



Risk Management

Health risk-informed telemedical help for people with neurodevelopmental disabilities

■ **By Craig Escudé, MD, FAAFP, FAADM**

There are an estimated 10 to 15 million people with intellectual and developmental disabilities (IDD) in the United States.¹ Numerous studies point to poor health outcomes for people with IDD. They experience high rates of diabetes, obesity, cardiovascular disease, osteoporosis, hypertension, and risk of dying from COVID-19.^{2,3}

Along with low rates of preventative screening for numerous preventable diseases, they also

have poor oral health. Overall, they have shorter lifespans compared to those without IDD, and the differences are seldom attributable to their developmental disability.⁴ A critical contributor to these health disparities is that people with IDD have limited access to competently trained healthcare providers willing to see people with IDD in their practices.^{5,6}

The need to improve healthcare and healthcare access for people with disabilities was

Health Risk Screening Tool

A Brief Guide to the Clinical Relevance of the HRST Health Care Levels and Rating Item Scores for Healthcare Providers

Health Care Level (HCL): 6

Health Care Level	Overall Health Risk	Ranges from one to six. Each one-point increase in Health Care Level correlates with an increased mortality.
Level 1	Low Risk	
Level 2	Low Risk	
Level 3	Moderate Risk	
Level 4	High-Moderate Risk	
Level 5	High Risk	
Level 6	Highest Risk	

Rating Item Scores for John Adams

Scores in each item range from 0–4 and reflect a person’s health status over the prior 12 months.

HRST Rating Item	Score	Risk and Clinical Relevance Associated with an Increasing Score
A. Eating	3	Increasing risk of aspiration and choking.
B. Ambulation	2	Increased risk for falls, pressure injuries, skin abrasion injuries, aspiration due to inability to eat with proper body alignment.
C. Transfer	3	Increased risk for falls, injuries from transfer (being dropped, pulled, or extremities twisted).
D. Toileting	3	Increased likelihood of hygiene-related issues, bowel issues, skin irritation from incontinence, infection from catheterization at level 4.
E. Clinical Issues Affecting Daily Life	3	Increasing numbers of healthcare visits and days missed from typical daily activities related to healthcare. Likely correlates with an overall increase in the number or significance of health conditions.
F. Self-Abuse	2	Higher risk of self-injury may include things like skin-picking, scratching, sticking things in eyes or ears, biting, slapping, or hitting themselves in the face, trunk, arms, or legs. Head injuries from banging their head on a wall or other object. Self-injurious behavior sometimes indicates underlying pain. A higher risk for infection for behaviors that cause open wounds.
G. Aggression	4	Increased risk for injury related to aggressive behavior or underlying pain-causing aggression.
H. Behavior Support – Physical	3	Increased likelihood of the use of a restraint such as a helmet, arm restraints, 5-point restraints or seclusion in a room. Injuries and death can result from restraint use or the actions that resulted in their use. Consider pain as an underlying cause of aggression.
I. Behavior Support – Chemical	4	Increased likelihood of medication side effects and drug-drug interactions; consider sedation, mental status changes, anticholinergic effects, tardive dyskinesia. Increased use of PRN medications for agitation warrants consideration of a medical cause of the underlying behavior.
J. Psychotropic Medications	4	Increased likelihood of medication side effects and drug-drug interactions. Consider sedation, mental status changes, anticholinergic effects, and tardive dyskinesia.

K. Gastrointestinal (GI) Conditions	3	Increasing risk for constipation, bowel obstruction, GERD, GI bleeding episodes, pica behavior. Pica can increase the risk of foreign body ingestion or airway obstruction.
L. Seizures	4	Increased risk of seizures, injuries, and seizure-related complications. A score of 3 or 4 is significant.
M. Antiepileptic Medication	3	Increased risk of medication side effects, drug-drug interactions, anticholinergic effects, and tardive dyskinesia.
N. Skin Integrity	0	Increased risk of ulceration or a health condition that causes an increased risk of non-intact skin and infection.
O. Bowel Function	4	Increased risk of constipation, ileus, bowel obstruction. A score of 3 or 4 also indicates being on a medication for constipation.
P. Nutrition	3	Increased likelihood of a nutritional condition affecting health, either over- or underweight, or unable to reach or maintain desired weight.
Q. High-Risk Treatments	4	Can only be scored a 0 or 4. A score of 4 indicates need for 1 or more significant medical interventions (tracheostomy; ventilator dependence; requires deep suctioning; complex insulin usage; daily IM, IV, or Hemaport injections; frequent urinary catheterization; chemotherapy; dialysis; end-stage cardiac, liver, lung, or kidney disease; end-stage terminal illness; progressive neurological disorder; 1:1 staffing more than 16 hours a day due to behavioral issues).
R. Injuries	4	Increased risk of injuries.
S. Falls	3	Indicates increased risk of falls and potential for resultant injuries and fractures.
T. Professional Healthcare Services	3	Increased risk of healthcare visits related to diagnosed conditions resulting in increased health or behavioral destabilization.
U. Emergency Room (ER) Visits	4	Increased number of urgent ER visits. (A score of 4 indicates that the visit resulted in hospitalization.)
V. Hospital Admissions	3	Higher score indicates higher number of hospital admissions. (A score of 4 indicates ICU admission.)

highlighted in 2022 with the release of reports and alerts from major national and international organizations. The National Council on Disability released its *Health Equity Framework for People with Disabilities* in February of 2022, calling for significant changes in the healthcare system to improve healthcare for people with disabilities.⁵ One of the most notable is the suggestion to require comprehensive disability clinical training in all U.S. medical, nursing, and other health professional training programs.

The Joint Commission released a Sentinel Event Alert in June 2022 warning of the risks of diagnostic overshadowing, when professionals attribute symptoms to the overall disability instead of looking for a treatable underlying cause.⁷ The alert calls out this phenomenon as a “failure to deliver a proper diagnosis.” Additionally, the World

Health Organization's release of its *Global Report on Health Equity for Persons with Disabilities* in December 2022 brought the need for action to an international level.⁸

Tools, Training, Education, and Tech

Tools to identify health risks, training for all levels of people who support people with IDD, education for healthcare providers, and technological advances are being developed and leveraged in innovative ways to improve the health and wellness of society's vulnerable people. One such advancement is called Health Risk Informed Telemedicine (HRIT).

HRIT is the product of a partnership between two leading companies in the field of health and wellness for people with IDD: IntellectAbility and StationMD.^{9,10}

IntellectAbility was formed in 2006 after its founder, Karen Green McGowan, RN, put together a group of people to turn the Health Risk Screening Tool (HRST), which she developed in the early 1990s, into a web-based software tool, making it available to states and provider agencies tasked with supporting people with IDD.¹¹ The HRST is designed to identify areas of health risk for at-risk populations and provide action steps to help mitigate those risks. IntellectAbility supports the field by providing tools like the HRST and training for supporters of all levels to improve their knowledge and ability to deliver effective, person-centered support while addressing missed health conditions in people with IDD.

The company StationMD was founded in 2016 out of the recognition by a group of emergency medicine physicians led by CEO Matt Kaufman, MD, that people with IDD need improved healthcare. They noted that people with IDD who were seen in the emergency department (ED) by clinicians with limited training and experience working with people with IDD could have that care delivered through telehealth.

HRIT consists of three components:

1. *Education* of clinicians on IDD healthcare
2. Effective healthcare delivery through *telemedicine*
3. Up-to-date *health risk profiles* to assist in real-time clinical decision-making

Below we examine each of these components:

1 Education. There is a dire need to educate all clinicians about how to provide healthcare to people with IDD. Incorporating IDD-specific training into health professional schools is an obvious first target; however, this leaves the need to educate clinicians already in practice. To reach students and practicing clinicians alike, training must be concise, practical, and accessible. IntellectAbility has developed a course called the Curriculum in IDD Healthcare that meets these components. This six-module eLearning course is explicitly designed to teach the fundamentals of IDD-competent healthcare.

The curriculum goes beyond teaching general concepts about disability by including practical, immediately implementable clinical information and case studies to improve clinicians' abilities to provide competent healthcare to people with IDD. Even with these components in place, clinicians must still understand that they need



this training. StationMD was aware that their clinicians would benefit from this type of training and chose to use IntellectAbility's course as an effective means to deliver it to their clinicians.

2 Telemedicine. Telemedicine has amplified advantages for people with IDD. People with IDD frequently seek—many times without success—physicians who understand how to provide healthcare to people with IDD. Telehealth brings clinicians with training in the field into the homes of people with IDD.

Also, “trauma of transportation” ensues when persons with IDD are transported to an ED for care. This trauma frequently includes arranging for extra support staff, long wait times, and unfamiliar environments, all to receive care from clinicians who may not understand their specific needs.

Telemedicine reduces this trauma, as many ED visits for people with IDD fall into the low-acuity, non-emergent range that can be handled via telehealth. According to StationMD, telehealth provided by their IDD-trained clinicians results in a 92% treat-at-home rate, meaning, 92% of all calls received are effectively handled without referral to an ED.

3 Health risk profile. This third HRIT component is the most innovative. It involves the delivery of a person-specific IDD-oriented health risk profile to trained telehealth clinicians. It informs them of risk levels specific to high-risk areas for people with IDD. IntellectAbility's HRST

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measures levels of risk in 22 areas, including eating risks such as aspiration, gastrointestinal risks such as bowel obstruction, fall risks, risks associated with adverse behaviors, seizures, nutrition, medication risks, and others.¹¹

Through a specially built interface between the web-based HRST and StationMD platforms, clinicians electronically receive the person's risk rating in each of the 22 areas along with the person's overall Health Care Level as determined by HRST. This Health Care Level has proved to correlate with a person's risk of death. For coding purposes, this information, along with other available data, is then used to inform the clinician's decisions and documents the clinical complexity of the patient encounter.

Decision-Making Impacts

To illustrate how HRST significantly influences clinical decision-making, suppose two people with IDD are evaluated for a fever and cough via telehealth. The first person has a low score for risk of aspiration, and overall Health Care Level is 1 (the lowest risk) and may be appropriately managed at home. The second person has a high score in the aspiration risk area and overall Health Care Level 6 (the highest risk) and may be appropriate for referral to the ED for an exam.

HRST combines the accessibility of trained IDD specialists with valuable health risk data to assist in clinical decision-making. However, even without the use of telemedicine, any clinician can use HRST data to inform healthcare decisions.

For anyone screened by HRST, a Clinical Relevance Document (see figure) can be converted to a PDF document or printed out and delivered to any clinician. The document contains the person's risk score for each of the 22 areas identified by the HRST and their overall Health Care Level. Next to each risk area, an explanation of the score's clinical relevance assists in interpreting the scores.

Risk Level Made Explicit

Clinicians who have not received IDD-specific training certainly understand health risks. Having a person-specific health risk profile available at the time of visit plays a key role in identifying risk and educating clinicians about commonly seen areas of health risk for people with IDD.

Using health risk information to inform clinicians' decisions is nothing new to the field of medicine. What is new is using a person-specific health risk profile geared to explicitly determine the level of risk in an at-risk population and making that information available to clinicians to assist in real-time clinical decision-making. Health Risk Informed Telemedicine stands to be an effective tool to reduce costs, prevent unnecessary ED visits, and improve health equity for people with neurodevelopmental disabilities and other at-risk populations. [GPI](#)

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