

March 2023

Find out how we help agencies and supporters to better support people with Intellectual and Developmental Disabilities (IDD).

# Utilizing the Health Risk Screening Tool

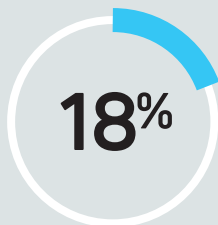
to Improve Health Equity for People with IDD

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## Introduction

An estimated 7.43 million people with intellectual and developmental disabilities (IDD) live in the United States, and approximately 18% receive Medicaid or State-funded long-term supports and services (LTSS) through state IDD agencies.<sup>1</sup> And Medicaid is the primary payer for acute medical and primary care services for people with IDD.<sup>2</sup>



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People with intellectual and developmental disabilities (IDD) live in the US.

State Medicaid programs, Medicaid Managed Care Organizations, and IDD providers play a crucial role in health risk management and health promotion for people with IDD. This white paper explores the intersection between health risk management and improvements in health equity for people with IDD.

# Health Equity and People with IDD

*People with IDD are at risk for debilitating and life-limiting health disparities.*

These disparities, preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health experienced by socially disadvantaged populations, have negatively impacted people with disabilities for decades. We see examples of this daily when people with IDD are unable to access equitable healthcare because they are unable to find healthcare providers who are educated in IDD healthcare.

People with IDD are also subject to “rationing” of essential resources during times of scarcity when health systems prioritize essential treatment for non-disabled people over those with disabilities.<sup>3</sup> Disparities are even further magnified based on race and ethnicity.

Over time, failure to appropriately manage health and health risks results in a downward spiral of adverse outcomes for people with IDD, including reduced quality of life, increased chronic disease burden, decreased function, and increased acute medical and LTSS costs, as illustrated.



## When Health Care Needs Are Not Addressed for People with IDD



### Increased

- Chronic Disease Burden
- Health Risk
- Emergency Department Visits
- Hospital Admissions
- Functional Disability
- Acute Healthcare Costs
- LTSS/Waiver Costs



### Decreased

- Quality of Life
- Health of the Medicaid Program
- Opportunities to “Bend” the Cost Trend
- Health of the State’s Population



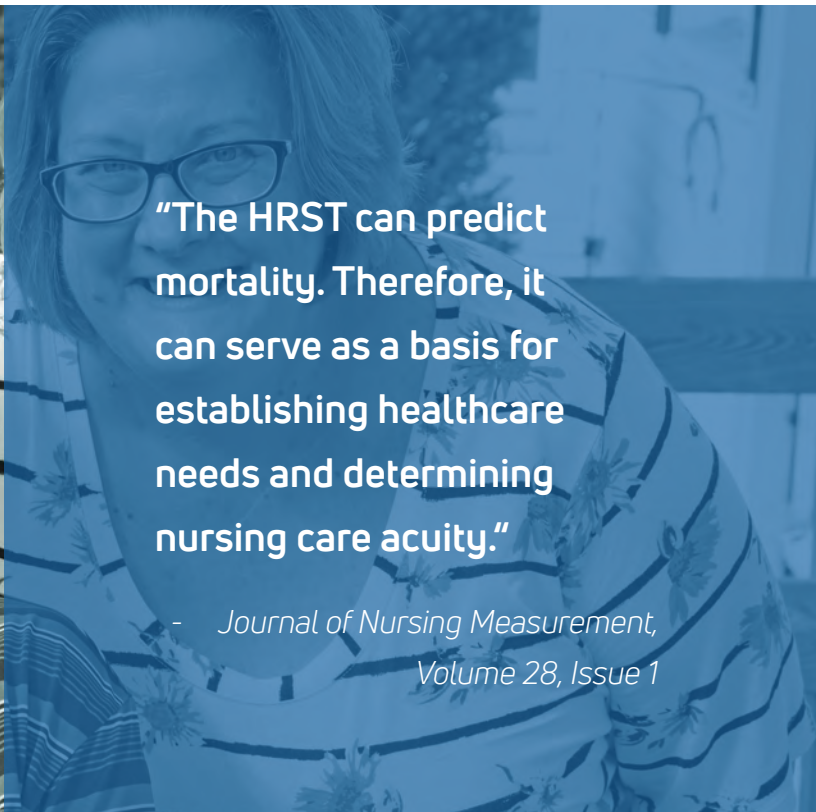


# Impact of the Direct Support Workforce Crisis on Health Risk Management

The risk for negative health outcomes is magnified further by the direct support workforce crisis, which, while already critical, was exacerbated by the COVID-19 pandemic.<sup>4</sup> Workforce issues significantly impact the health of people with IDD, particularly those who require health-related support for the management of aspiration, bowel obstruction, dehydration, seizures, sepsis, and gastroesophageal reflux (GERD), considered to be the “[Fatal Five Plus](#)” top conditions most likely to result in preventable morbidity and mortality in the IDD population.

The Health Risk Screening Tool (HRST) provides easy access to information about these, as well as other health risks and the person’s unique response to illness, medications, and medical diagnoses.

Immediate access to this information is essential in an environment where direct support staff turnover is rampant, and education for those who step into vacated positions is often abbreviated and completed “on the job.”



**“The HRST can predict mortality. Therefore, it can serve as a basis for establishing healthcare needs and determining nursing care acuity.”**

- *Journal of Nursing Measurement, Volume 28, Issue 1*



# Health Equity Calls to Action

In February 2022, the National Council on Disability released the Health Equity Framework for People with Disabilities<sup>5</sup>, emphasizing the need to address education for clinicians in disability healthcare, require the use of accessible medical and diagnostic equipment, improve disability-specific data collection and designate people with disabilities as a Special Medically Underserved Population (SMUP) under the Public Health Services Act.

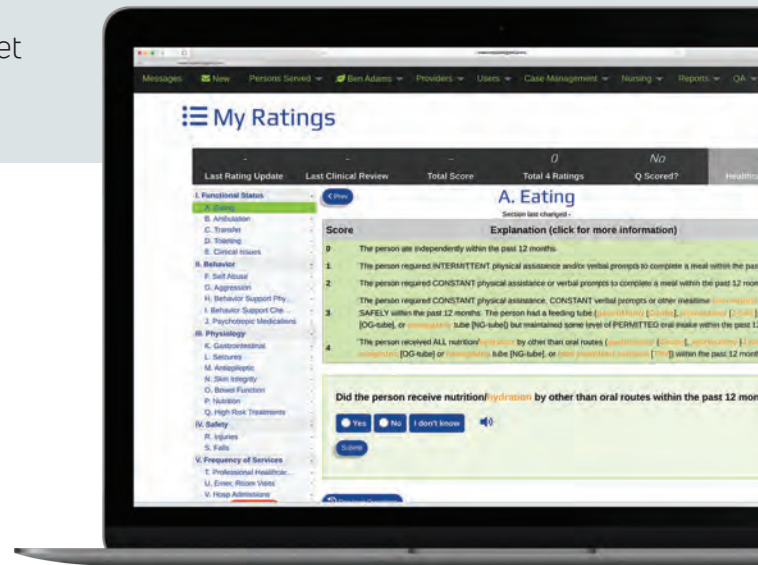
In June 2022, The Joint Commission released Sentinel Event Alert Number 65, warning of the dangers of diagnostic overshadowing leading to misdiagnosis in people with disabilities. And in December 2022, the World Health Organization (WHO) issued the Global Report on Health Equity for Persons With Disabilities<sup>6</sup>, highlighting the dire need to improve the competency of health systems to deliver equitable healthcare for people with disabilities.



# The Impact of Diagnostic Overshadowing

Diagnostic overshadowing, highlighted in The Joint Commission Sentinel Event Alert<sup>7</sup>, can contribute to delayed or missed diagnosis for people with IDD because of a tendency for clinicians to attribute behavioral symptoms such as head-banging, screaming, or refusal to eat to the person's IDD rather than looking for a treatable, underlying medical condition. The HRST addresses diagnostic overshadowing by identifying health conditions that are frequently attributed to a person's IDD and provides recommendations for clinical follow-up designed to get to the root of the problem.

## IntellectAbility's Health Risk Screening Tool (HRST) can improve health equity for people with IDD and other at-risk populations.



It is a data-rich, valid, reliable, low-cost, high-value, HIPAA-compliant, interoperable web-based health risk screening instrument that can be completed by non-licensed support staff. It provides online access to the person's health risk profile and other essential health-related information.



It monitors for health risks associated with the person's developmental and physical disabilities and detects early indicators of health destabilization.



It guides the user through a series of straightforward, easy-to-understand yes/no questions to identify the person's degree of risk intensity in 22 specific areas of health risk, then additionally assigns an overall Health Care Level ranging from 1-6. Lower Health Care Levels correlate with lower health risk, while higher levels correlate with higher risk.



It goes beyond simply identifying health risks by providing person-centered considerations for clinical follow-up to evaluate previously undiagnosed or undetected medical conditions. Action steps for direct supporters are also offered, designed to prevent the health conditions most likely to lead to morbidity and mortality.



It was demonstrated to show predictive value in a study of the tool published in 2020 in the Journal of Nursing Management<sup>8</sup>, which found that "the HRST can predict mortality. Therefore, it can serve as a basis for establishing healthcare needs and nursing acuity".



It is a robust source of healthcare data, available 24/7 to all levels of supporters, and is in use for 93,000 people across 2,400 provider agencies and 26 states.



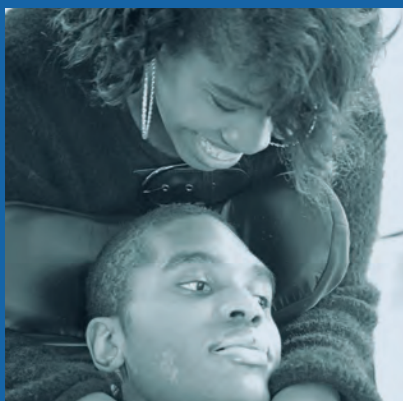
# Adjacent Uses of the HRST

In addition to serving as a 24/7 source of web-based information about a person's health risk, data from the HRST has been leveraged to provide information to:



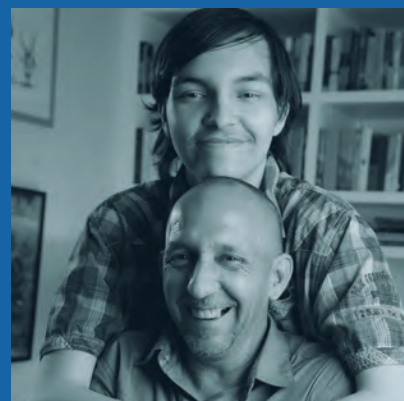
## Provide

- Provide direct access to health risk information during selected IDD specific telemedicine encounters
- Provide context for state mortality reporting processes
- Provide data for initial and annual Level of Care (LOC) determinations
- Provide an electronic platform for nursing assessment data, health care plans, and person-centered plans
- Provide information to determine appropriateness for IDD Medical Health Homes



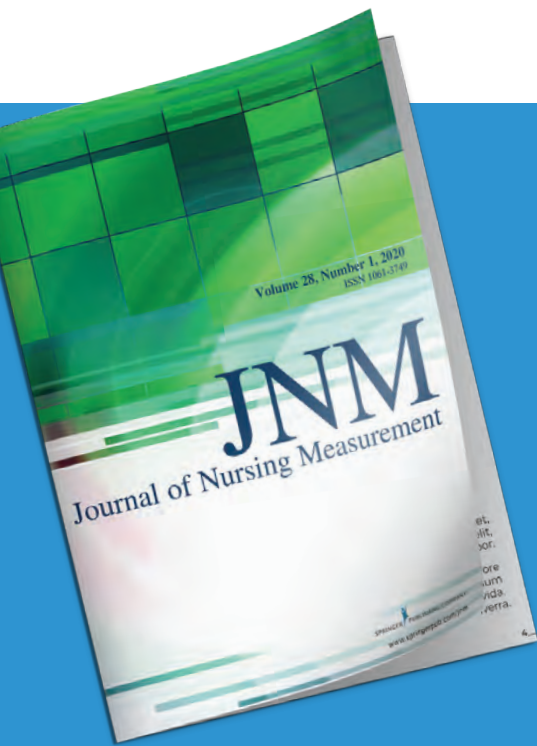
## Inform

- Inform state Medicaid IDD program individualized budget and rate setting activities
- Inform prioritization for individuals on IDD HCBS Waiver waiting lists
- Inform state and provider direct support staff training initiatives
- Inform support needs in person-centered plans
- Inform and assign case management support levels
- Inform and complement state incident management and sentinel event reporting processes
- Inform direct support and nursing staffing needs by measuring healthcare acuity



## Address

- Address continuity of care concerns related to direct support and case management staffing turnover
- Address CMS Home and Community Based Services (HCBS) Waiver Health and Safety Performance Measures (PMs) and provide data for valid and reliable reporting on PMs



## Validated and Proven Predictor of Mortality

“All three methods of analysis employed in our study (Kaplan–Meier, Cox regression, and binary logistic regression) indicate that the six-point health risk score (i.e., Healthcare Level) produced by the HRST was prognostic of mortality in a sample of persons with intellectual disability. That is, the instrument is able to identify the degree of vulnerability in such a population.”

- *Journal of Nursing Measurement, Volume 28, Issue 1*

## Conclusion

The impact of health disparities on people with IDD is well established, as is the value of health risk informed data collection. The Health Risk Screening Tool identifies person-specific health risks, provides actionable steps to direct supporters to mitigate those risks, and informs oversight bodies about the overall health of people being supported.

The HRST also identifies people who require more intensive health supports and, ultimately, reduces unnecessary illness, suffering, and death.

The HRST is a cost-effective, valid, and reliable tool for improving health equity for people with IDD and other at-risk populations. Additional information can be found at [ReplacingRisk.com](http://ReplacingRisk.com).



IntellectAbility  
REPLACING RISK WITH HEALTH AND WELLNESS

<sup>1</sup>Institute on Community Integration. 2021. Long-Term Supports and Services for Individuals with Intellectual or Developmental Disabilities: Status and Trends Through 2018. <https://ici-s.umn.edu/files/yFXkkmRteg/2018-risp-full-report?preferredLocale=en-US>

<sup>2</sup>Medicaid and CHIP Payment and Access Commission (MACPAC). 2021. Managed long-term services and supports. <https://www.macpac.gov/subtopic/managed-long-term-services-and-supports/>

<sup>3</sup>Health Affairs. October 2022. Identifying And Exploring Bias In Public Opinion On Scarce Resource Allocation During The COVID-19 Pandemic. Vol 41, No.10. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00504>

<sup>4</sup>ANCOR. 2021. The State of America's Direct Support Workforce Crisis. [https://www.ancor.org/wp-content/uploads/2022/08/the\\_state\\_of\\_america\\_as\\_direct\\_support\\_workforce\\_crisis\\_2021.pdf](https://www.ancor.org/wp-content/uploads/2022/08/the_state_of_america_as_direct_support_workforce_crisis_2021.pdf)

<sup>5</sup>National Council on Disability Health Equity Framework. February 2022. [https://ncd.gov/sites/default/files/NCD\\_Health\\_Equity\\_Framework.pdf](https://ncd.gov/sites/default/files/NCD_Health_Equity_Framework.pdf)

<sup>6</sup>WHO Global Report on Health Equity for Persons With Disabilities. December 2022. <https://www.who.int/publications/i/item/9789240063600>

<sup>7</sup>The Joint Commission. June 2022. Sentinel Event Alert 65. <https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/sentinel-event/sea-65-diagnostic-overshadowing-6-16-22-final.pdf>

<sup>8</sup>Journal of Nursing Measurement. 2020. An Examination of the Validity of the Health Risk Screening Tool: Predicting Mortality in People With Intellectual Disabilities. Vol. 28, Issue 1. <http://replacingrisk.com/downloadables/examination-of-validity-of-hrst.pdf>