



## **WIN for the win: Wellness Inclusion Nursing helps improve quality of life of individuals with disabilities through nursing consulting**

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Rachel Karch started having some medical complications after her 30th birthday. She was born with a genetic syndrome called Dup15q syndrome, characterized by a duplication in a portion of chromosome 15. This duplication can result in some motor delays, variable intellectual disability, autism spectrum disorder (ASD), and epilepsy. Other than seizures, Rachel's mom, Anne Karch, says her daughter was perfectly healthy until six years ago. Individuals with disabilities sometimes require specialized healthcare that involve multiple providers. Nurses at the Wellness Inclusion Nursing (WIN) connect individuals with intellectual and developmental disabilities to appropriate community resources, provide nursing assessments, and educate those around them on how to best provide support.

*They (WIN) focus on restoring, maintaining, and promoting maximal health and independence for adults with developmental disabilities.*

Rachel's first complication was a severe pleural effusion, a buildup of fluid between the layers of tissue that line the lungs and the chest. It landed Rachel in the intensive care unit. After the first episode, the family started looking for ways to prevent another one. Looking back, they identified signs they had overlooked such as Rachel getting tired and having to sit down often. Her doctor recommended getting an x-ray of her lungs anytime they saw the signs. When they brought this up to Marcia Stickel, BSN, Rachel's former nurse at the WIN she told them "Why are you exposing her to all those x-rays? Just get a pulse oximeter." Now taking Rachel's oxygen levels is literally at her fingertips. They do it three times a day, and if it is low, they know to seek medical help.



Rachel goes hiking with her dad, Paul Karch

WIN is a Waisman Center Community Outreach Wisconsin (COW) program with nurses that serve as consultants for individuals with intellectual and developmental disabilities (IDD) and their families, caregivers, residential and vocational team members, and health care providers. They focus on restoring, maintaining, and promoting maximal health and independence for adults with developmental disabilities.

Rachel, who is 36, has significant cognitive challenges. She was diagnosed with Dup15q syndrome after she started having seizures at four months old. “They had no information for us because [at that time] they really just only had the technology to begin to diagnose this,” Anne says. Anne now co-chairs the Dup15q Alliance, providing families with accessible information upon diagnosis. Rachel’s seizures were controlled with medication, but started again when she turned 10. Now, they have found a balance for controlling seizures with medication that still allows Rachel to perform her daily activities, even though it doesn’t fully prevent the seizures.



Rachel on a bike ride

The Karch family was referred to WIN by Rachel’s support broker in Dane County in 2015, eight years after moving to Madison. Stickel, her first WIN nurse, provided very practical solutions to some of Rachel’s health challenges.

Rachel had also developed a toenail fungus that wouldn’t go away. Her doctor kept prescribing medicines that kept getting higher in price. “Marcia said, ‘just use Vick’s Vapor Rub’,” Anne recounts. That did the trick. “Marcia and now Sherry, they’re so practical. They just know so many easy, simple ways to do things,” Anne says. Sherry Schultz, RN, MSN, CDDN, directs WIN and is Rachel’s current nurse. Coincidentally, Schultz had also been Rachel’s nurse when she worked at Easter Seals Camp, which Rachel attended.

## Wellness consulting and support

WIN was established in 2009 and is located on Olin Ave in the Community Outreach Wisconsin offices. Anyone with an IDD and living in Dane County is eligible for WIN services. They currently serve approximately 85 children and adults combined. Some individuals attend WIN episodically, whenever a medical concern arises. For others, WIN is a continuous support. “There’s some individuals that WIN has been working with for years and years, and we will likely continue to work with them through the rest of their lives,” Schultz says.

In addition to Schultz, nurse Carmella Smith, RN, BSN, is also a consultant at WIN.

The program provides individualized consultation to clients, support brokers and agency staff. They connect clients with the appropriate community resources, provide nursing assessments, train and educate vocational support staff, advocate and help plan for end-of-life care, coordinate hospital stays and discharges, help promote healthy living, and work together with teams to support individuals with complex medical needs. “WIN is what the individual needs it to be,” Schultz says.

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For individuals with an IDD, healthcare can get very complex due to having multiple health care providers for different specialized areas. For these individuals, WIN acts as a historian, too. “We have to put all of those pieces together and package it up for the providers or their physicians so they have all of the information that they need in order to make a diagnosis or give a good treatment plan,” Schultz says.

Schultz and Smith also provide nursing assessments for a wide range of health concerns that can include mobility issues, fall prevention, complex seizure disorders, assistance with cancer chemotherapy treatment, acute changes in medical conditions, diabetes education, nutrition, and more.

At the beginning of 2022, Rachel lost a lot of weight, so Rachel and Anne started meeting with Schultz more often to strategize how to get more calories in her diet. With the COVID-19 pandemic, Rachel had started going on walks and moving around more often but wasn't keeping up with the calorie intake to support that. This was further complicated by esophageal dysfunction and constant aspiration of food. Rachel had a feeding tube placed, and started gaining back some weight. Schultz sees Rachel every month and tracks her weight, making sure it is headed in the right direction.

"It's just all those little helpful things that allowed us to keep her safe and have the right equipment to know what to do for her," Anne says.

For Anne, WIN provides an additional perspective when trying to think something over, from someone who knows her daughter's medical history very well, and is a consistent support in her life. "Sherry provides a consistent knowledge of Rachel that we sometimes can't get with the primary care providers because they seem to be coming and going," Anne says.

Rachel spends her mornings working at the Department of Natural Resources (DNR), shredding documents to keep information safe for people who apply for a fishing or hunting license. "And she does it very well. Her brother and sister have gone and watched her work and they're still astounded at her level of concentration," Anne says. Her coworkers also love having her around. She has also taken two Madison legislators to work, to show what people with disabilities can do.

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Rachel also loves interacting with people, and during her free time, she likes going on walks. She lives in her own condo in an intentional cohousing community, and has ten caregivers that provide support.



Rachel (middle) with her sister Lydia (left) and brother Chas (right)

### Community education

Another way in which WIN helps improve the lives of individuals with IDD is through educating those around them on how to best support them. WIN nurses work closely with other Community Outreach Wisconsin programs to offer routinely scheduled trainings on topics such as living with diabetes, identifying pain, skin care, gut health, and more.

Their series, called Waisman WIN Distance Learning, provides expertise, training, and resources through videoconference workshops offered to individuals who support individuals with IDD. This series intends to increase access to resources and



clinical services in many rural and underserved communities in the state and beyond.

"I think that the WIN program is really focused not only on fixing problems, but on trying to improve quality of life and working to prevent problems," Schultz says. "Looking at the bigger picture of not just things that are going well now, but what we can do to make lives better."