



Waisman WIN: Wellness Inclusion Nursing Program

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AUCD 2022 Conference

11/13 -11/16/2022

Health Equity: Serving the Whole Person

Wellness Inclusion Nursing (WIN) - Promoting Health Equity through IDD-Informed Community Nursing.

What is WIN?

WIN stands for Wellness Inclusion Nursing. WIN is part of the Waisman Center's Community Outreach Wisconsin programs. The Waisman Centers hosts Wisconsin's UCEDD (University Center for Excellence in Developmental Disabilities) and is located on the University of Wisconsin, Madison campus.

WIN nurses work with both children and adults with IDD (Intellectual and Developmental Disabilities) who have complex health care needs and live in the Dane County, Wisconsin. Dane County, as the second most populous county in Wisconsin had 561,504 residents according to the 2020 census. Dane County includes the city of Madison which is also the state capital.

WIN nurses partner with the person, their families, paid and unpaid caregivers, and health care providers. WIN services focus on restoring, maintaining and promoting maximal health and independence for children and adults with intellectual disabilities so they can achieve their best life possible.

What do WIN Nurses do?

WIN Nurses work to develop positive, trusting relationships with families and health care professionals and strive to understand an individual's unique communication strategies, preferences, and perspectives. WIN Nurses work as a member of diverse, community teams in supporting the individuals' efforts to effectively communicate their needs and wishes to their respective health care providers. WIN Nurses also collaborate and consult with health care providers how to safely implement tailored interventions in supported community living. Most importantly, the WIN Program strives to provide advocacy and to identify resources based on proven, practical approaches, that can be utilized in the long run and contribute to the best health care and health outcomes possible.

Why WIN?

Individuals with intellectual and developmental disabilities often experience unaddressed complex medical, psychological, and behavioral needs which can make it challenging to access typical healthcare settings and benefit from services available. This can negatively impact the individual's general health, but also limit the person's participation in general wellness activities and quality of life in the community. WIN is an ongoing effort to build a collaborative partnership with individuals with disabilities, their families and care teams, to improve communication with health care providers, serve as a unique training resource to ensure that individuals' needs are met throughout the lifespan.

When did WIN get started?

The WIN program was created in 2009 in partnership with Dane County Human Service. At the time Dane County had the highest proportion of people with intellectual disabilities opting to self-direct their services of any county in Wisconsin. A very high proportion of people served – these included individuals with complex health care or behavior health needs - were living in small homes and apartments supported by local, supported-living agencies. Supported Living agencies, however, did not necessarily have the resources to employ their own nursing staff, but needed consultation and training from IDD-informed nurse consultants who were familiar with local health care resources, but also had a thorough understanding of supported community life.

The WIN program was added to Dane County's shared infrastructure of public services - which already included several other Waisman Center Community Outreach programs: an extensive behavioral consultation and support program (Community TIES), IID-informed psychiatry for people requiring unique accommodations and a coordinated (TIES Clinic), and rapid crisis response to individuals at risk of hospitalization, institutionalization, or inappropriate arrest (Crisis Response).

How is WIN funded today?

In 2018 Dane County was one of the last Wisconsin counties joining the State of Wisconsin's care model of providing long term care services through contracted Managed Care Organizations (Family Care). This service model also includes a self-determination option named IRIS (Include Respect, I Self-Direct). Many individuals served by WIN chose the IRIS program which has become the primary funder of the WIN program. Additional fee-for-service program revenue is generated through Wisconsin's Medicaid waiver Long-Term Care programs for children, and through contracts with local service providers.

How many people are served by WIN?

In FY 2022 84 individuals were served by WIN.

Age of participants:

- 1-21: 21 (25%)
- 21-55: 30 (36%)
- 55 & older: 33 (39%)

Individuals served by WIN tend to be somewhat older than individuals served through other Waisman Center Community Outreach program. In general, the health care needs of participants 50 years and older were more complex and required substantially more WIN nursing time compared to younger participants.

What are Common Health Care needs encountered by WIN?

- Dehydration, constipation, diet, and weight changes
- Aspiration, swallowing, feeding tubes
- Orthopedic issues and falls
- Seizures
- Pain
- GI issues
- Mental health needs
- End of life support

What Barriers & Challenges does WIN Nurses help to navigate?

Difficulty scheduling appointments that are sufficient in length

Appointment time with individual providers is very limited and often not enough time is available for all concerns to be addressed. WIN Nurses can work with individuals and teams to help them prepare for medical appointments to better use available time. This can include working to create written questions to ask providers and specific concerns to bring forward during the appointment. For individuals with complex healthcare needs the WIN Nurse can attend appointments to facilitate communication and to work with staff to ensure medical recommendations are understood and followed.

Transportation, physical barriers, few accommodations for alternative communication or behavior health needs

Individuals with physical, communication, or regulation difficulties have barriers to receiving health care services. WIN works to overcome these barriers in multiple ways. For individuals who have transportation barriers to be seen in person at their providers clinic the WIN Nurse can complete home visits and provide physical assessment findings to the physician team. This partnership can provide information for making treatment decisions by providers or at times elevate the need to seek medical attention more emergently. WIN Nurses ability to develop relationships with individuals in their homes through time allows them to often be able to complete physical exams and vital assessments more successfully than medical providers can in the clinical setting. This can allow information for providers to make treatment decisions.

Lack of plain language information/misconceptions about supported community life, diagnostic overshadowing

Instructions provided by medical providers can be difficult for non-medically trained individuals to follow, and inadequate time is available during appointments for provider to give very specific step by step instructions for staff to follow. WIN nurses work with physician orders and recommendation to create written protocols and step by step procedures to help guide care. The WIN nurse is also available when needed to provide 1:1 staff training to help them understand and follow providers orders.

Medical providers often are not used to receiving information from care provider when patients are not able to communicate directly with them. The WIN nurse can attend appointments and work in consultation with medical providers to help them understand the individuals home environment and support resources. They can help the support team verbalize symptoms and observations to providers to avoid unnecessary tests, and to ensure needed tests are not missed due to not understanding the full extent of the individual's health symptoms and experience.

High caregiver turnover and few hands-on training opportunities for caregivers

Training that the WIN nurses provide can be specific for individuals needs and can be provided to new care providers to ensure quality care continues despite high staff turnover that is common in the supportive care world. WIN nurses also provided more general training courses with a focus on IDD and the special nuances and limitations can impact their care needs. These trainings are available for anyone in the community to increase their comfort and skills working with someone with IDD.

Reluctance from funders, fears to duplicate services

WIN nursing services are different than nursing services that are available through other areas of the medical care system. WIN Nurses skills and experience working with individuals with IDD living within the community allows them to have insight into the experience of the individuals and teams they work with. They can share this perspective with medical providers to help ensure recommendations are practical and manageable for the individual's life.

What Are Examples of Past Training Tools?

Go With Your Gut: This course is focused on ways to improve nutrition, increase exercise, and optimize bowel health. The course includes topics such as eating well on a budget-simple ways to plan, shop and cook healthy meals, adaptable exercise and movement ideas, constipation prevention with natural foods and medications, risks of constipation, and ways to document bowel concerns

Living with Diabetes: Learning, Coping, Helping: This was a series of hands on training and resources that were created for both community care providers and those individuals living in the community with IDD and a diagnosis of diabetes. The training provided would be specified to the individuals needs and could include topics such as diet and nutrition, carb counting, exercise, medication regimen, insulin administration, blood sugar checks, and health and safety practices all related to their diabetes.

Is It Pain? Many individuals with IDD have difficulty identifying their pain or telling others about it. A person's life can be greatly improved when pain and the cause of pain is discovered. This course helps raise awareness of pain possibilities that may negatively affect individuals that they support. WIN nurses share they experience looking for and finding individual's hidden pain clues, and how to work to better manage that pain.

Save My Skin: This training focused on teaching how to keep the skin whole and healthy to help individuals feel comfortable and prevents infection. Course participants learn what they can do to prevent clients from having skin problems such as open sores and rashes. Focus was made on developing participants knowledge of what to watch for and what to do when they would see a possible problem concerning the skin.

Taking Charge of Your Own Health Care: This was a webinar that covers how to use the Self-Directed Health Care Kit. This kit was designed to help individuals with developmental and intellectual disabilities (I/DD) advocate for their own health care needs and supports clear communication between the individual and their health care providers.

How does WIN evaluate their services?

An ongoing evaluation of intermediate outcomes (six months after start of services) began in early 2022. The evaluation focuses on how WIN services impact the person's ability to manage the health conditions that led to a referral for WIN services, and on the impact on the person's overall quality of life.

For more information: <https://cow.waisman.wisc.edu/win/>

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