# Risk, Rates, and Resolution of Events for Individuals with Complex Needs

Georgia Department of Behavioral Health and Developmental Disabilities

Office of Performance Analysis


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# Introduction

An analysis of health and behavior risks, adverse events, and resolution activity is a component of health and safety oversight and is part of DBHDD's quality management and improvement system. It is important to understand the level of risk for certain key conditions in the IDD population, to consider how frequently a negative health or negative behavioral outcome occurs for those at risk of such events, and how, when they do occur, the system responds to resolve them.

The purpose of this report is to examine what DBHDD has learned about health and behavioral risks and adverse events, and when adverse events do occur, to understand both how the system responds to those events and how they may be resolved.

## 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,[1] resulting in a subset of the full population. DBHDD may consider other theoretically-sound methods and procedures to understand or address missing data.[2]
- Third, in some cases, DBHDD utilizes some form of random sampling[3] (e.g., a random subset of providers or random subset of all events that occurred). For this approach to be valid, one must be able to define the entire population from which it is being drawn, and each unit (e.g., individual, situation, etc.) must have an equal chance of being included in the sample. This method is unbiased, and the resulting sample is representative of the full population under study.
- Fourth, DBHDD also occasionally makes use of purposive sampling, a non-probability sampling method. This method is typically reserved for specific instances (e.g., identifying when a situation occurred, selecting specific cases, identifying specific errors, etc.). Purposive sampling is a selective, non-probabilistic method, and purposive sampling is not representative of the full population under study; therefore, findings or results based on purposive sampling are not generalizable to the full population, rather only to the cases from which data were sampled.
- Fifth, a goal of inferential statistics is to make inferences about the population based on a sample smaller than the population. DBHDD considers sample sizes carefully and analytically to create empirical samples large enough to have sufficient statistical power to detect associations or differences and allow valid inferences to be drawn from and generalized about the population being studied.

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

[2] 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. DBHDD may use multiple imputation for data that are MCAR or MAR, which allows missing data to be accounted for in a statistically valid and unbiased way. Multiple imputation assumes that data are from a continuous multivariate distribution and contain missing values that can occur for any of the variables. If these key statistical assumptions are satisfied, then this method can be used for data that are missing completely at random or missing at random.

[3] 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.

## Interpreting Statistical Tests

Some of the following sections report statistical analyses. Statistical analyses are useful to identify associations and trends among variables. Statistics commonly refers to "statistical significance." Sometimes associations or patterns occur due to random chance. A statistically significant difference for a result or relationship has a likelihood that it is caused by something other than mere random chance. It is a natural tendency to assume when there is a statistically significant difference or association that it must result from the something other than a random chance and that the difference must have a specific cause.

It is important to exercise caution when interpreting statistical significance in this manner, as sufficient facts may not necessarily be present to conclude a specific idea of what that something is. Statistical significance should be studied further by gathering additional information and by completing a more extensive analysis through additional steps. Also, statistical significance does not equate to importance or meaningful significance. Meaning and importance of findings can only be determined by more careful examination of additional information.

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

# Elevated Risk and Adverse Events in the DBHDD IDD Population

This report examined health and behavior events that occurred between January 1, 2018 and December 31, 2018. The date parameters used in this report will be considered as the baseline for elevated risk and incidence prevalence, thereby facilitating future comparisons and reporting.

## Elevated Risk: HRST

These analyses examine *elevated risk* of health and behavior events. The most recent health risk data were extracted from the Health Risk Screening Tool (HRST) as of December 31, 2018 and were used as a measure of elevated risk. The HRST is designed specifically to identify and quantify health and behavior risks, and the HRST items, risk dimensions, and other detailed information can be found at the end of this report (Appendices A and B). Each HRST item may receive a score from zero to four, except item Q, which is scored either zero or four. Health Risk Screening, Inc. (the company that owns the HRST) states that a risk score of three or higher on any item within a risk area indicates elevated risk. DBHDD operationally defined *elevated* risk accordingly. Additional information about the operational definition of each risk area can be found in Tables 1 and 2.

## Elevated Risk: Statewide Clinical Oversight

DBHDD, via the Office of Health and Wellness (OHW), utilizes the Statewide Clinical Oversight (SCO) program for individuals in all regions with intellectual and developmental disabilities (IDD) to minimize risks due to the complexity of their medical or behavioral needs. This includes multidisciplinary assessment, monitoring, training, technical assistance, and mobile response to contracted providers, individuals, and support coordinators who provide care and treatment to individuals with IDD in the community. The SCO program enhances the department's activities to identify, support, and monitor individuals with heightened risks, which include, for example, the following:

- Health-related: an increase in the HRST score; known emergency department visit or hospitalization; recurring serious illness without resolution; diagnosis with an episode of aspiration, seizures, bowel obstruction, dehydration, gastro-esophageal reflux disease (GERD); or unmet need for medical equipment or healthcare consultation;
- Behavioral: material changes in behavior; known emergency department visit or hospitalization; a behavioral incident with intervention by law enforcement, or functional or cognitive decline;
- Environmental: threat of or actual discharge from a residential provider, change in residence, staff training or suitability concern, or accessibility issues that relate to the health or safety of the individual (including loss of involved family member or natural supports or discharge from a day provider);

- Other: confirmed identification of any factor above by a provider, support coordinator, family member, or advocate.

The OHW identifies individuals in need of SCO through surveillance of many processes and mechanisms, including Critical Incident (ROCI) reports and referrals from the Intensive Clinical Support Team (ICST), email, and transitions reviews (e.g., Service Review and Technical Assistance monitoring). SCO surveillance data is captured and maintained in the Developmental Disabilities Clinical Oversight (DDCO) database.

## Measurement of Health and Behavioral Events

DBHDD used event information captured in the DDCO database for this population to establish incidence percentage rates (i.e., per 100 individuals) for each risk subgroup that rose to the level of statewide clinical oversight. Fortunately, there is tremendous overlap between the risk areas of the HRST and the health and behavioral events captured in the DDCO; only those areas measured by both datasets are included in this analysis. DBHDD is exploring additional ways to identify both health risks as well as identify health and behavioral outcomes for future analyses.

Health and behavior events were identified using data between January 1, 2018 and December 31, 2018 from the DDCO database. Count data extracted from the DDCO yielded counts of incidents (event qualifiers) that resulted in individuals being included in SCO. Individuals may have had multiple event qualifiers; therefore, the total count indicates the number of qualifying events, not the number of individuals.

## Results

Results are presented in Tables 1 and 2 and are organized by descending order of proportion rate of adverse outcome that rose to the level of SCO. Table 1 focuses on those individuals at elevated HRST risk for common, IDD-specific risk events, as well as the percent or rate of adverse outcomes that rose to the level of SCO. The occurrence of these IDD-specific events is considered an adverse outcome that rose to the level of SCO. Table 2 focuses on those individuals who had elevated HRST risk for repeated hospital or emergency department utilization, as well as the percent or rate of hospital readmission or emergency department repeated visits.

*Table 1: Elevated Risk and Adverse Outcomes Among IDD Individuals, CY18 (n = 12,798)*

| | | Elevated Risk | | Adverse Events | | |
|---|---|---|---|---|---|---|
| **Risk Area** | **HRST Item** | **Individual Count** | **Percent** | **Individual Count** | **Percent of Subgroup** | **Count of Potentially Averted** |
| Behavior Events | F, G, H, I, or J | 7,212 | 56.35% | 360 | 4.99% | 6,852 |
| Seizures | L or M | 1,885 | 14.73% | 51 | 2.71% | 1,834 |
| Bowel Obstruction | O | 2,041 | 15.95% | 34 | 1.67% | 2,007 |
| Aspiration | A | 2,760 | 21.57% | 33 | 1.20% | 2,727 |
| Dehydration | P | 5,177 | 40.45% | 22 | 0.42% | 5,155 |
| GERD | K | 3,194 | 24.96% | 2 | 0.06% | 3,192 |

*Notes: Elevated risk was measured using HRST items >=3 and indicates the risk of experiencing a health or behavior event. Adverse events / incidents that rose to the level of SCO were determined using DDCO data. Individuals may have had multiple events which could result in lower subgroup percentages.*

Major findings from examining the levels of elevated HRST risk in the IDD population and incidence rates for each risk group are presented below.

## Behavior Events

- Over half (56%) of the population was at elevated HRST risk for a negative behavior event, the largest risk group.
- About five percent of those at elevated HRST risk for a negative behavior event experienced a negative behavioral outcome that rose to the level of SCO.
- These findings suggest that DBHDD services and supports potentially averted adverse behavioral outcomes that rose to the level of SCO for 6,852 of those individuals at elevated HRST risk for a negative behavioral outcome.

## Seizures, Aspiration, Bowel Obstruction, Dehydration, and GERD

- These conditions are prominent risk areas for individuals with IDD, and some of these conditions are also some of the top 10 leading causes of death for individuals with IDD.[4]
- At least 15 percent (and up to about 41 percent) of the entire DBHDD IDD population is at elevated HRST risk for at least one of these events.
- Despite the percentage of the DBHDD IDD population at elevated HRST risk for negative outcomes for these conditions, these conditions have the lowest incident rates that rise to the level of SCO.
- Less than 3 percent of those at elevated HRST risk for any of these conditions experienced a negative outcome in the respective risk areas that rose to the level of SCO.

These findings suggest that DBHDD services and supports potentially averted adverse outcomes that rose to the level of SCO for those with elevated HRST risk as indicated below:

- Seizures: 1,834 potentially averted events
- Aspiration: 2,727 potentially averted events
- Bowel Obstruction: 2,007 potentially averted events
- Dehydration: 5,155 potentially averted events
- GERD: 3,192 potentially averted events

[4] Mortality Report Calendar Year 2018

# Elevated Risk and Occurrence of Hospital and Emergency Department Visits in the SCO Population

Unlike the IDD-specific conditions identified in Table 1 that can be defined as adverse outcomes, hospital and emergency department (ED) visits are not necessarily adverse outcomes. For instance, a hospital visit for a chronic condition may be appropriate and avert more serious risks. DBHDD is investigating additional data and methods that will allow differentiation of negative or adverse outcomes in future analyses. However, DBHDD considers it important to understand prevalence of elevated HRST risk for inpatient and ED utilization, as well as the occurrence in those at elevated risk for chronic hospitalizations and ED utilization.

*Table 2: Elevated Risk and Incident Percent of Hospitalizations and EUD Utilization Among IDD Individuals, CY18 (n = 12,798)*

| | | Elevated Risk | | Events | | |
|---|---|---|---|---|---|---|
| **Risk Area** | **HRST Item** | **Individual Count** | **Percent** | **Individual Count** | **Percent of Subgroup** | **Count of Potentially Averted** |
| Chronic Hospitalization | V | 853 | 6.67% | 376 | 44.08% | 477 |
| Chronic ED Visits | U | 2,223 | 17.37% | 524 | 23.57% | 1,699 |

*Notes: Elevated risk was measured using HRST items >=3 and indicates the risk of experiencing a health or behavior event. Adverse events / incidents that rose to the level of SCO were determined using DDCO data. Chronic indicates at least 2 hospitalizations or visits. Individuals may have had multiple events which could result in lower subgroup percentages.*

## Hospital Risk and Incident Rate

- Seven percent of the population was at elevated HRST risk of chronic hospitalization, which is the lowest risk area.
- However, the incidence rate of chronic hospitalizations among those at elevated HRST risk is the highest.
- This means that almost half of the people at elevated HRST risk for hospitalization experienced chronic hospitalization.
- The HRST indicator for risk of hospitalization in this situation, then, is associated with and sensitive to chronic hospitalization occurring.
- These findings suggest that DBHDD services and supports potentially averted chronic hospitalizations for 477 of those at elevated HRST risk for hospitalization or about 56 percent of the time.

## ED Utilization

- Seventeen percent of the population was at elevated HRST risk for chronic ED visits.
- The incidence rate of chronic ED visits among those at elevated HRST risk was the second highest.
- This means that about 24 percent of the individuals at elevated HRST risk for an ED visit also experienced chronic ED visits.
- These findings suggest that DBHDD services and supports potentially averted chronic ED visits for 1,699 of those at elevated HRST risk for ED visits or about 76 percent of the time.

# Resolution of Events for Individuals with Complex Needs

The previous section looked at adverse events (as well as hospital and emergency department utilization, which may not indicate adverse events). When adverse events occur, DBHDD works towards resolution. Resolution is defined individually and may include, for example, a return to baseline level of function, establishment of a new baseline, or confirmation of a disease process that will result in a continued decline.

DBHDD manages the IDD service system to deliver services that prevent, avert, intervene, mitigate, and resolve health issues before they become adverse events. When evaluating the performance of a system, it is important to consider how the system of services and supports respond to events, not just the adverse events, as the analyses clearly demonstrate that exponentially more adverse events that rise to the level of statewide clinical

oversight are avoided than occur. The following sections will look at event resolution through Statewide Clinical Oversight, Support Coordination Services Coaching and Referrals, and the Individualized Quality Outcomes Measures Review (IQOMR).

## Data Collection Process

Individuals were identified from the list of 1,933 individuals from the DDCO database, and the data were extracted in March 2019.

Hospital and ED admissions were identified from the ROCI database, DBHDD's critical incident management system. Critical incident data for hospital and ED utilization can be captured across different critical incident categories in ROCI. Therefore, hospital and ED admissions for this study were determined through utilizing and consolidating data from multiple critical incident categories. Individuals' IQOMR data (as of December 2018), as well as baseline and follow-up health risk data, were extracted from the Consumer Information System (CIS), DBHDD's case management system.

Data from 1,369 individuals were included in the hospital and ED admission analysis. Forty-three individuals' Health Care Level (HCL) data were not current; therefore, 1,326 individuals' data were included in the HCL analysis.

## Data Analysis Process

The first analysis compared the number of times individuals were admitted into hospitals and EDs six months prior to their first CY18 qualifying event and the six-month period afterwards. The second analysis compared the baseline HCL on September 2018 and as of December 2018. Paired t-tests were used to complete both analyses. Statistical analyses proceeded with determining statistical significance at $p < 0.01$ ($a = 0.01$).

## Hospital and Emergency Department Utilization

The mean number of hospital admissions during the six-month period before the CY18 qualifying event (mean = 0.22, SD = 0.78) and the six-month period after the qualifying event (mean = 0.31, SD = 1.02) were not statistically different (Table 3).

The mean number of ED admissions during the six-month period before the CY18 qualifying event (mean = 0.21, SD = 0.68) and the six-month period after the CY18 qualifying event (mean = 0.24, SD = 0.80) were not statistically different (Table 3).

There was a statistically significant increase ($t = 4.84$; $df = 1,325$; $p < 0.001$) in the mean HCL score at baseline (mean = 3.95, SD = 1.62) and the mean HCL score during the follow-up period (mean = 4.04, SD = 1.59; Table 3).

*Table 3: Hospital and ED Admissions compared to HCL Scores at Baseline and Follow-Up*

| Outcome | Baseline | | Follow-Up | | Statistical Significance |
|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | |
| Hospital Admissions | 0.22 | 0.78 | 0.31 | 1.02 | NS |
| ED Admissions | 0.21 | 0.68 | 0.24 | 0.80 | NS |
| HCL Score | 3.95 | 1.62 | 4.04 | 1.59 | $p < 0.001$ |
| 6-month period prior to CY18 qualifying event | | | | | |

*Notes: Shown are means at baseline and follow up, with standard deviations in parentheses. Statistical significance tested using paired t-tests.*

The findings presented above indicate that individuals receiving SCO services have a similar number of hospital and ED admissions during the follow-up period. This is significant given that HCL scores, which are a measure of health risk and comorbid conditions, increased in the latter half of 2018. Previous research indicates that IDD individuals who have higher levels of health risk and comorbidity face a significantly higher likelihood of being

admitted to hospitals,[5,6] EDs,[7] and have increased complications of care.[8] That hospital and ED admissions for those receiving SCO remained constant while health risk increased are especially positive indicators of not only SCO effectiveness but also overall IDD services.

Prior to conducting the analyses presented above, DBHDD was aware that extant research indicates that additional clinical oversight and involvement with IDD individuals may actually result in increases in hospital admissions.[9] Research has also concluded that having increased physician or clinical involvement (such as increased SCO and increased intensive support coordination) actually is an indicator of chronic illness or increasing comorbidity.[1,10] Therefore, it would not have been a necessarily negative finding had hospital and ED admissions increased. That they neither increased nor decreased, then, led DBHDD to consider other markers for quality of outcomes for individuals receiving SCO. Additional analysis, detailed later, did find that this was an overall positive outcome.

It is important to note that only approximately one calendar year of individuals who received SCO were included in this analysis, and only a limited number of outcomes were examined. As additional years of SCO data are collected in the DDCO database, the impact of SCO and other IDD services can be integrated better with additional outcomes and process data. Moreover, SCO can be examined not only as a standalone support service but also in combination with other DBHDD services.

## Resolution of Events for Individuals with Complex Needs Through SCO

DBHDD provides SCO and high-risk surveillance to individuals with intellectual and developmental disabilities receiving DBHDD-funded services in the community. That an individual is identified for SCO indicates the individual may have complex needs, thus a need for clinical oversight. Clinical oversight is designed to engage as needed, episodically, and through coordination of community resources to the extent possible for those individuals with complex needs who reside in the community. *Therefore, SCO provides the oversight for resolving the issues—not the actual resolution activities*.

DBHDD uses a system of services, providers, state and field office staff, clinical processes, administrative processes, analysis, and performance monitoring to deliver an effective system of supports to assist individuals. The data capturing the resolution processes and outcomes of issue resolution is captured in other areas than the DDCO, such as consumer medical records, case management systems, coaching, referrals, and IQOMR activities of support coordination, which is also responsible for the resolution of events for individuals with complex needs. Therefore, event resolution analysis in this report pulls from coaching, referrals, and IQOMR activities of support coordination.

Additional data about the oversight of issue resolution activities is captured in the DDCO database. DBHDD is working to develop systematic reporting and analytical reports that illustrate and provide information about the oversight of resolution activities of SCO; later reports may provide additional information concerning oversight activities. Analytical reports, such as this one, rely mainly on information about the actual resolution activities and outcomes of the resolution activities. That said, current resolution status of events tracked within the DDCO database for 2018 follows:

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[5] Balogh, R.S., Ouellette-Kuntz, H., Brownwell, M., & Colantonio, A. (2013). Factors associated with hospitalizations for ambulatory care-sensitive conditions among persons with an intellectual disability—a publicly insured population perspective. *Journal of Intellectual Disability Research, 57(3)*, 226-239.

[6] Kelly, C. L., Thomson, K., Wagner, A. P., Waters, J. P., Thompson, A., Jones, S., Holland, A. J., & Redley, M. (2015). Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: a single-site study of 30-day readmission rates. *Journal of Intellectual Disability Research, 59(9)*, 835-844.

[7] Hosking, F. J., Carey, I. M., DeWilde, S., Harris, T, Beighton, C., & Cook, D. G. (2017). Preventable emergency hospital admissions among adults with intellectual disability in England. *Annals of Family Medicine, 15(5)*, 462-470.

[8] Ailey, S. H., Johnson, T. J., Fogg, L., & Friese, T. R. (2015). *Intellectual and Developmental Disabilities, 53(2)*, 114-119.

[9] Roos, L. L., Walld, R., Uhanova, J., & Bond, R. (2005). Physician visits, hospitalizations, and socioeconomic status: ambulatory care sensitive conditions in a Canadian setting. *Health Services Research, 40*, 1167-1185.

[10] van Walraven, C., Seth, R., Austin, P. C., & Laupacis, A. (2002). Effect of discharge summary availability during post-discharge visits on hospital admission. *Journal of General Internal Medicine, 17*, 186-192.

*Table 4: SCO Resolution Status Summary, CY18 (n = 5,200)*

| SCO Resolution Status | | Events | Percent |
|---|---|---|---|
| **Inquiry Initiated** | An action step which involves accessing pertinent data sources to gather additional information about the status of the individual or issue. | 589 | 11% |
| **Resolved** | The qualifier resulting in entry into SCO was resolved or the person is deceased and no longer requires oversight of the issue. | 1,353 | 26% |
| **Continue to Monitor** | Follow-up has occurred, and the issue not resolved. Monitoring and outreach will continue to occur until is resolved. This option may also be elected for those individuals, who are stable, but required continue monitoring or for those individuals, who are diagnosed with chronic or end of life conditions. | 2,755 | 53% |
| **Stabilized with Continued Surveillance** | Frequently related to more complex individual, experiencing long term/ongoing complications, or with chronic condition that will not resolve (i.e., diabetes, cancer in remission, seizure disorder). | 503 | 10% |

# Resolution of Events for Individuals with Complex Needs through Support Coordination Services: Coaching and Referrals

Support coordination services are a set of interrelated activities for identifying, coordinating, and overseeing the delivery of services to enhance the health, safety, and general wellbeing of waiver participants within the context of the person's goals toward maximum independence.

The IQOMR is the services and support evaluation tool used for support coordination services. The IQOMR is divided into seven focus areas: Environment, Appearance and Health, Supports and Services, Behavioral and Emotional, Home and Community Opportunities, Financial, and Satisfaction. Each focus area contains one or more questions that guide the support coordinator to do the following:

- Observe and interact with the participant as it relates to the elements of the item reviewed;
- Observe the setting for evidence pertaining to the item reviewed;
- Review any pertinent documentation relating to the item reviewed;
- Engage in discussion with staff members or natural supports who may have information on the item reviewed; and
- Observe staffs' or natural supports' interaction with the individual as it relates to the item reviewed.

According to DBHDD policy, support coordinators can report and record concerns within the IQOMR using coaching and referrals.[11] Support coordinators also capture information regarding critical incident follow-ups. That information can lead to using coaching and referrals as well. Analyzing coaching and referrals provides a better understanding of activities support coordinators deliver to individuals to effect positive outcomes for individuals.

*Figure 1: Coaching and Referrals Description, CY18*

## Coaching

Required when a concern/issue/deficit is discovered in an element of a focus area question, and, in the support coordinator's professional judgment, (s)he determines that the concern/issue/deficit can be resolved in collaboration with the staff members or natural supports without intervention by the field office or clinical staff.

## Referrals

Required for more serious risks than those addressed by coaching. Referrals are made to DBHDD or clinical staff to address serious concerns in the areas of the IQOMR. Referrals can also be used to escalate the urgency of a coaching due to slow response or worsening circumstances.

[11] DBHDD Policy: Outcome Evaluation "Recognize, Refer, and Act" Model, 02-435

Figure 2 and Table 5 highlight the amount of effort and productivity of support coordinators in working with providers to assist individuals. When considering all categories of coaching, support coordination agencies provided 17,271 coaching sessions aimed at addressing issues to provide improved outcomes for individuals from January through December 2018. Support coordinators also provided 8,320 referrals in response to individuals' needs in order to facilitate positive outcomes. To understand more fully the tremendous prevention and resolution efforts, consider that combined, support coordinators initiated and followed up on 25,591 coachings and referrals to improve the services, supports, and outcomes of individuals they serve.

*Table 5: Coaching and Referral Activities by IQOMR Area, CY18*

| | | | Referrals Open/ In Progress Beyond Intended Close Date | |
|---|---|---|---|---|
| **IQOMR Activity** | **Coachings** | **Referrals** | **Number** | **Percent** |
| Appearance and Health | 9,326 | 3,512 | 476 | 14% |
| Supports and Services | 3,596 | 752 | 108 | 8% |
| Critical Incident Follow-Up | 176 | 3,056 | 257 | 14% |
| Environment | 1,475 | 366 | 50 | 14% |
| Home and Community Opportunities | 1,023 | 162 | 27 | 17% |
| Behavioral and Emotional | 830 | 307 | 53 | 19% |
| Financial | 665 | 141 | 27 | 17% |
| Satisfaction | 180 | 24 | 1 | 4% |
| Total | 17,271 | 8,320 | 999 | 12% |

Twelve percent of referrals are open beyond the intended close date; this is a positive indicator of DBHDD's successful event resolution performance. Moreover, with an eye toward continued system performance and delivery of quality services, DBHDD has hired three additional staff whose job includes working to resolve referrals, thus strengthening the resolution process and further increasing positive outcomes.

## Resolution of Events for Individuals with Complex Needs through Support Coordination Services: Individual Quality Outcome Monitoring and Review (IQOMR)

Figure 2 presents the percentage of SCO individuals with positive outcomes in five of the IQOMR focus areas, with comparisons between CY18 Q1 and CY18 Q4, as well as between CY18 Q4 and the overall IDD population from CY18 Q4. Statistical significance is indicated by the asterisks and carets. (The IQOMR Critical Incident Follow Up, Financial and Satisfaction focus areas were not scored for positive compliance.)

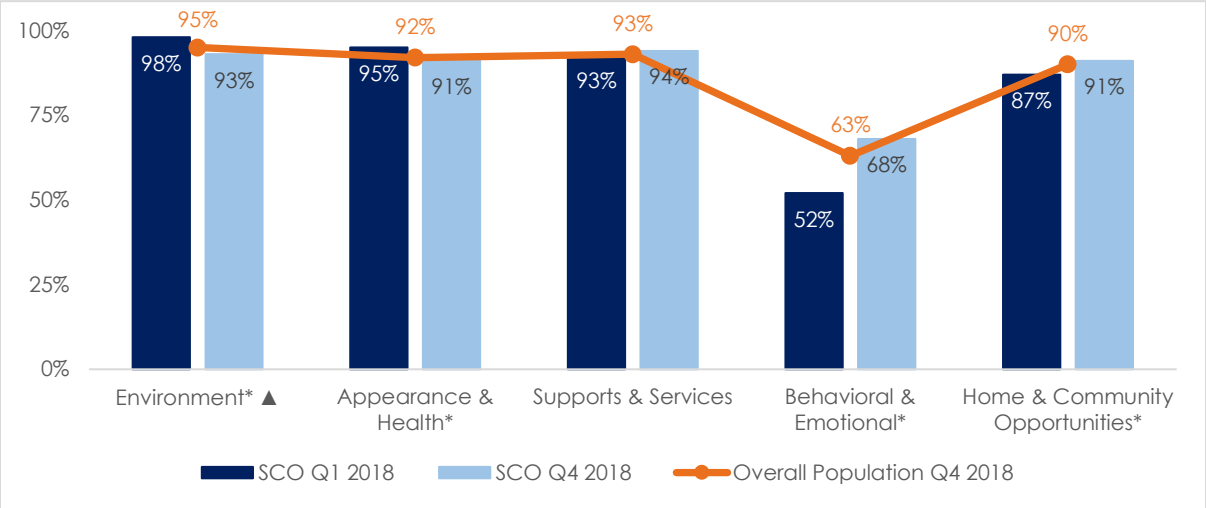
Each IQOMR area consists of a small number of questions selected to measure different dimensions of quality such as environmental and health factors. The scores for CY18 Q4 were relatively similar to the overall population in that most of the proportions were over 90 percent. There were two statistically significant differences. First, compared to the overall IDD population, a smaller percentage of individuals receiving SCO had positive ratings in the IQOMR Environmental area; however, a greater percentage of SCO individuals had positive ratings in the IQOMR Behavioral and Emotional area.

Comparisons were also made between CY18 Q1 and CY18 Q4 (Figure 2. There were four statistically significant differences. In the IQOMR areas of Environmental and Appearance / Health, the percentage of SCO individuals with positive IQOMR ratings decreased from 2018 Q1 to 2018 Q4; however, IQOMR scores still demonstrated positive findings at 93%. Alternatively, in the IQOMR areas of Behavioral and Emotional and Home / Community Opportunities, the percentage of SCO individuals with positive IQOMR ratings increased from 2018 Q1 to 2018 Q4. Despite the increase in the number of individuals with positive ratings in the IQOMR area of Behavior and

Emotional, the percentage remains relatively low, especially in comparison to other IQOMR areas. This finding of low Behavioral and Emotional scores also occurred in the larger IDD population.[12]

Overall, then, it is a positive finding that individuals with complex needs (i.e., individuals on SCO) have not only high rates of favorable resolution, but also increased rates of behavioral event resolution.

*Figure 2: Percentage of Individuals with Positive IQOMR Ratings*




*Notes: Statistical significance tested using paired z-tests. * indicates statistically significant differences between SCO 2018 Q1 and SCO 2018 Q4. ▲ indicates statistically significant differences between SCO 2018 Q4 and the overall IDD population (2018 Q4).*

IQOMR data indicate that support coordinator processes and procedures are producing positive outcomes in most areas; however, improvement can be made, especially in the Behavioral and Emotional outcomes area. Coaching and referral data indicate that support coordinators could use additional supports in resolving some referrals that remain open past the expected close date.

## Elevated HRST Risk Limitations

Several limitations to the data, methods, and findings exist, and the major ones are listed below. DBHDD is actively considering ways of improving later studies by addressing limitations of the current study for future analysis.

- These analyses are based on those at *elevated risk* for an outcome as defined by the HRST. Should analyses have been conducted with a reduced risk level, potentially averted events likely would be different.
- These analyses focused only on those at elevated risk for whom negative outcomes were more likely to happen. It is possible that individuals with a lower level of risk could have had negative outcomes; if someone had an adverse outcome with a lower level of risk, these analyses may not have captured it.
- Risks for negative outcomes were defined using HRST data. It is possible that some risks were not captured by the HRST.
- These analyses considered adverse events recorded in the DDCO. It is possible that other negative outcomes occurred that did not rise to the level of SCO or that were not included in DDCO data.
- DBHDD acknowledges that there are opportunities for improvement within SCO and the Office of Health and Wellness to identify additional potentially negative or adverse outcomes. For example, over the past twelve months, SCO staff have been examining the narratives for hospitalizations, ED visits, and critical incident information to detect indicators of eventual or delayed onset of "Fatal Five" diagnoses or other conditions or events that may increase the potential of a negative outcomes. It is likely this will have the effect of increased detection of events captured by DDCO.

[12] Therefore, considering similar positive IQOMR outcomes comparable to the general waiver population, it is reasonable to conclude that similar levels of pre- and post-SCO hospital and ED admissions were, indeed, indicative of positive outcomes for individuals receiving SCO for at least six months.

- The number of adverse outcomes (and corresponding incidence percentages) may seem lower than expected for some conditions. For example, consider that GERD has the fewest number of adverse outcomes (and lowest incidence rate of adverse outcomes). This is because GERD is a common and broad diagnosis; the impact of which would not typically result in an adverse outcome that would be captured in the DDCO. Rather, a related but more serious event or diagnosis such as esophageal cancer or Barrett's esophagitis—diagnoses for which GERD is a precursor—could be the adverse event that would trigger SCO engagement.
- Due to the differing and overlapping date parameters used in earlier reports, trend analyses were unable to be conducted. Future reports will utilize calendar year comparisons, thereby treating prevalence and incidence rates from calendar year 2018 as the baseline.

## SCO Hospital and Emergency Department Visits Limitations

This study has other limitations. First, only a limited number of variables were analyzed; however, hospital admissions, ED utilization, health risk scores, and individualized outcomes are key, basic variables that shed light on the positive outcomes of SCO. DBHDD is in the process of exploring additional clinical and outcomes data. Future studies may seek to evaluate the effectiveness of SCO further, which would allow for more sophisticated analysis to identify and understand complex relationships and contributors to outcomes such as reasons for entry into SCO, emergent conditions, comorbidity, and length of time under the auspices of SCO.

Second, hospital and ED admissions were identified from critical incident reports submitted to ROCI. It is possible that not all hospital and ED admissions were identified. DBHDD is currently working to identify hospital and ED admissions from Medicaid claims, which will address potentially missing hospital and ED admissions data.

Third, this study also relied heavily on manual data processes. For example, the SCO list that was used in this study was maintained by manual data entry; furthermore, critical incident data used to identify hospital and ED utilization were extracted and reconciled across data sources manually, which included careful review of critical incident data for all individuals. Errors are more likely to occur when manual data entry and review processes are used. Current and future information and technology improvements will allow for more sophisticated integration and inclusion of additional data for future investigations.

Fourth, it should be noted that individuals receiving SCO also receive additional supports and services that work in tandem to improve outcomes for individuals (e.g., intensive support coordination, provider supports, community services, families, and specialized clinical initiatives of DBHDD, such as ICST, SRTA, and Improving Health Outcomes Initiative [IHOI]) and this led to increased awareness that resulted in early recognition and, hence, early intervention that may have prevented more adverse outcomes. Additional data and analysis over a much longer time may allow DBHDD to determine with more specificity how different elements of DBHDD's provider network and system are related to the benefits that individuals receive.

Fifth, this study's findings are also limited by the lack of a comparison group, making it difficult to assess fully the potentially positive impact of SCO and other DD service programs. That the lack of variation in hospital and ED admissions was accompanied by relatively positive IQOMR findings suggests that SCO may have positive benefits, but without a comparison group, the conclusions should be regarded as preliminary.

## Major Findings

This second study of elevated HRST risk and adverse outcomes for DBHDD IDD individuals has several limitations; DBHDD will continue to strengthen the data, methods, and analyses for future studies. Though limitations exist, several major findings should be noted. The majority of the DBHDD IDD population are at elevated HRST risk for a negative outcome or adverse event in the areas listed above in Table 1. That said, for all individuals with an elevated HRST risk for an adverse event that arose to the level of SCO in the aforementioned risk areas, DBHDD services and supports potentially averted 21,767 negative outcomes or adverse events. Many individuals (i.e., at least 17%) are at elevated HRST risk of repeated inpatient or ED utilization, though inpatient and ED utilization are not necessarily adverse outcomes. That said, for all individuals with an elevated HRST risk for chronic hospitalization or ED utilization, DBHDD services and supports potentially averted 2,176 inpatient and ED visits.

Having received at least six months of SCO did not significantly increase or reduce the number of hospital and ED admissions among individuals receiving SCO. This finding is important considering that individuals' measured

health risk and comorbid conditions (as indicated by HCL) did increase during this time. Therefore, that hospital and ED admissions for those receiving SCO remained constant while health risk and comorbidity increased are especially positive indicators of SCO effectiveness. Further evidence of positive outcomes of SCO for at least six months was evidenced by SCO individuals having comparable IQOMR scores to the larger IDD waiver population.

Overall, then, it is a positive finding that individuals with complex needs (i.e., individuals on SCO) have not only high rates of favorable resolution and positive outcome ratings on the IQOMR process but also increased rates of behavioral event resolution. IQOMR data indicate that support coordinator processes and procedures are producing positive outcomes in most areas; however, improvement can be made, especially in the Behavioral and Emotional outcomes area. Coaching and referral data indicate that support coordinators could use additional supports in resolving some referrals that remain open pasts the expected close date.

In summary: Most individuals in the IDD population have an elevated risk for an adverse event. Yet, very few of those individuals had adverse events; conversely, DBHDD's service system potentially averted over 20,000 negative outcomes or adverse events. Support coordination delivered over 17,000 coaching, referral, and resolution activities to individuals with complex needs, yielding positive outcomes in all major areas measured, with exception to behavioral and emotional outcomes. DBHDD continues to work towards resolution on events that are within and beyond expected timeframes of event resolution, including adding new staff with responsibilities to facilitate resolution of events.

# Appendix A: HRST Items and Risk Dimensions

| 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 B: HRST Expanded Score Descriptors by Item

| A | Functional Status - Eating |
|---|---|
| **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. |

| B | Functional Status - Ambulation |
|---|---|
| **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. Non-ambulatory 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. |

| C | Functional Status - Transfer |
|---|---|
| **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".* |

| D | Functional Status - Toileting |
|---|---|
| **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. |

| E | Functional Status - Clinical Issues |
|---|---|
| **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. |

| F | Behavior - Self Abuse |
|---|---|
| **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. |

| G | Behavior - Aggression |
|---|---|
| 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.** |

| H | Behavior - Physical Restraint |
|---|---|
| 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, has 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. |

| I | Behavior - Chemical Restraints |
|---|---|
| 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.** |

| J | Behavior - Psychotropic Meds |
|---|---|
| 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. |

| K | Physiology - Gastrointestinal |
|---|---|
| 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. |

| L | Physiology - Seizures |
|---|---|
| **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. |

| M | Physiology - Anticonvulsant |
|---|---|
| **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.** |

| N | Physiology - Skin Breakdown |
|---|---|
| **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. |

| O | Physiology - Bowel Function |
|---|---|
| **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".* |

| P | Physiology - Nutrition |
|---|---|
| **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. |

| Q | Physiology - Requirements for Licensed Intervention |
|---|---|
| | **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: |
| **6a** | Medication therapy requiring intramuscular or intravenous injections or hemaport irrigations one or more times daily. |
| **6b** | Daily or more frequent catheterization, requiring sterile technique. |
| **6c** | Physician ordered treatments that CANNOT be delegated to a non-licensed person such as chemotherapy or renal dialysis. |
| **6d** | Sterile dressing/wound treatments routinely performed only in clinical settings or by licensed practitioners. |
| **6e** | Individuals in acute and/or end stages of cardiac, liver, lung or kidney disease. |
| **6f** | 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. |

| R | Safety - Injuries |
|---|---|
| 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. |

| S | Safety - Falls |
|---|---|
| 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.** |

| T | Frequency of Services - Professional Healthcare Services |
|---|---|
| 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. |

| U | Frequency of Services - Emergency Room Visits |
|---|---|
| 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.** |

| V | Frequency of Services - Hospital Admissions |
|---|---|
| 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 of time (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. |