Annual IDD Mortality Report CY2024

GEORGIA DEPARTMENT *of*

BEHAVIORAL HEALTH *and* DEVELOPMENTAL DISABILITIES

Office Data, Analytics, and Research

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EXECUTIVE SUMMARY

This report includes data and information concerning adults who died during calendar year 2024 (CY2024) while receiving intellectual and developmental disability (IDD) Medicaid waiver services authorized by the Georgia Department of Behavioral Health and Developmental Disabilities ("DBHDD") 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 DBHDD's eleventh annual mortality report. This report provides information about what DBHDD has learned about deaths occurring in CY2024, to identify trends or patterns in mortality, and to identify indicators that may assist DBHDD in the prevention and treatment of certain illnesses or conditions that may lead to deaths or other disorders or 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 CY2024, DBHDD served 14,220 adults with intellectual and developmental disabilities in waiver services. A total of 216 deaths occurred in CY2024, resulting in a crude mortality rate of 15.2 deaths per 1,000 individuals, or 1.5%.[1, 2]

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. Several variables were analyzed to determine their association with mortality in CY2024. These included age, gender, health risk, residential setting, race, region, marital status, service intensity and the 22 rating items of the Health Risk Screening Tool (HRST). Major analytical findings from CY2024 mirror those from CY2022 and CY2023: increasing health risk and increasing age were most strongly associated with mortality, while gender, residential setting, race, region, marital status, service intensity, and other variables were not significantly related to mortality.

DBHDD's Community Mortality Review Committee (CMRC) uses a standardized, systematic process to conduct mortality reviews to identify opportunities to reduce morbidity, mortality,

[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.

and identify opportunities to improve the quality of services. CMRC data review identified low-, moderate-, high-, and critical-risk provider deficient practices.

In CY2024, the most common provider deficiency category was “Medication and Healthcare Management.” This category accounted for 55.97% of the deficiencies cited, with the deficiencies primarily being rated as high risk or critical risk. These deficiencies include issues such as proxy caregiving, healthcare plans and risk mitigation, medication administration, nursing oversight, responding to a change in condition, and bowel tracking, monitoring, and intervention.

PURPOSE AND SCOPE OF THIS REPORT

This is the eleventh annual report on mortality, mortality trends, and related information pertaining to individuals on NOW and COMP waivers. The report focuses on an analysis of mortality data and findings from DBHDD's mortality review process for calendar year 2024.

Reports are produced annually 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, and other state-specific issues, comparing mortality rates or drawing conclusions between states is difficult. Therefore, this report will only present findings for individuals on Georgia NOW and 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, aggregating causes of death is difficult, and the reliability is somewhat questionable because 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.

DBHDD's process presents 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).[3] 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**).

[3] (2017). Retrieved from https://www.cdc.gov/nchs/data/dvs/2a_2017.pdf. Accessed January 10, 2020.

Table 1: Leading Causes of Death[4]

Rank	U.S. (CY2024) provisional[5]	Georgia (CY2024)[6]	DBHDD (CY2024)
1	Heart Diseases (27.0%)	Heart Diseases (29.7%)	Heart Diseases (21.1%)
2	Malignant Neoplasms (24.4%)	Malignant Neoplasms (19.5%)	Respiratory Diseases (15.3%)
3	Unintentional Injuries (7.8%)	Nervous System Diseases (11.0%)	Disability (9.2%)
4	Cerebrovascular Diseases (6.6%)	Respiratory Diseases (8.7%)	Cerebrovascular Diseases (5.8%)
5	Respiratory Diseases (5.7%)	Unintentional Injuries (8.6%)	Sepsis (5.3%)
6	Alzheimer's Disease (4.6%)	Endocrine, Nutritional, and Metabolic (5.5%)	Malignant Neoplasms (5.0%)
7	Diabetes Mellitus (3.7%)	Digestive System Diseases (3.7%)	Pneumonia (4.4%)
8	Renal Disease (2.2%)	Infectious and Parasitic Diseases (3.5%)	Endocrine, Nutritional, and Metabolic (3.6%)
9	Chronic Liver Disease (2.1%)	Reproductive and Urinary System Diseases (2.8%)	Seizures (2.8%)
10	Intentional Self Harm (1.9%)	Mental and Behavioral Disorders (2.5%)	Aspiration Pneumonia (2.5%)

[4] 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. 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. 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.

[5] https//wonder.cdc.gov.

[6] Data for Georgia mortality is from the Georgia Department of Public Health (https://oasis.state.ga.us/oasis/webquery/qryMortality.aspx). Georgia now includes COVID in its infectious and parasitic diseases category. It is no longer a standalone category.

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 six:

- Heart diseases
- Respiratory diseases
- Pneumonia (included in Respiratory diseases counts for U.S. and GA)
- Endocrine, Nutritional, and Metabolic diseases
- Cerebrovascular diseases
- Cancer

Four of the 10 leading causes of IDD deaths in CY2024 were not common to the general population:

- Sepsis
- Seizures
- Disability
- Aspiration 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 on death certificates – a notable fact. 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 CY2024

This section contains information on deaths reported to DBHDD among the IDD waiver population during CY2024. Appendix A describes the method used to collect and analyze information and data contained in this section.

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 only DBHDD's data.

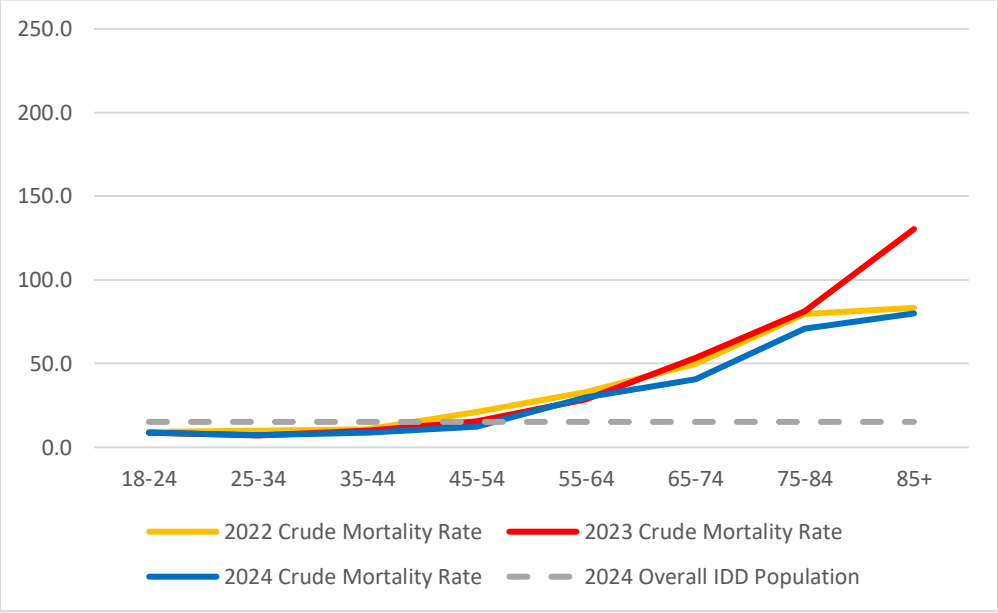
During CY2024, there were 216 deaths reported for the total 14,220 waiver population served. This is a mortality rate of 15.2 deaths per thousand, or 1.5%, which is explored in further detail in the pages that follow.

AGE AND MORTALITY

The average ages of death in CY2022 and CY2023 were 52.50 and 54.34 respectively. The average age of death in CY2024 was 53.16.

As in previous years, CY2024 mortality rates increased with increasing age as displayed in Figure 1. For additional statistical context, please see Appendix F, Table 4. One can see from the graphic that mortality rates increased with age across the entire age range, and the mortality rates began increasing more dramatically after ages 55-64.

Figure 1: Mortality Rates by Age Category, CY2022-CY2024



This report's findings were supported by other research[7] 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)[8] is a standardized mechanism designed to evaluate an individual's susceptibility to potential health risks. It aids in the early detection of health deterioration and guides healthcare providers in determining the need for further assessments, evaluations, services, or modifications to the individual's care plan.

The HRST consists of 22 rating items categorized into five health domains: Functional Status, Behavior, Physiological, Safety, and Frequency of Services. Each item is assigned a weighted score, with most items scoring from zero to four, except for Requirements for Licensed Intervention (Item Q), which is scored either zero or four.

The HRST is specifically designed to identify and quantify health and behavior risks. The scored risk dimensions and other detailed information can be found in Appendices D and E of this report. After scoring each rating item, the HRST generates Health Care Levels (HCLs), as noted in Table 2 below, that correspond to the individual's overall risk.

Table 2: HRST Health Care Levels

HCL	Description
1	Low Risk
2	Low Risk
3	Moderate Risk
4	High Moderate Risk
5	High Risk
6	Highest Risk

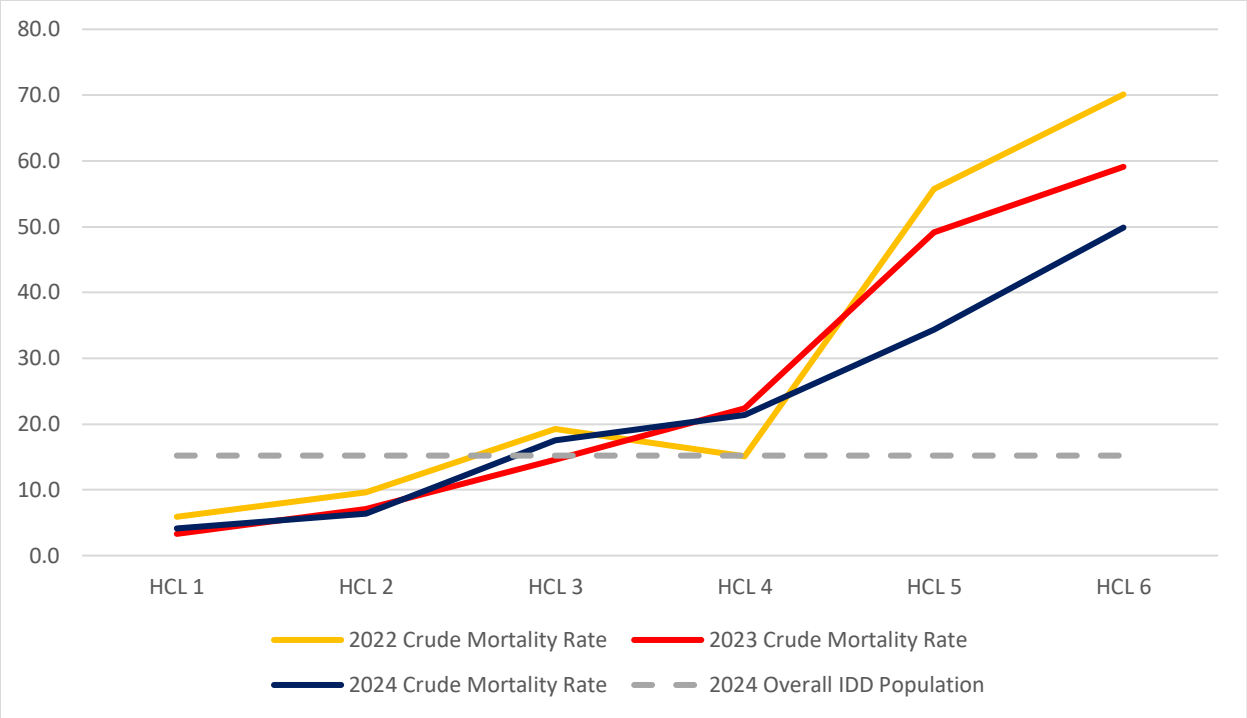
Consistent with previous years, there was a statistical association between HCL and mortality rate in CY 2024. Individuals with lower HCLs (1-3) had a group mortality rate (8.6 deaths per 1,000) that was below the population mortality rate in CY 2024 (15.2 deaths per 1,000). Conversely, individuals with higher HCLs (4-6) had a group mortality rate (33.2 deaths per 1,000) that significantly exceeded the overall population mortality rate. Results from previous years have consistently indicated that a two-point increase in HCL is associated with a significant increase in mortality. This underscores the importance of the HRST in predicting health outcomes and

[7] 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.

[8] IntellectAbility. (n.d.). Understanding the HRST and SIS-A. Retrieved from https://support.replacingrisk.com/portal/en/kb/articles/understanding-the-hrst-and-sis-a

guiding healthcare interventions. Figure 2 presents a graphic illustration of the association between HCL and mortality.

Figure 2: Crude Mortality Rates by HCL, CY2022-CY2024[9]



Additional data on crude mortality rates by HCL, including statistical significance can be found in Tables 5 and 6 of Appendix F.

THE CENTRAL IMPORTANCE OF AGE AND HEALTH RISK

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 = 0.028, p = 0.0009313). Although 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

[9] The horizontal gray line indicates the crude mortality rate (15.2 per 1,000) for the overall IDD population.

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. COMP), current living situation, intensity of residential setting, and health risk (using HCL) were associated with mortality to determine which variables may be of key importance. Such associations were examined using logistic regression.

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. Gender, region, and intensity of residential setting were not significantly related to mortality in CY2024. These logistic regression results have remained consistent over time.

This analysis 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 CY2024. 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 CY2024 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 dying; it only means that people in those groups were more likely than others to die. It is also worth noting that statistical association does not indicate causation.

HRST RATING ITEMS AND MORTALITY

A more in-depth analysis focused on identifying the top three HRST rating items out of 22 that affect mortality. A binary logistic regression was used to quantify the relationship and identify the HRST Rating Items that were more likely to influence mortality among the IDD population. To learn more about the binary logistic regression and its outputs, see Table 7 in Appendix E.

The results suggest that toileting, falls, and emergency room visits are considered the top 3 HRST rating items in terms of their significant impact on mortality risk. The odds ratio results suggest that for each unit increase in the toileting risk item, the probability of mortality increases by 30%. Similarly, for each unit increase in the falls risk item, the probability of mortality increases by 27%. Lastly, for each unit increase in the emergency room visits risk item, the probability of mortality increases by 21%.

Further analysis was performed to construct a mortality risk profile based on these selected rating items and to analyze the crude mortality rate at each risk level (Low, Medium, and High). This analysis supports an understanding of the variations in mortality rates across different risk levels. Furthermore, this model compares these rates with the overall crude mortality rate of CY2024, which stands at 15.2. This comparison provides a comprehensive view of the mortality trends and helps identify areas that require further investigation. To learn more about the binary logistic regression and its outputs, see Table 8 in Appendix E.

The entire model explains 13% of the variations in mortality using these 22 HRST Rating Items. This suggests that while these items are important, other factors not included in this model may also play a significant role in determining mortality rates.

COMMUNITY MORTALITY REVIEW COMMITTEE RELATED DEFICIENT PRACTICE ANALYSIS

BACKGROUND

DBHDD investigates expected deaths, unexpected deaths, suicides, deaths of enrolled individuals, and homicides of individuals receiving services by or through DBHDD community providers. Retrospective analysis of the deaths by DBHDD's Community Mortality Review Committee (CMRC) is an integral part of the DBHDD quality management and improvement system. The CMRC seeks to understand the factors contributing to deaths, to recommend appropriate care and quality improvement strategies, and to identify systemic issues that may benefit from scrutiny and analysis to make system improvements. This multi-disciplinary standing committee has the authority to direct resources and accountability to improve care and future health outcomes. More information about the CMRC can be found in DBHDD policy 04-108, Community Mortality Review Committee[10].

At a minimum, DBHDD requires providers to correct deficient practices that have the potential for causing harm, which include moderate-, high-, and critical-risk deficient practices. Deficiencies are tracked in DBHDD's incidents and investigations application, Image. Among other things, 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 risk determinations can be found in DBHDD policy 13-101, Corrective Action Plan Management[11].

CLASSIFICATION OF DEATHS

Community providers report the deaths of individuals receiving services by or through community providers. Each death is classified as one of the following types:

Expected Death: Cause of death is attributed to a terminal diagnosis or diagnosed disease process identified more than 30 days before the date of death, where the reasonable expectation or outcome is death and the individual was receiving residential or community living support services, in the company of or onsite at a community provider or discharged/transferred from a community provider within 30 days of the death.

Unexpected Death: Cause of death is not attributed to a terminal diagnosis or diagnosed disease process where the reasonable expectation or outcome is death and the individual

[10] https://gadbhdd.policystat.com/policy/17372681/latest
[11] https://gadbhdd.policystat.com/policy/12697461/latest

was receiving residential or community living support services, in the company of or onsite at a community provider or discharged/transferred from a community provider within 30 days of the death.

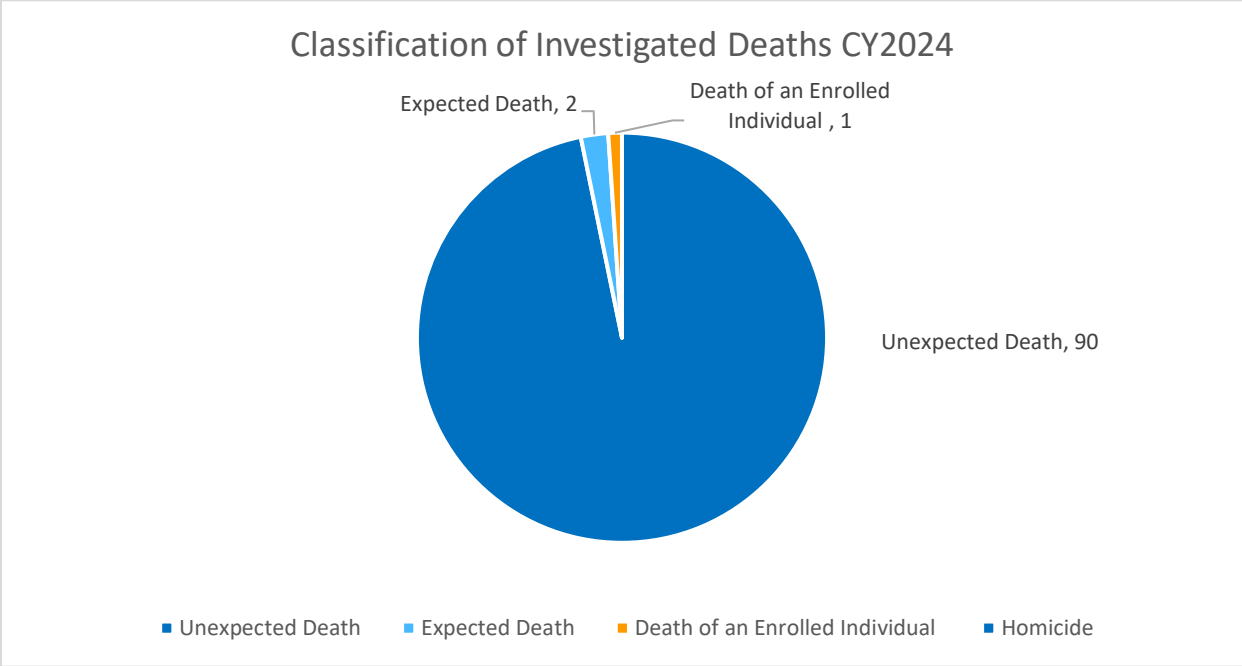
Suicide: Self-inflicted death of an individual and the individual was enrolled in community services or discharged/transferred from a community provider within 30 days of the death.

Homicide: Injury inflicted on an individual resulting in death and the individual was enrolled in community services or discharged/transferred from a community provider within 30 days of the death.

Death of an Enrolled Individual: Death of any individual enrolled in services, excluding any other death incident type.

A health and safety risk review is conducted to determine if a referral will be made for investigation as outlined in DBHDD policy 04-118, Investigating Deaths and Other Incidents in Community Services[12]. In CY2024, there were 93 investigations of deaths of waiver individuals.

Figure 3: Classification of Investigated Deaths CY2024



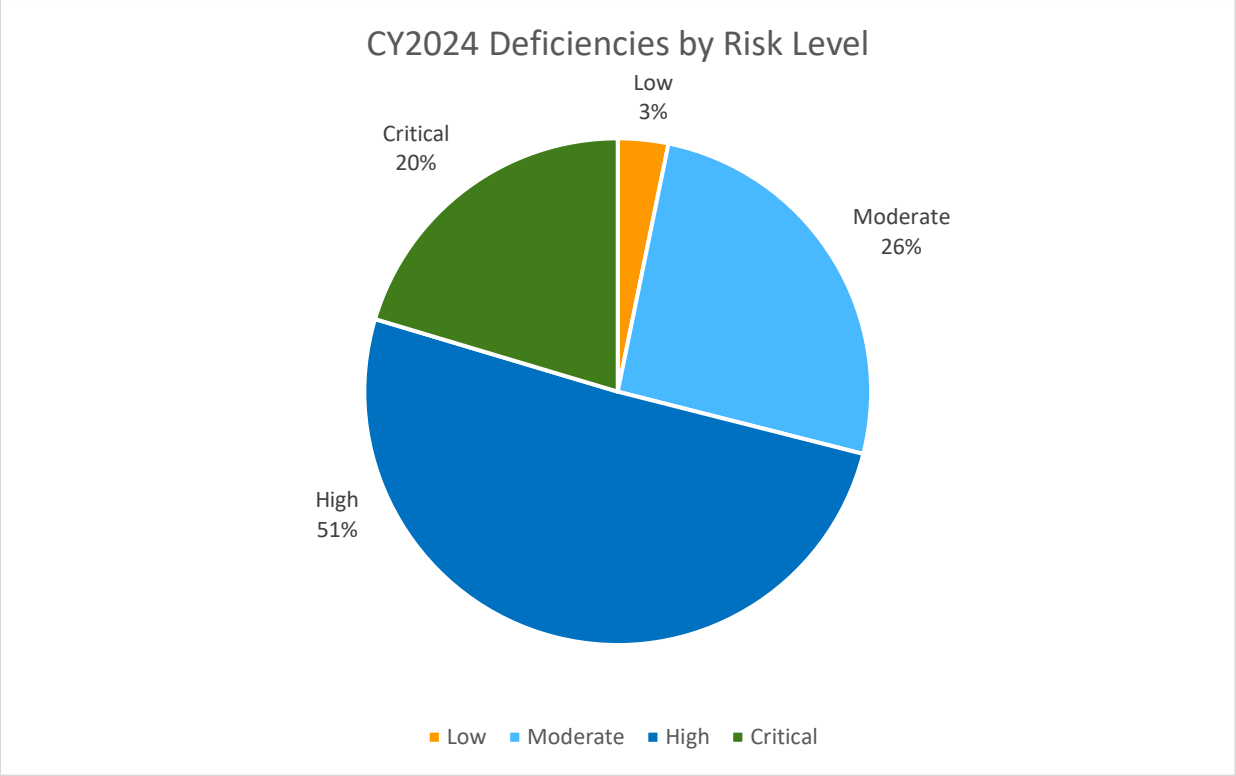
[12] https://gadbhdd.policystat.com/policy/13421590/latest

STATEWIDE ANALYSIS OF NUMBER AND TYPE OF DEFICIENT PRACTICES[13]

The analysis of deficiencies presented below is based on provider deficiencies entered into the Image system that were related to deaths CMRC reviewed.

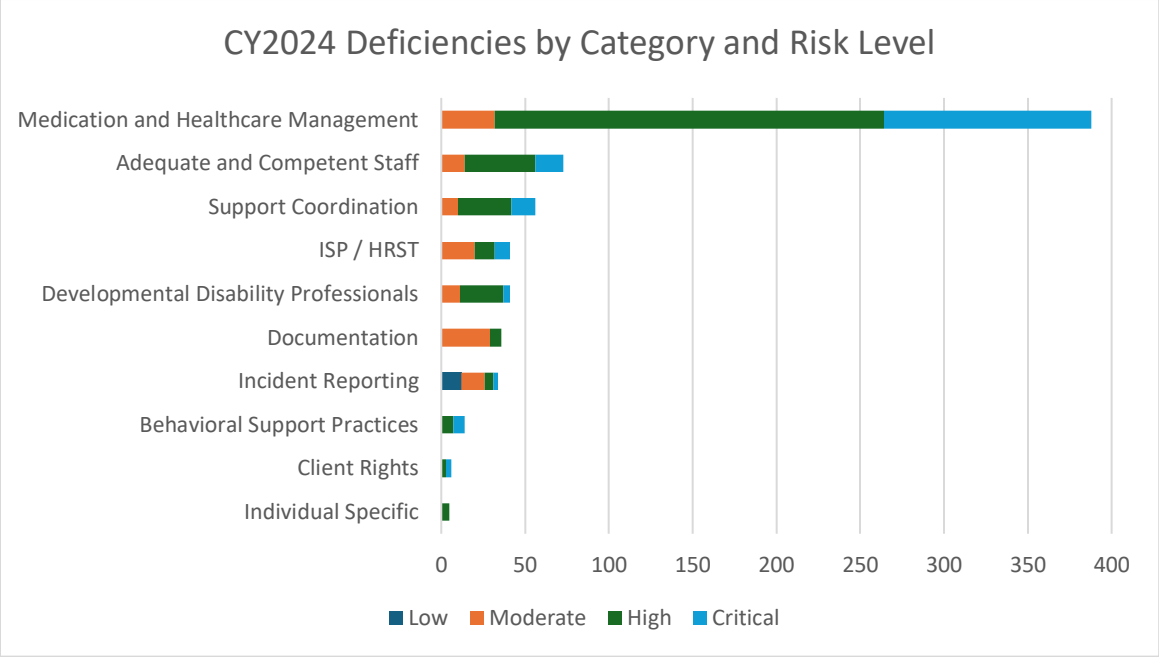
In CY2024, there were 373 unduplicated deficiencies entered into Image. Each deficiency may have multiple issues. Each issue has its own unique risk level, category and sub-category for classification purposes. There were 695 unique issues within the 374 deficiencies

Figure 4: CY2024 Deficiencies by Risk Level



[13] Due to small sample sizes, statistical analysis is not advisable. The reader is cautioned from generalizing findings and observations from the analyses above and below to DBHDD's population of individuals with intellectual and developmental disabilities.

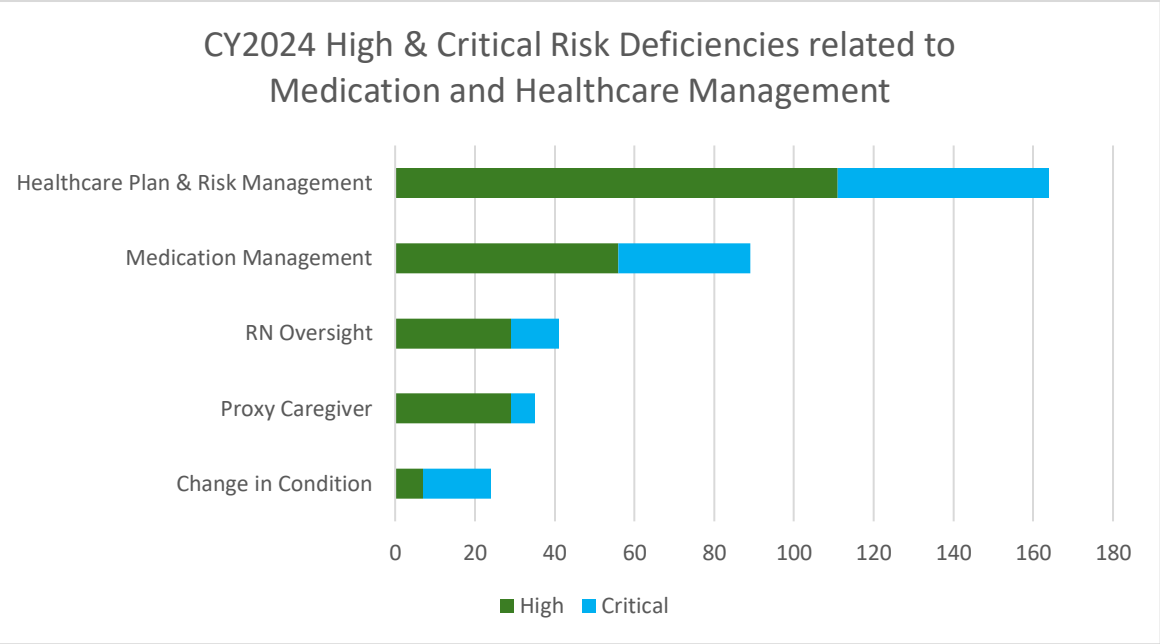
Figure 5: CY2024 Deficiencies by Category



In CY2024, the "Medication and Healthcare Management" category accounted for 55.97% of the deficiencies cited. Moreover, most of these deficiencies are risk rated high or critical. Deficiencies that are healthcare related are more likely to negatively affect an individual's health, and therefore, are more likely to be risk rated high or critical.

Closer examination of the types of sub-categories that were risk rated as high or critical under "Medication and Healthcare Management" shows the following:

Figure 6: CY2024 Medication and Healthcare Management Deficiencies by Sub-Category



The top 3 deficiency types are RN Oversight, Medication Management, and Healthcare Plan and Risk Management. These deficiencies include the following issues:

Healthcare Plan and Risk Mitigation

- Not having a healthcare plan or risk mitigation document when required
- Not implementing the healthcare plan or risk mitigation document as instructed
- Lack of documentation of staff training

Medication Management

- Not having prescriptions available for review
- Not documenting medication administration in accordance with standards of care
- Delayed medication procurement
- Not administering medications as ordered

RN Oversight

- Not monitoring the individual's health status or coordinating health services
- Not providing required oversight visits
- Inadequate documentation of services

KEY FINDINGS

Below is a summary of the key findings identified in the CY2024 Mortality Report:

The CY2024 DBHDD NOW/COMP waiver mortality rate was 15.2 deaths per 1,000 individuals, which is lower than the 2 previous calendar years.

Increasing age was significantly associated with mortality.

Increasing health risk was significantly associated with mortality.

Mortality increased markedly for individuals in the 55-64 age group. Increased risk of mortality due to increasing age is also found in the general U.S. and Georgia populations.

The top four HRST rating items - toileting, falls, and Emergency Room Visits - are significant predictors of mortality among the IDD population. Each unit increase in these scores correspondingly increased the probability of mortality: 30% for toileting, 27% for falls and 21% for emergency room visits. These 3 items, among the total 22 HRST Rating Items, accounted for 13% of the variations in mortality as indicated by a Pseudo R2 value of 0.13.

The analysis of mortality rates by risk level reveals a strong correlation between the level of risk and the crude mortality rate. This correlation is evident in the significant increase in mortality rates as we move from low to high risk levels. Furthermore, the proportion tests provide statistical evidence of this correlation, confirming significant differences in mortality rates across all risk levels.

Six 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 six:

- Heart diseases
- Respiratory diseases
- Pneumonia (included in Respiratory diseases counts for U.S. and GA)
- Endocrine, Nutritional, and Metabolic diseases
- Cerebrovascular diseases
- Cancer

Four of the 10 leading causes of IDD deaths in CY2024 were not common to the general population:

- Sepsis
- Seizures
- Disability
- Aspiration pneumonia

In CY2024, the most common provider deficiencies by category and risk level were "Medication and Healthcare Management." This category accounted for 55.97% of the deficiencies cited, with the deficiencies primarily being rated as high risk or critical risk. These deficiencies include issues such as proxy caregiving, healthcare plans and risk mitigation, medication administration, nursing oversight, responding to a change in condition, and bowel tracking, monitoring, and intervention.

APPENDIX A: METHOD FOR MORTALITY REVIEW AND ANALYSIS

This mortality report analyzes information on the death of individuals reported to DBHDD who 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 covers the time period January 1, 2024 through December 31, 2024. Individual level data was compiled beginning February 1, 2025.

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 waivers during CY2024 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 the Health Risk Screening Tool (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 HRST and IDD Connects)
- Rating Items (HRST assessment tool)
- Tracking of deficient practices and corrective action plans (Image)

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.

In the analysis of crude mortality rates, proportion z-test was employed to compare mortality rates across different age categories (Table 4), health care levels (Table 5) and risk levels (Table 8).

Deaths were included, regardless of death category, for all population-eligible adults who died in CY2024.

ANALYSIS AND MEASURES

Analysis was conducted using R Studio, an integrated development environment (IDE) tailored for the R programming language. A variety of statistical techniques were employed to comprehensively assess the relationships between variables and mortality, including significance testing through the Chi-Square test. The chi-square test with an alpha level set at 0.01, demonstrated that gender, region, and marital status variables were not significantly associated with mortality, as their p-value exceeded alpha = 0.01. Consequently, these variables were removed from further analysis. The remaining variables were then examined using measures of association such as Cramer's V, and assessment of multicollinearity using variance inflation factor (VIF).

To enhance the interpretability of coefficients and odds ratios, variables underwent appropriate transformations as needed. The variables utilized in logistic regression were categorized as follows:

- **Death** (outcome): Factor with levels, No Death (0) and Death (1)
- **Age**: Continuous Numeric (ranging from 18 to 93; Categorical (18-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+
- **Health Risk** (HRST Health Care Level [HCL]): Continuous Numeric (ranging from 1-6; Table 5); Ordered Factor (HCL 1, HCL 2, HCL 3, HCL 4, HCL 5, HCL 6
- **Intensity of Residential Setting:** Factor with levels, Lower Intensity (0) (independent apartment/home; live with family/relative/caretaker/friend/other; other)**;** Higher Intensity (1) (personal care home; community living arrangement; host home)
- **Rating Items**: Continuous Numeric (ranging from 0 to 4, with the exception of Item Q (Requirements for Licensed Intervention), which can only be rated as either 0 or 4); Rating Items variables are Eating, Ambulation, Transfer, Toileting, Clinical issues, Behaviors, Self-

abuse, Aggression, physical, Emergency drugs, psychotropic medications, Physiological, Gastrointestinal conditions, Seizures, Anticonvulsant medication, Skin breakdown, Bowel function, Nutrition, Requirements for licensed interventions, Safety, Injuries, Falls, Frequency of services, Professional health services, Emergency visits, Hospital admissions

All variables were entered into regression models individually, and the remaining 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 CY2024 IDD waiver population:

- The total number of unduplicated IDD individuals with active NOW/COMP waivers in CY2024 was 14,220.
- These individuals were aged 18-93, with a mean age of 42.18.
- Of these, 60.4 percent were male, and 39.6 percent were female.
- Region 3 (25.5%) was the most populous region, followed by Region 1 (23.3%), Region 2 (16.9%), Region 6 (13.3%), Region 5 (10.9%), and Region 4 (10.0%).
- Most of the population had COMP waivers (68.9%) as opposed to NOW waivers (31.1%).

More information about the characteristics of the population can be found on the following page (**Table 3**).

Table 3: Characteristics of the Adult IDD Waiver Population, CY2022-CY2024[14]

Characteristic	2022		2023		2024	
	n	%	n	%	n	%
Age						
18-24	1,087	7.8	1,167	8.4	1,151	8.1
25-34	3,976	28.7	3,953	28.4	4,116	28.9
35-44	3,301	23.8	3,424	24.6	3,540	24.9
45-54	2,274	16.4	2,229	16	2,264	15.9
55-64	1,940	14.0	1,877	13.5	1,838	12.9
65-74	985	7.1	997	7.2	1,032	7.3
75-84	264	1.9	246	1.8	254	1.8
85+	24	0.2	23	0.2	25	0.2
Gender						
Male	8,338	60.2	8,405	60.4	8,588	60.4
Female	5,510	39.8	5,506	39.6	5,625	39.6
Unknown	3	0.0	5	0.0	7	0.0
Region						
Region 1	3,193	23.1	3,238	23.3	3,307	23.3
Region 2	2,335	16.9	2,349	16.9	2,405	16.9
Region 3	3,478	25.1	3,539	25.4	3,633	25.5
Region 4	1,358	9.8	1,380	9.9	1,417	10.0
Region 5	1,631	11.8	1,564	11.2	1,549	10.9
Region 6	1,816	13.1	1,832	13.2	1,896	13.3
Region 99/Unknown	40	0.3	14	0.1	13	0.1
Waiver Type						
NOW	4,448	32.1	4,339	31.2	4,428	31.1
COMP	9,403	67.9	9,577	68.8	9,792	68.9
Residential Setting						
Lower Intensity	9,363	67.6	9,500	68.3	9,866	69.4
Higher Intensity	4,488	32.4	4,416	31.7	4,354	30.6
Race						
American Indian/Alaskan Native	5	0.0	4	0.0	6	0.0
Asian	103	0.7	124	0.9	141	1.0
Black/African American	6,021	43.5	5,994	43.1	6,071	42.7
Multiracial	97	0.7	102	0.7	120	0.8
Native Hawaiian/Other Pacific Islander	13	0.1	12	0.1	12	0.1
Other Single Race	291	2.1	301	2.2	315	2.2
Unknown/Refused	566	4.1	708	5.1	876	6.2
White/Caucasian	6,755	48.8	6,671	47.9	6,679	47
Total	13,851	100	13,916	100.0	14,220	100.0

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

APPENDIX C: 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

APPENDIX D: HRST EXPANDED SCORE DESCRIPTORS

Functional Status - Eating (Item A)	
Score	**Expanded Explanation**
0	**Eats independently:** May require simple adaptive equipment (hand splint, special eating equipment) but is able to eat without assistance/supervision. Individuals needing help only to cut food into regular, bite-sized pieces still rate a 0. Those who require altered food/fluid textures require a higher score.
1	**Requires INTERMITTENT physical assistance and/or verbal prompts to eat:** May need occasional physical help due to physical limitation or occasional verbal prompts due to issues with attentiveness or behavior.
2	**Requires CONSTANT verbal and/or physical assistance to complete a meal:** Has difficulty attending to task or may have motor limitations which require constant physical and/or verbal assistance. No issues with safety or swallowing.
3	**Requires constant assistance or other mealtime intervention to eat SAFELY OR has a feeding tube but maintains some level of oral intake:** May have difficulty coordinating breathing/swallowing while eating, dangerous behaviors or other conditions which impair their ability to eat safely. Unable to obtain adequate calories and fluids without assistance. Interventions are required (specific positioning support, eating devices, presentation techniques and/or modifications in food/fluid consistency). May have enteral (feeding) tube but maintains some level of oral eating.
4	**Receives ALL nutrition/hydration via other than oral routes (gastrostomy, jejunostomy or nasogastric tube, or total parenteral nutrition-TPN):** Unable to swallow safely OR has other issues requiring other than oral feeding procedures. Individuals who receive food by mouth against physician orders still qualify for a score of 4.

Functional Status - Ambulation (Item B)	
Score	**Expanded Explanation**
0	**Ambulates independently in ALL settings:** May use a walker or other means of support but does so independently in all settings without problems of safety.
1	**Walks with minimal supervision:** Requires the support of another person in close proximity in one or more settings. The primary issue is safety during ambulation.
2	**Predictably dependent on wheelchair for at least some mobility needs:** May or may not have the ability to walk in some settings. Individuals are able to use their upper body strength for repositioning AND have the ability to independently maintain trunk alignment. Able to recognize the need to change positions on a consistent basis.
3	**Requires mechanical assistance to maintain upright, seated position in wheelchair. Needs assistance to change position or shift weight:** Unable to walk. Able to be placed in an upright sitting position but cannot maintain a seated posture without outside mechanical support (specialized positioning equipment, adaptive wheelchair, etc.) or assistance. Needs assistance to reposition OR may not recognize need to reposition on a consistent basis. May need assistance to propel wheelchair.
4	**Disability prevents sitting in an upright position:** UNABLE to flex the hips to at least 45o OR unable to approach reasonable alignment of the head, shoulders, and pelvis. Due to degree of musculoskeletal deficits or deformity has limited positioning options.

Functional Status - Transfer (Item C)	
Score	**Expanded Explanation**
0	**Transfers independently in ALL settings:** May require verbal prompts, but no physical assistance.
1	**Needs someone to supervise the transfer for safety:** May need minor hands-on assistance, but able to bear their own weight and transfer safely in all settings.
2	**Needs physical assistance of 1 person to transfer or change position:** Individual is able to participate in transfers with the assistance of one other person managing a portion of their weight OR is completely dependent for lifting assistance but weighs less than 50 pounds.
3	**Needs physical assistance of 2 people to transfer or change position:** Individual is able to participate in transfers with the assistance of two other persons managing a portion of their weight OR is completely dependent for lifting assistance and weighs between 50 and 75 pounds.
4	**Needs lifting equipment or specialized procedures to safely transfer OR has a history of a fracture caused by a transfer procedure:** Requires specialized lifting equipment due to inability to participate in transfers. Includes individuals who weigh more than 75 pounds and are completely dependent for transfers, whether or not they actually use lifting equipment. May need range of specially designed positions due to severe spasticity, history of bone fragility, potential for injury due to size, or due to degree of physical deformity OR has had a history of a fracture caused by a transfer procedure at some time in their life. *Note: The influence of this item on the HCL extends beyond 12 months, because it relates to "history of".*

Functional Status - Toileting (Item D)	
Score	**Expanded Explanation**
0	**Independently accomplishes ALL toileting tasks:** No assistance required or appreciated.
1	**Minimal supervision or adaptation required:** May require reminders or some verbal and physical assistance to maintain hygiene or manage clothing adjustments. May require adaptations to restroom facilities (grab bars or built-up commode seat) Beyond this, minimal assistance is necessary.
2	**Continent of bladder and bowel, but constant attention is needed:** Requires physical assistance to complete hygiene tasks (wiping, hand washing) and clothing repositioning. May have occasional accidents but NOT routine, predictable incontinence.
3	**Incontinent of bowel or bladder:** Individual is predictably incontinent of bowel or bladder in one or more settings (nighttime, work or school settings or engages in willful incontinence.) May require scheduled toileting or use incontinence briefs. Includes infants, for whom incontinence is age appropriate.
4	**ANY use of catheterization procedures or colostomy for elimination within the past 12 months:** Urinary catheterization for ANY reason or elimination via colostomy, urostomy or ileostomy within the past year.

Functional Status - Clinical Issues (Item E)	
Score	**Expanded Explanation**
0	**None, or person does not participate due to personal preference or guardian objections. No clinical restrictions:** No ADLs changed or missed within the past year due to illness, behaviors, or necessary medical appointments (Full or partial day).
1	**Less than 2 days (full or partial) in a month on average due to clinical issues:** Able to participate in usual activities of daily living, but participation may occasionally be interrupted by illness, behavioral or mental health issues, or may have physician appointments to monitor a diagnosed condition or receive treatment.
2	**2 to 4 days (full or partial) in a month on average due to clinical issues:** Able to participate in usual activities of daily living, but participation may be interrupted by illness, behavioral or mental health issues, or may have physician appointments to monitor a diagnosed condition or receive treatment.
3	**5 to 10 days (full or partial) in a month on average due to clinical issues:** Able to participate in usual activities of daily living, but due to chronic unstable or progressively worsening health or behavioral issues, there is a significant impact on usual activities. May be due to physician appointments to monitor a diagnosed condition or receive treatment.
4	**More than 10 days (full or partial) in a month on average or normal daily activities are completely disrupted due to intensity of clinical issues:** Due to chronic, unstable, or progressively worsening health or behavioral issues participation in usual activities is severely impaired. May be ill or have physician appointments to monitor condition or receive treatment OR may be completely unable to participate in usual activities due to intensity of clinical issues.

Behavior - Self Abuse (Item F)	
Score	**Expanded Explanation**
0	**No self-abuse within the past year.**
1	**Minimal self-abuse, no additional consequences:** Behaviors that are considered self-abusive have been identified but have not required first aid or other intervention within the past year.
2	**Self-abuse needing additional observation LESS than 2 times a month:** Demonstrates behaviors that cause minor self-injury which may require treatment or other intervention but averaging to less than two interventions per month over the past year.
3	**Self-abuse needing medical/nursing attention or other intervention 2 OR MORE times per month:** Demonstrates behaviors that cause minor self-injury, which may require treatment or other intervention, but averaging two or more interventions per month over the past year.
4	**Self-injury interferes with the ability to engage in structured activities, requires increased staffing or causes extensive physical harm:** May be due to an existing behavioral pattern or the result of a single, isolated incident.

Behavior - Aggression (Item G)	
Score	**Expanded Explanation**
0	**No aggression within the past 12 months.**
1	**LESS than 5 incidents per month of minor aggression (verbal or physical) WITHOUT injury to others or property damage within the past 12 months.**
2	**5 OR MORE incidents per month of aggression (verbal or physical) WITHOUT injury to others or property damage within the past 12 months.**
3	**LESS than 5 episodes of aggression per month WITH minor injuries to others (injuries not needing medical TREATMENT) or property damage within the past 12 months.**
4	**Episodes of aggression have required increased staffing ratios, restrictive interventions OR caused serious physical harm within the past 12 months,**

Behavior - Physical Restraint (Item H)	
Score	**Expanded Explanation**
0	**Has NOT been physically restrained in the past 12 months.**
1	**Has been physically restrained less than once per month on average in past 12 months:** May include restraints used to facilitate some type of urgent medical procedure or care that without using restraint would have been impossible OR an acute behavioral event that required an immediate response.
2	**Has been physically restrained more than once per month on average in past 12 months:** Restraint use would require a physician's approval. Less restrictive options would have been explored and ruled out.
3	**Use of physical restraint procedures or devices MORE than 5 times per month on average but LESS than 12 hours per day:** Generally behavioral issues (hitting, biting, head-banging, etc.) that cause injury to self and/or others. May wear protective devices, including helmets to protect from injuries due to anticipated falls.
4	**Individual sustained and injury requiring medical TREATMENT as the result of application of physical restraint procedures/devices OR use of some sort of device 12 or more hours per day:** Generally, has significant behavioral issues (severe and continuous tissue damage, significant aggression, causing injuries). Includes use of helmets to protect from injuries due to anticipated falls or confinement of individual to a restricted space such as a prison cell.

Behavior - Chemical Restraints (Item I)	
Score	**Expanded Explanation**
0	**Has NOT received additional medications to control mood, mental status, or behavior in the past 12 months:** May have behavior issues but coping skills and behavioral intervention are sufficient to help the individual calm down without the necessity of drug/medication administration.
1	**Received pre-sedation before any medical or dental appointment in the past twelve months:** Anxiety/pain threshold has resulted in use of drugs prior to medical or dental procedure.
2	**Has received medications to control mood, mental status, or behavior 1 time in last 12 months.**
3	**Has received medications to control mood, mental status, or behavior 2-3 times in last 12 months.**
4	**Has needed medications to control mood, mental status, or behavior 4 or more times in last 12 months.**

Behavior - Psychotropic Meds (Item J)	
Score	**Expanded Explanation**
0	**Has NOT received medication to control behavior or a psychiatric disorder within the past year.**
1	**Receives 1 medication not associated with or known to cause tardive dyskinesia (TD) to control behavior or psychiatric disorder. Medication dosage has NOT CHANGED within the past year.**
2	**Receives 2 medications not associated with or known to cause tardive dyskinesia (TD) to control behavior or psychiatric disorder. Medication dosage has NOT CHANGED within the past year:** May or may not be taking a traditional psychotropic drug, but is taking medication (e.g., Benadryl, Inderal, Tegretol) for identified behavior or psychiatric diagnosis.
3	**Receives 3 or more behavioral or psychiatric medications not associated with or known to cause tardive dyskinesia (TD) OR psychotropic medication type or dosage has been changed in the past year:** On 3 or more medications to control behavior or psychiatric disorder OR receives ANY medication to control behavior or psychiatric disorder with at least one change in type or dosage in past year. Individuals on a drug tapering program will remain a 3 for one year after the medication is discontinued.
4	**Has received one or more medications associated with or known to cause Tardive Dyskinesia within the past year:** Includes medications such as metoclopramide (Reglan), even when they are not used for psychiatric purposes.

Physiology - Gastrointestinal (Item K)	
Score	**Expanded Explanation**
0	**None:** No GI concerns within the past 12 months AND no history of GI bleed.
1	**Occasional (2 or less) episodes of GI symptoms per month in the absence of acute illness**: Health is very stable. Only has an occasional episode of GI symptoms (2 or less per month). GI distress occurs with no apparent explanation.
2	**3-6 episodes of GI symptoms per month:** Occasional episodes of GI symptoms occurring 3 - 6 times per month. A documented pattern of incidents may be developing. These episodes are more likely to be associated with a disorder of the stomach or GI tract instead of an acute illness like the flu. This includes individuals who take over the counter medications for upset stomach, heartburn, or other GI symptoms.
3	**MORE than 6 episodes of GI symptoms per month, OR coughing within 1-3 hours after meals or during the night, OR hand-mouthing or PICA behaviors, OR has a history of GI bleeding OR has a current diagnosis of gastroesophageal reflux (GER)** *Note: The influence of this item on the HCL extends beyond 12 months, because it relates to "history of"*.
4	**GI condition requiring hospital admission in past 12 months OR receives more than one medication for GER: Conditions requiring hospital admission include GI bleeding, ulcerative conditions, vomiting, persistent dehydration, aspiration pneumonia, intestinal infections, bariatric surgery, gallbladder or pancreatic surgery, bowel impaction, obstruction or ileus, parasites, etc. OR individual regularly takes more than one medication (including over-the-counter medications) to control GER.**

Physiology - Seizures (Item L)	
Score	**Expanded Explanation**
0	**No seizure in lifetime OR more than 5 years since last seizure:** Individual has never had seizures OR has a known seizure history but has not had a seizure in more than 5 years. May or may not be taking antiepileptic medication.
1	**More than 2 but less than 5 years since last seizure:** Has a history of seizure activity but has been seizure-free for at least the last 2 years. May or may not be taking antiepileptic medication.
2	**Less than 1 seizure per month which DOES NOT interfere with functional activity:** Seizure activity occurs less than one time per month AND does not affect the person's ability to engage in functional activities for longer than 30 minutes.
3	**Seizure activity that DOES interfere with functional activities:** Seizures of any type which occur more than once a month OR seizure activity of ANY frequency that interferes with functional activities for longer than 30 minutes.
4	**Has required hospital admission for seizures in past the 12 months:** Any classification of seizure requiring a hospital ADMISSION (not just an ER visit) to treat seizure complications, diagnose or evaluate a seizure disorder or for surgery to treat a seizure disorder.

Physiology - Anticonvulsant (Item M)	
Score	**Expanded Explanation**
0	**None:** Has not taken antiepileptic medication within the past year.
1	**Use of SINGLE antiepileptic medication:** Dosage or medication type has NOT CHANGED within the past year.
2	**Use of 2 antiepileptic medications:** Dosage or medication type(s) have NOT CHANGED within the past year.
3	**Use of 3 or more antiepileptic medications OR any change in antiepileptic medication type or dosage in past 12 months OR receives valproic acid derivatives (Depakene or Depakote, etc.) in combination with any other antiepileptic medication OR receiving felbamate (Felbatol):** Individuals on a drug tapering program will remain a 3 for one year after the medication is discontinued.
4	**ER visit OR hospitalization due to antiepileptic drug toxicity in past 12 months.**

Physiology - Skin Breakdown (Item N)	
Score	**Expanded Explanation**
0	**No current or potential skin problems within the past year:** No issues with skin integrity in the past 12 months AND no known conditions associated with increased skin vulnerability.
1	**Red or dusky discolorations or other minor disorders of skin:** Skin may be reddened or have signs of poor circulation. This may also include individuals with typical presentations of psoriasis, acne, eczema, severe dryness, or other skin issues. Individuals with diabetes mellitus or other issues associated with skin vulnerability require a higher score (3 or greater).
2	**Either currently has or has had significant disruptions of skin integrity within last 12 months OR has a history of pressure sores:** Includes ANY significant wound, including surgical wounds, in individuals who do not have a known condition associated with skin vulnerability AND individuals who have had pressure sores, even if they resolved more than 12 months ago. *Note: The influence of this item on the HCL extends beyond 12 months, because it relates to "history of".*
3	**Within the past 12 months a significant break in skin has developed which required MORE than 3 months to heal OR has a condition directly associated with skin vulnerability:** Examples include spina bifida, spinal cord injury, nutritional compromise, low serum albumin, diabetes mellitus, continuous incontinence, self-injurious behaviors involving skin damage. Individual may NOT have had any actual issues with skin integrity in the past year.
4	**The skin condition required recurrent medical treatment or hospitalization in past 12 months:** Individuals have required hospitalization or surgery for a skin problem (invasive skin cancer, graft surgery for wounds or burns, etc.) OR have required visits to a wound care clinic, infectious disease or other specialist for a severe or potentially life-threatening skin issue.

Physiology - Bowel Function (Item O)	
Score	**Expanded Explanation**
0	**No bowel elimination problems within the past year AND no history of hospitalizations for bowel obstruction or ileus** *Note: The influence of this item on the HCL extends beyond 12 months, because it relates to "history of".*
1	**Bowel elimination is easy to manage with diet:** Receives a diet modification and/or increased fluids to assist with proper elimination.
2	**Bowel elimination is easy to manage with diet and routine supplements:** Has slight problems with constipation requiring intermittent or routine stool softener or fiber supplement.
3	**Receives at least one medication that affects bowel motility OR regularly receives more than one supplement or medication of ANY type to treat diarrhea or constipation:** Has recurrent problem with constipation or experiences episodes of intermittent diarrhea. May require suppositories, enemas or manual assessment for impaction.
4	**Any hospitalization in past 12 months required to treat an impaction, bowel obstruction or ileus OR history of ANY hospitalizations for bowel obstruction or ileus** *Note: The influence of this item on the HCL extends beyond 12 months, because it relates to "history of".*

Physiology - Nutrition (Item P)	
Score	**Expanded Explanation**
0	**Within ideal body weight range and able to maintain weight:** Requires no diet modifications, prescribed nutritional supplements or other intervention to maintain health. Individual may voluntarily take vitamins or other nutritional supplements without physician prescription or recommendation.
1	**Is slightly above or below ideal body weight range. May require extra calories or some dietary restrictions:** Health is generally stable, though weight is not within ideal range (not more than 10% above or below the far ends of the ideal body weight range.) May require additional calories through supplemental products or snacks, OR may require dietary restrictions (single servings at mealtime, low fat and low-calorie foods, restricted sweets, etc.).
2	**Is well managed on a prescribed diet:** Within desired weight range, but has a diet prescription for health maintenance or health concerns which have been under control for the past 12 months (low sodium, low cholesterol, etc.) This includes individuals receiving tube feeding formula who are otherwise nutritionally stable and well maintained.
3	**Has demonstrated weight instability in the past OR has an identified nutritional risk which required nutrition status monitoring within past 12 months: May have displayed unstable nutritional status episodes or trends in past 12 months which have produced health issues requiring intervention to maintain health OR is being monitored for one or more of the following:**
	Inability to reach or maintain desired body weight.
	Unplanned changes/trends in body weight (up or down).
	A chronic medical condition which affects nutritional status (diabetes mellitus, anemia, low serum albumin, renal or hepatic disease, GI disorder, impaction, pressure ulcer, etc.).
	Medical conditions that require monitoring and control of fluid intake levels.
	Difficulty consuming adequate intake, poor appetite, or frequent meal refusals.
	Food allergies or intolerance which limits intake of major food groups.
4	**Nutritional status unstable within the past 12 months: High risk with an unstable nutritional status. Required intensive nutritional intervention to address any of the following conditions:**
	Unplanned weight loss >10% of usual weight in past 12 months.
	Morbid obesity (body weight 100 pounds greater than, or twice the desired weight range or BMI >35).
	Hospitalization and/or treatment in the past 12 months for recurrent aspiration pneumonia, choking episodes, GI bleeding, unresolved diarrhea, vomiting, or unresolved wounds caused by pressure, diabetes, circulatory disorders, etc.
	Inability to consume an adequate diet due to chewing or swallowing disorder (for individuals receiving only oral intake).
	Gastrostomy or jejunostomy tube placement OR complications with existing enteral tube in the last 12 months.

Physiology - Requirements for Licensed Intervention (Item Q)	
Expanded Scoring Descriptors	
Treatments -- Includes interventions or procedures which MAY be performed independently or by unlicensed family/staff but, by their nature, are inherently high-risk. Also includes treatments which may not, under ANY circumstances, be delegated to non-licensed personnel. Scoring is intended to be consistent from setting to setting, regardless of policies dictating professional practice delegation. In many cases a Q-score qualifies the person to receive 24-hour nursing services, although not all individuals require such a restrictive setting. Item is scored either 0 or 4 regardless of how many qualifying issues apply.	
1	**Tracheotomy that requires suction.**
2	**Ventilator dependent.**
3	**Nebulizer treatments one or more times daily**: Receives medications such as Ventolin or Theophylline, by oxygen mist nebulizer at least once per day.
4	**Deep suction:** Requires deep suction, which means entering a suction catheter 6" or more into or below the voice box either via tracheotomy, oral or nasal routes.
5	**Requires complex medication calculations for insulin given via insulin pump or injection.**
6	**Has an unstable condition that requires ongoing (usually daily or more frequent) assessment and treatment by a licensed health care professional. Including but not limited to:**
	Medication therapy requiring intramuscular or intravenous injections using a PICC line or port, once or more times daily.
	Daily or more frequent catheterization, requiring sterile technique.
	Physician ordered treatments that CANNOT be delegated to a non-licensed person such as chemotherapy or renal dialysis.
	Sterile dressing/wound treatments routinely performed only in clinical settings or by licensed practitioners.
	Individuals in acute and/or end stages of cardiac, liver, lung, or kidney disease.
	End-stage terminal illness (cancer, AIDS) or persons with end-stage progressive neurological disorders (Sanfilippo Syndrome, Multiple Sclerosis, Huntington's chorea).
7	**1:1 staffing for behavioral issues:** Requires 1:1 staffing 16 or more hours EACH day due to behavioral issues.

Safety - Injuries (Item R)	
Score	**Expanded Explanation**
0	**No injury within the past year OR minor bruises/abrasions requiring only simple first aid:** Small cuts or scratches that do not require attention beyond cleansing and simple bandaging or minor bruises, sprains or strains that do not require immobilization.
1	**Bruises or cuts 1 or 2 times in the past year requiring first aid or nursing intervention within the past year:** Injuries of any type requiring minor first aid or nursing attention (but NOT physician treatment).
2	**Bruises or cuts requiring first aid or nursing intervention occurring 3 or more times within the past year:** Injuries of any type requiring first aid or nursing intervention (but NOT physician treatment) occurring 3 or more times within the past year.
3	**Injury requiring medical TREATMENT in the past year:** Sustained an injury that required treatment by a physician or in an emergency room (sutures, casting a fracture, etc.) within the past year. Injuries receiving physician evaluation as a precaution but NOT requiring treatment should receive a lower score.
4	**Major injuries requiring hospital admission within the past year:** Has documented evidence of fracture or other major trauma which required hospital admission within the past year.

Safety - Falls (Item S)	
Score	**Expanded Explanation**
0	**No falls within the past year.**
1	**1 - 3 falls within the past year.**
2	**4 - 6 falls within the past year OR wears a helmet to protect from injuries due to anticipated falls from events such as seizures or narcolepsy.**
3	**More than 6 falls in the past year.**
4	**Any fall that resulted in a fracture or hospital admission due to injuries in the past year.**

Frequency of Services - Professional Healthcare Services (Item T)	
Score	**Expanded Explanation**
0	**No visits other than routine screening or health maintenance visits within the past year:** Visits to licensed health care providers that did NOT identify or manage a diagnosed condition. These visits are normally only to primary health care providers and NOT to specialists.
1	**Required 2 visits per quarter on an average over the past year to health care provider(s):** Visits to ANY health care providers intended to identify or manage a diagnosed condition.
2	**Required 1-2 visits per month on average to health provider(s) OR required daily nursing services greater than 14 days continuously in past 12 months.**
3	**Required 3 visits per month on average to health care providers within the past year.**
4	**Required 3 visits per month to health care providers PLUS unscheduled appointments within the past year:** In addition to 3 or more visits per month, unplanned visits to health care providers were required to treat acute health incidents within the past year.

Frequency of Services - Emergency Room Visits (Item U)	
Score	**Expanded Explanation**
0	**No emergency room visits within the past year.**
1	**Emergency room visit due to physician absence or non-emergency situation within the past year.**
2	**One emergency room visit in last year for acute illness or injury.**
3	**Two or more emergency room visit for acute illness or injury in the past year.**
4	**Any emergency room visit in the past year that resulted in hospital admission.**

Frequency of Services - Hospital Admissions (Item V)	
Score	**Expanded Explanation**
0	**No hospital admissions within the past year.**
1	**Hospital admission in the past year for scheduled surgery or procedure:** Normally for conditions that are not deemed urgent where there is an elapsed period (days to weeks) between diagnosis and admission, including routine childbirth.
2	**Hospital admissions for acute illness or injury within the past year:** Often occurs from an emergency room or physician's office with little or no elapsed time between diagnosis of the condition and hospital admission. Includes admissions to psychiatric facilities or ICFs.
3	**2 or more hospital admissions for acute illness or injury in the past year.**
4	**Admission to ICU during a hospitalization in past year:** Initial hospitalization may have been for an acute illness or injury, but ICU admission may also occur as the result of scheduled or elective procedures.

APPENDIX E: ADDITIONAL STATISTICAL INFORMATION

Table 4: Mortality Rates Among the Adult IDD Waiver Population by Age Category, CY2024

Age Category	Population	Deaths (#)	Deaths (%)	Crude Mortality Rate	Significance
18-24	1,151	10	4.6%	8.7	--
25-34	4,116	30	13.9%	7.3	NS
35-44	3,540	31	14.4%	8.8	NS
45-54	2,264	28	13.0%	12.4	NS
55-64	1,838	55	25.5%	29.9	|z|=3.9714; p = 0.00004
65-74	1,032	42	19.4%	40.7	NS
75-84	254	18	8.3%	70.9	NS
85+	25	2	0.9%	80.0	NS
Total	**14,220**	**216**	100.0%	15.2	--

Table 5: HRST Description with Statistical Analysis

HCL	Description	HRST Risk Scores Statistics, mean (SD)
1	Low Risk	3.1(1.7)
2	Low Risk	6.6 (1.7)
3	Moderate Risk	9.3 (1.7)
4	High Moderate Risk	11.3 (2.0)
5	High Risk	12.6 (2.2)
6	Highest Risk	13.8 (2.3)

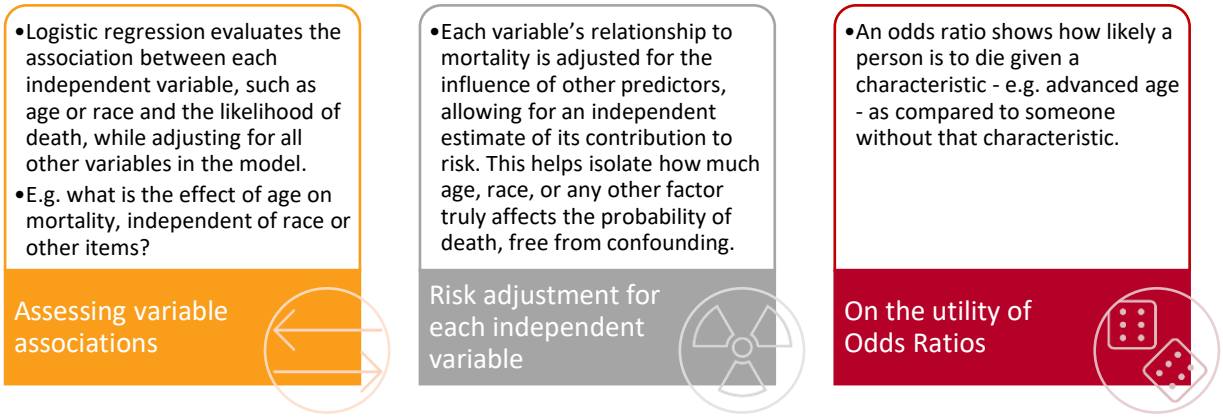
Table 5 provides a summary of the HRST risk scores corresponding to each Health Care Level (HCL). It is evident that there is a consistent increase in the average HRST risk scores as we move from lower to higher HCLs.

Table 6: Mortality Rates by HCL, CY2024[15]

HCL	Population	Deaths (#)	Deaths (%)	Crude Mortality Rate	Significance
1	3,392	14	6.5%	4.1	--
2	4,262	27	12.5%	6.3	NS
3	2,742	48	22.2%	17.5	|z|= 4.4332; p = 0
4	1,635	35	16.2%	21.4	NS
5	1,106	38	17.6%	34.4	NS
6	1,083	54	25.0%	49.9	NS
Total	**14,220**	**216**	**100.0%**	**15.2**	--

LOGISTIC REGRESSION

Logistic regression was selected as the analytical method to evaluate the association between each HRST rating item and mortality, while simultaneously adjusting for the influence of all other items. In our multivariable logistic regression model (mortality ~ rating item1 + … + rating item22), the effect of each individual item is estimated while holding the remaining 21 items constant. This approach minimizes confounding and allows us to isolate the adjusted contribution of each rating item to the outcome. To interpret the magnitude and direction of these associations, we converted the regression coefficients into odds ratios (OR = e^β). The odds ratio quantifies how a one-unit increase in a rating item (or a shift from the reference category) affects the odds of mortality. An OR greater than 1 indicates an increased likelihood of mortality, whereas an OR less than 1 suggests a decreased likelihood. Finally, we identified the top three rating items most strongly associated with mortality by selecting those with statistically significant p-values at the 99% confidence level. These items demonstrated the most robust and meaningful contributions to the model.



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

Table 7: Odds Ratio for Logistic Regression Model of Mortality on 22 rating items; CY2024

Rating Items (Predictors)	Odds Ratio	99% CI	p-value
Toileting	1.30	1.05, 1.61	**0.001**
Falls	1.27	1.05, 1.53	**0.001**
Seizures	1.21	0.99, 1.48	0.013
Emer Room Visits	1.20	1.01, 1.43	**0.006**
Ambulation	1.19	0.84, 1.68	0.2
Transfer	1.14	0.88, 1.49	0.2
Hosp Admissions	1.13	0.93, 1.38	0.11
Prof Healthcare SVCS	1.12	0.90, 1.38	0.2
Psychotropic Meds	1.11	1.00, 1.25	0.013
Gastrointestinal	1.09	0.96, 1.24	0.092
Skin Integrity	1.04	0.87, 1.25	0.6
Eating	1.04	0.87, 1.25	0.6
High Risk Treatments	1.04	0.92, 1.17	0.4
Bowel Function	1.01	0.87, 1.18	0.8
Beh Support Chemical	0.99	0.83, 1.16	0.9
Self-Abuse	0.96	0.79, 1.16	0.6
Nutrition	0.94	0.82, 1.07	0.2
Clinical Issues	0.93	0.75, 1.14	0.4
Beh Support Physical	0.91	0.68, 1.15	0.3
Injuries	0.89	0.73, 1.07	0.12
Aggression	0.86	0.71, 1.03	0.038
Antiepileptic	0.85	0.67, 1.05	0.049
Pseudo R^2: 0.13			

Table 7 presents the Odds Ratio for the Logistic Regression Model of Mortality, which is based on 22 rating items for CY2024. The odds ratio results suggest that for each unit an increase in the Toileting score, the probability of mortality increases by 30% [OR = 1.30, 99% CI (1.05, 1.61), p = 0.001]. Similarly, for each unit increase in the Falls score, the probability of mortality increases by 27% [OR = 1.27, 99% CI (1.05, 1.53), p = 0.001]. Lastly, for each unit increase in the Emergency Room Visits score, the probability of mortality increases by 20% [OR = 1.20, 99% CI (1.01, 1.43), p = 0.006].

The Pseudo R2 value is 0.13, indicating that the entire model explains 13% of the variations in mortality using these 22 HRST Rating Items. based on the significance level of Alpha = 0.01.

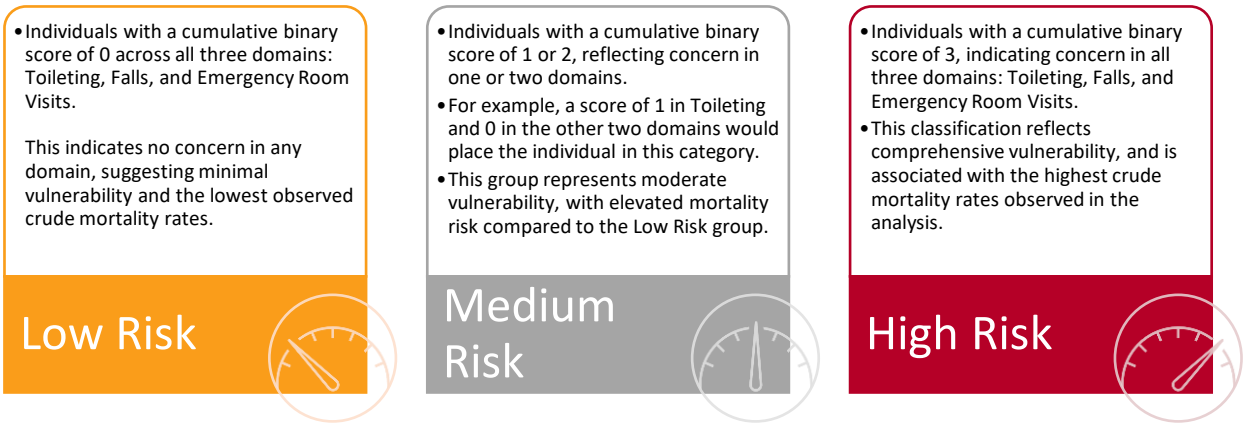
Table 8: Mortality Rates by Risk Level based on Top 3 HRST Rating Items; CY2024[16]

Risk Levels	Population	Deaths (#)	Death (%)	CMR	Significance		
					Total	Low	Medium
Low	4,049	11	5.09	2.72	|z| = 6.3212; p = 0	--	--
Medium	8,685	138	63.89	15.89	|z| = 0.4164; p = 0.33854	|z|=6.4372; p= 0	--
High	1,486	67	31.02	45.09	|z| = 8.2442; p = 0	|z| = 11.8518; p = 0	|z| = 7.401; p = 0
Total	**14,220**	**216**	**100.00**	**15.19**	--	--	--

Table 8 provides a comparative analysis of the top three crude mortality rates for Calendar Year 2024, based on three HRST rating items: toileting, falls, and emergency room visits. Each item is originally scored on a scale from zero to four. For the purpose of risk classification, we applied a binary transformation in which a score of zero was retained to indicate no concern, while any score from one to four was re-coded as one to reflect the presence of concern at any level.

Using these binary values, we calculated a cumulative score for each individual by summing across the three items. Individuals with a total score of zero, indicating no concern in any domain, were classified as Low Risk. Those with a total score of three, indicating concern across all three domains, were classified as High Risk. Individuals with a total score of one or two were categorized as Medium Risk, reflecting partial concern in one or two domains.

Based on this new classification system, we stratified individuals into Low, Medium, and High Risk categories for each of the three HRST rating items (toileting, falls, and emergency Room Visits). This stratification enabled a more targeted analysis of mortality outcomes across varying levels of concern within each domain.



[16] "--"indicates that a statistical test was not conducted. The term 'CMR' is employed as an abbreviation for Crude Mortality Rate, which is calculated per 1000 individuals.

The overall crude mortality rate (CMR = 15.19) is significantly higher than the rates observed at low (CMR = 2.72, z| = 6.3212, p = 0). Although the rate at the medium risk level (CMR = 15.89, |z| = 0.4164; p = 0.33854) is close to the overall CMR, it is not statistically significant at Alpha = 0.01. However, the mortality rate at a high-risk level (CMR = 45.09, |z| = 8.2442; p = 0) markedly exceeds the overall rate. In essence, the crude mortality rate increases by approximately 2.97 times at the high-risk level compared to the overall rate, while it decreases by about 5.58 times at the low risk level.

Subsequently, proportion tests were conducted to compare crude mortality across different risk levels. The results revealed a statistically significant difference between the total crude mortality and the crude mortality at low and high-risk levels at Alpha = 0.01, with |z| = 6.3212 (p = 0) and |z| = 8.2442 (p = 0), respectively. The comparison between total and medium risk level yielded |z| = 0.4164 (p = 0.33854), indicating no significant difference.

Moreover, a statistically significant difference was found between the crude mortality at low risk level and those at medium and high-risk levels at Alpha = 0.01, with |z| = 6.4372 (p = 0) and |z| = 11.8518 (p = 0), respectively. Lastly, a significant difference was observed between the crude mortality at medium risk level and at high risk level at Alpha = 0.01, with |z| = 7.401 (p = 0).