



# HCQU CARES

NURSING EDITION

**Nurses Make  
a Difference**



*The Kepro HCQU chose “Nurses Make a Difference”, the American Nurses Association’s theme for Nurses Month 2022, as the theme of this issue of the HCQU CARES: Nursing Edition newsletter. The articles focus specifically on nurses who support individuals with intellectual disability/autism (ID/A).*

People with ID/A experience a range of medical/behavioral conditions, have individualized care needs, and reside in a wide range of care settings with caregivers of different skill levels. There are many rewards to being a developmental disabilities nurse, including working with people who have ID/A. By providing education and resources to individuals and caregivers, nurses in the ID/A field assist individuals to learn about their health, make decisions, and improve their quality of life. They assist caregivers to investigate symptoms, rule out medical causes of behavioral concerns, and communicate with healthcare professionals. These nurses are trusted advocates who ensure individuals, families and populations receive quality care and services.

Professional development for nurses in the ID/A field must be constant. There are professional organizations that advocate, network, and provide continuing education for these nurses. Continued support empowers these nurses to influence health policy decisions for the individuals they support. This issue of the HCQU CARES: Nurse Edition offers information about being a nurse in the ID/A field and how the Kepro HCQU can assist you to provide quality care.



## ATTRIBUTES OF NURSES IN THE ID/A FIELD

*"The American Nurses Association (ANA) believes that nurses must provide compassionate, comprehensive, and person-centered care to all people, inclusive of at-risk populations such as people with IDD (intellectual disability) who experience health disparities across practice settings" (ANA Ethics Advisory Board, 2020).*

Nurses who work specifically with people who have intellectual disability/autism (ID/A) have the opportunity to provide person-centered care to at-risk populations 100% of the time. Nursing in this field is different from other fields/specialties because nurses in the ID/A field do not focus on fixing or curing the person; their focus is on recognizing and supporting the person's abilities. This can be achieved through understanding how factors such as environment, communication, personal perceptions, attitudes, and values can impact interactions with individuals with ID/A. Recognizing these factors in yourself and others helps ensure that a person is fully

supported to live a healthy and fulfilling life (Birmingham City University School of Nursing and Midwifery, n.d.).

Nurses in the ID/A field work with individuals across the lifespan, ranging from children to older adults. The individuals have diverse health needs, which might include physical disabilities, neurological conditions, and specific syndromes such as autism, Down syndrome, Williams syndrome, and Prader Willi syndrome. The role of the nurse is to support individuals and their families to ensure health needs are met and individuals reach their full potential.



## IMPORTANT ATTRIBUTES OF NURSES IN THE ID/A FIELD

- ❖ Interpersonal skills—help build relationships, trust, and mutual respect between the nurse and the individual as well as the providers, families, and the rest of the care team
- ❖ Openness—willing to recognize personal limitations or faults and value others' opinions
- ❖ Non-judgmental
- ❖ Flexibility in thinking and doing
- ❖ Ability to work as part of a team
- ❖ Person-centered—putting the individual at the center of care
- ❖ Understanding
- ❖ Creativity

(University of Hertfordshire, n.d.; Birmingham City University School of Nursing and Midwifery, n.d.)

One of the rewards of nursing in the ID/A field is the privilege to get to know a person and work to develop a therapeutic relationship. In doing so, all nursing skills will be used to encompass a holistic approach to care that is meaningful and person-centered. The nurse's daily routine includes listening and communicating, problem solving, using good judgement, and offering advice.

## RESPONSIBILITIES OF NURSES IN THE ID/A FIELD

- ❖ Improve and maintain a person's physical and mental health
- ❖ Reduce health inequalities that lead to premature death of individuals with disabilities

- ❖ Reduce barriers to health and care services to promote an individual's well-being

- ❖ Support the person in living a fulfilling life

(Birmingham City University School of Nursing and Midwifery, n.d.)

The Developmental Disabilities Nurses Association (DDNA) developed "The Developmental Disability Nursing Professional Practice Model" which has four (4) essential components of a nurse's role in supporting the health and wellness of people with ID/A:

- ❖ Collaboration
- ❖ Advocacy
- ❖ Coordination
- ❖ Expertise

(Developmental Disabilities Nurses Association [DDNA], 2020)

Advocacy is defined as "the act or process of supporting a cause or proposal" (Merriam-Webster, n.d.). Advocating for individuals constitutes protection of their civil and constitutional rights, improvement of services to meet individual preferences or desires, full access to and participation in community life, and recognition of individuals as valued and contributing members of society. One conversation at a time, one day at a time, nurses in the ID/A field can make a difference.

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## COLLABORATION BENEFITS THE INDIVIDUAL AND THE SUPPORT TEAM

*Paul Solarz, a 5th grade teacher and inspirational leader in Chicago known for excellence in teaching, stated, "Collaboration allows us to know more than we are capable of knowing by ourselves" (Walker, 2022). Nurses working at provider agencies are often the only nurse at their agency, which offers minimal (if any) opportunity to collaborate with other nurses. The Kepro HCQU has expert nurses experienced in the ID/A field who are happy to collaborate with you.*

### COLLABORATION WITH OTHER PROFESSIONALS IS HELPFUL WHEN

- ❖ Problem-solving and brainstorming
- ❖ Continuing education to obtain current information
- ❖ Exploring behaviors that challenge

Collaboration to problem-solve can lead to successful outcomes. For example, a provider nurse was advocating for medical care for an individual with a pressure injury. The physician felt that the pressure injury was not going to

heal and would eventually lead to other health concerns, but the individual and the nurse did not agree. By using the resources suggested by the Kepro HCQU, the nurse spoke with a Special Needs Unit (SNU) representative at the healthcare insurance provider and located two specialists. The individual was referred to another health care provider and re-evaluated. As a result, the wound was debrided and a wound vac was implemented. Eventually, the care team took over wound care once the wound vac was discontinued. The wound continues to heal, and the individual is doing very well.

Collaboration promotes the sharing of current information and continuing education. The Kepro HCQU is developing clinical news briefs that will be distributed monthly to nurses working at ID/A provider agencies in southwestern Pennsylvania. The information is researched and reviewed by a certified developmental disability nurse (CDDN). The intent is to provide agency nurses with current information and resources relevant to best practices for supporting people with ID/A. If you would like to contribute suggestions and/or information for future monthly nursing new briefs, please contact the HCQU nurse assigned to your agency.

Collaboration is helpful when exploring behaviors that challenge to identify unmet medical needs that might be causing them. After more than 25 years of research and treating people with ID/A, Dr. Ruth Ryan made the following observations:

- ❖ **Uncommon conditions present more often.**
- ❖ **Common conditions present in unusual ways.**
- ❖ **Physical exams require more effort.**
- ❖ **A greater number of blood tests and imaging are required compared to the general population.**

(Myers & Myers, 2017)

When supporting an individual with complex medical and/or behavioral needs, consider collaboration through the Kepro HCQU's complex technical assistance (CTA) process. During a CTA, a Kepro HCQU nurse and behavioral health educator collaborate with the individual's support team, including the agency nurse, to rule out medical causes for an individual's change in symptoms and behavior. The CTA referral form is available for download at <https://hcqu.kepro.com/informational-materials>, in the "General" section. Speak with the individual's supports coordinator to determine if the criteria for a CTA are met.

Together, nurses and other support professionals can identify strategies, customize them to meet the needs of the individual, and develop a person-centered care plan. Sharing current, reliable resources among the support team can benefit the individual and the team. The Kepro HCQU is committed to sharing quality resources with agency nurses. In return, we welcome agency nurses to share professional resources relevant to supporting the health and wellbeing of people with ID/A with the HCQU.

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# COMPLEX TECHNICAL ASSISTANCE

*The Kepro HCQU's Complex Technical Assistance (CTA) process offers person-centered assistance to interprofessional teams supporting individuals with ID/A. The process utilizes positive practices endorsed by the Office of Developmental Programs, such as Everyday Lives, Positive Approaches, and the Sanctuary Model.*

## TO QUALIFY FOR A CTA, AN INDIVIDUAL'S SITUATION/CIRCUMSTANCES MUST SATISFY THE FOLLOWING CRITERIA

- ❖ Major conditions/factors negatively affecting their quality of life, such as changes in behavior, health, and/or environment
- ❖ Deteriorating outcomes, evidenced by a decline in their ability to function at baseline

Typically, a CTA referral is submitted to a designated representative of an individual's administrative entity of oversight by the individual's supports coordinator or provider agency. Upon approval, the administrative entity forwards the referral to the Kepro HCQU, where it is assigned to a HCQU team consisting of a nurse and/or a behavioral health educator, depending on the situation.

The HCQU team works with the supports coordinator to schedule meetings with members of the individual's support team, including provider agency administrators and caregivers, family members, and the individual. The HCQU team researches clinical documentation, facilitates meetings with the individual's team, and offers suggestions to help identify and support the individual's needs and improve their quality of life. If applicable, the HCQU team collaborates with a consulting pharmacist and/or psychiatrist for additional expertise.

## THROUGHOUT THE CTA PROCESS, THE HCQU TEAM OFFERS

- ❖ Resources to increase the team's skills
- ❖ Resources to increase the individual's skills
- ❖ Resources for best practice standards
- ❖ Training and education
- ❖ Health-related strategies

At the initial CTA meeting, the individual's team is asked to develop a person-centered goal to guide activity throughout the CTA. The HCQU continues to facilitate CTA meetings until the individual's team feels their goal for the CTA has been met.

The CTA process has enabled many support teams to discover undiagnosed medical conditions, identify medication concerns, recognize alternative means of communication, and learn best practice techniques that support the needs of individuals with ID/A positively and effectively. Please contact the HCQU if you believe the CTA process might benefit individuals in your care.

## NURSES ARE EDUCATORS

*Everyday Lives: Values in Action 2021 emphasizes the importance of education for individuals with ID/A and their caregivers to promote the health, wellness, and safety of each individual and to ensure quality of care (Pennsylvania Department of Human Services, Office of Developmental Programs, 2021). Education is imperative to prevent health crises, explain diagnoses, convey procedures and medications, and ensure follow up care. It provides necessary information to empower individuals to manage their own health conditions. People with ID/A may need assistance to manage health, so educating their caregivers is important, too.*

Nurses are trained to perform many tasks: assess, implement, observe, treat, monitor, document, assist, supervise, and educate. By providing focused education to caregivers, nurses working at ID/A provider agencies can communicate best practices for an individual in their care at a level that everyone on the care team is able to understand and follow.

Instruction may be presented through oral presentation, written documents, or applied teaching. In addition, caregivers can benefit from learning about general care and safety topics, such as management of diabetes and heart disease, fall risk and prevention, and others.



**"Education is the most powerful weapon which you can use to change the world"**  
— Nelson Mandela, (Loo, 2018).

Education can prevent unnecessary illnesses, injuries, and fatalities. Caregivers provide around-the-clock care, and nurses are not available at all locations where people with significant health conditions reside or visit. Therefore, caregivers need to be educated about health conditions pertinent to the people they support. The most effective education prevents or mitigates health concerns before they become a factor. Furthermore, it is best practice to incorporate the specific needs of the person being supported.

Knowledge around individual care may be placed in an easily accessible document or plan of care that is person-centered. All pertinent medical data should be placed in this plan and shared with caregivers, along with education on all aspects of

the plan. Diagnoses, activity level, medications, and dietary guidelines should be included in the care plan. Nurses should use all resources available to them, including the Health Risk Screening Tool (HRST), to develop a comprehensive plan and communicate the plan to the caregivers.

Individuals with ID/A rely on their support team to assist them to make the best choices. This can include choices that affect their social, emotional, and physical wellbeing. The nurse is the front-line health educator for people with ID/A and their caregivers. Education fortifies the preparedness of a care team, ensuring they are knowledgeable about the health needs of those in their care. Educated caregivers can support a person with ID/A to live their best everyday life.

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## HEALTH RISK SCREENING TOOL —A TOOL TO IDENTIFY RISK

*Risk management is the process by which vulnerabilities are identified and, therefore, changes are made to minimize the consequences of adverse outcomes (McGowan et al., 2022). Vulnerabilities of an individual's overall well-being may be identified through tools used to assess an individual's health stability. These tools produce data that can be used to identify trends in a person's health status. The trends can be analyzed to develop an action plan to maintain health status and mitigate the risk of further decline.*

The multifaceted chronic health conditions among people with ID/A can make caring for their health more challenging. These chronic conditions often include aspiration, dehydration, constipation, seizures, motor deficits, allergies, gastroesophageal reflux disease (GERD), diabetes, dysmenorrhea, sleep disturbances, thyroid disorders, mental health conditions, vision and hearing impairments, and oral health concerns (Auberry, 2018). Along with chronic health conditions comes a need to identify individuals at most risk of developing a life-threatening health concern because of their health status.

The ODP announced the implementation of the Health Risk Screening Tool (HRST) for individuals receiving residential services in Pennsylvania, effective July 1, 2019 (Office of Developmental Programs [ODP], 2019). The HRST was designed to predict health care risks in vulnerable populations by providing measurable data on 22 rating items separated into five categories—functional status, behaviors, physiological, safety, and frequency of services. Raters gather information from various sources to answer yes or no to questions about the person related to areas such as eating, ambulation, toileting, self-abuse, nutrition, gastrointestinal, seizures, falls, and hospital admissions.



**SCORES IN EACH OF THE INDIVIDUAL ITEMS RATED WILL RANGE FROM 0 TO 4 AND FOLLOW THIS GENERAL PATTERN**

**0 NO ISSUES WITHIN THE PAST 12 MONTHS**

**1 OCCASIONAL ISSUES WITHIN THE PAST 12 MONTHS; NO IDENTIFIABLE PATTERN**

**2 EMERGENCE OF AN IDENTIFIABLE PATTERN OF ISSUES**

**3 INCREASING FREQUENCY AND/OR INTENSITY OF IDENTIFIED ISSUES**

**4 POTENTIALLY LIFE-ALTERING OR LIFE-DEFINING ISSUE OR HOSPITALIZATION WITHIN THE PAST 12 MONTHS**

❖ "0" indicates no involvement;

❖ "4" indicates intense involvement involving significant health risk.

❖ Each point on continuum is designated a numerical score.

❖ As points go up, Health Care Level rises.

**"THE OUTCOME OF SCORING ALL 22 RATING ITEMS IS AN OBJECTIVE HEALTH CARE LEVEL (HCL) THAT REPRESENTS THE PERSON'S OVERALL DEGREE OF HEALTH RISK AND DESTABILIZATION."**

*(IntellectAbility, n.d.a).*

Health Care Levels (HCL's)		
Low Risk	Moderate Risk	High Risk
Level 1	Level 3	Level 5
Level 2	Level 4	Level 6

HCLs are significant, as they represent the overall degree of risk identified and are accurate indicators of longevity. Studies on the HRST have shown that as HCLs increase, so do the odds of dying and therefore experiencing a shorter lifespan (Roszkowski, 2020).

Person-centered nursing and support plans can be developed based on data from the HRST. Tools are available within the HRST website to:

- ❖ Assist nurses to make care plans
- ❖ Track data that may indicate destabilization
- ❖ Generate agency specific reports

- ❖ Generate a list of considerations about the person's health
- ❖ Provide education to caregivers and healthcare professionals

*(IntellectAbility, n.d.a).*



## BENEFITS AND OUTCOMES OF HRST TOOLS

Empowers families and caregivers to be responsive to health-related risks

- ❖ Allows for early detection and early action
- ❖ Points out the need for other services and training that may be less than obvious
- ❖ Educates case managers, families, and direct support professionals with knowledge of where risks are present and how to intervene
- ❖ Empowers families and staff with talking points while visiting community doctors and clinicians
- ❖ Helps caregivers and doctors discover the root cause of risks
- ❖ Gives actions steps on how to mitigate or eliminate risks before they become chronic or life-threatening
- ❖ Identifies and addresses obstacles to a well-lived life

- ❖ Assists with person-centered planning and continuity of care
- ❖ Objectively quantifies the level of risk as signified in the assigned Health Care Level
- ❖ Helps avert preventable deaths  
[\(IntellectAbility, n.d.a\)](#)

The HRST is a tool that, when utilized properly, may mitigate health risks and prevent premature deaths in individuals with ID/A. According to an article in the Journal of Nursing Management, "The HRST can predict mortality. Therefore, it can serve as a basis for establishing healthcare needs and determining nursing care acuity" (Roszkowski, 2020).

For more information or to learn more about the functions and features of the HRST please contact:



**KEPRO HCQU**

<https://hcqu.kepro.com/contact-us>



**INTELLECTABILITY**

<https://replacingrisk.com/contact/>

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# SUPPORT ORGANIZATIONS FOR NURSES IN THE ID/A FIELD

*Nurses have a unique role on the frontline of healthcare supporting individuals with ID/A. Key responsibilities include advocating for patients, influencing and/or developing policies, providing training to caregivers, health promotion, assessment, case management, medication administration, and collaborating with interdisciplinary teams to provide the best standard of care to individuals with ID/A. Nurses who support individuals with ID/A practice in various settings including intermediate care facilities, community group homes, schools, and/or personal homes. Support from a community of nurses involved in the same field of practice is helpful.*

## LOCAL AND NATIONAL SUPPORT ORGANIZATIONS FOR NURSES IN THE ID/A SERVICE SYSTEM INCLUDES

- ❖ **Developmental Disabilities Nurses Association (DDNA)**  
 The DDNA is a nationwide organization that has provided education and support for nurses specializing in developmental disabilities since 1992. The DDNA mission is “to educate, empower, and advocate for nurses practicing in the specialty of developmental disabilities nursing” (Developmental Disabilities Nursing Association [DDNA], n.d.). The DDNA offers nurses the opportunity to become a certified developmental disabilities nurse (CDDN). Information about the certification program is available at <https://ddna.org/certification/>.
- ❖ **Pennsylvania Developmental Disabilities Nurses Network (PADDNN)**  
 The PADDNN is an organization specific to the state of Pennsylvania that has been supporting nurses in the field of ID/A with networking and education for over 20 years (PADDNN, n.d.). Information about PADDNN membership is available at <https://paddnn.nursingnetwork.com/membership/new>.

An article titled, *Delivering Person-Centered Cancer Care to Individuals with Developmental Disabilities*, summarized a nurse’s experience working at an ID/A provider agency. In the article, a provider nurse stated, “It was tough in the beginning, as I was the only healthcare person in the agency” (Tichich, 2020). The nurse recognized her need for the guidance and support of other nurses in the field of ID/A, because techniques for meeting needs specific to people with ID/A are not taught in nursing school. The nurse in the article found resources and networking through the Developmental Disabilities Nursing Association (DDNA). “Here was this wonderful network of nurses who all provided the same type of care. Resources were few and far between, so we kind of MacGyvered our way through situations and helped each other learn along the way” (Tichich, 2020). The nurse in this article attributes her success in the ID/A field to her continued involvement with DDNA (Tichich, 2020).

Nurses in the ID/A field might spend years not aware of organizations like DDNA and PADDNN. Membership in such organizations is available to assist nurses in the field of ID/A with continuing education and resources for support and networking.

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