
	I	Use of emergency drugs
	J	Use of psychotropic medications
Physiological	K	Gastrointestinal conditions
	L	Seizures
	M	Anticonvulsant medication
	N	Skin breakdown
	O	Bowel function
	P	Nutrition
	Q	Requirements for licensed interventions
Safety	R	Injuries
	S	Falls
Frequency of services	T	Professional health services
	U	Emergency department visits
	V	Hospital admissions