

Wisconsin Aging and Disability Resource Centers (ADRCs) and Dementia Care Specialist Program



Kristen Felten is with the Wisconsin Department of Health Services in the Bureau of Aging and Disability Resources (BADR) and the Office on Aging (OOA). **Cori Marsh** is a Dementia Care Specialist with the Aging and Disability Resource Center (ADRC) of Rock County, Wisconsin. We're very grateful that both participated in key informant interviews with the NYU BOLD Public Health Center of Excellence on Early Detection of Dementia and are excited to feature their work in this partner spotlight.

Key takeaways:

- Memory screening can be done effectively in a non-clinical setting.
- Wisconsin's memory screening program includes many additional services, such as education and connection to resources beyond screens themselves.
- The personal connection that is made with individuals in the community can ease stigma and encourage action among those who may be hesitant.

Please start by telling everyone a bit about the work that you're doing.

Kristen: In Wisconsin, the Aging and Disability Resource Centers (ADRCs) are county-level agencies that provide resources and services at no cost to the public. Anybody can contact or visit them, and they also do home visits which are a popular service. The ADRCs are all about providing information and assistance, and decision support, around anything related to long-term care for older adults and adults with disabilities at any age. I created the dementia care specialist program in Wisconsin, which supports people with dementia and their caregivers in order to ensure the highest quality of life possible while living at home.

The program is in its final expansion, growing from serving 56 counties to statewide coverage of all 72 counties in 2022. Dementia care specialists are also employed by tribal agencies. There are currently four tribal dementia care specialists, covering five tribes, but this will also expand to provide service to all 11 federally recognized tribes in Wisconsin in 2022. The dementia care specialists around the state currently meet bi-weekly as a unique peer group. In their individual ADRCs, the dementia care specialists provide training to all the frontline staff on dementia, the needs of caregivers, dementia specific resources and how to provide a memory screen. They also act as catalysts for dementia friendly community work, and meet with individuals and families to provide support and evidence-based programs.

Cori: I am one of the dementia care specialists in Wisconsin and I'm focused on one county, Rock County which is a blend of urban and rural areas in the very Southern part of Wisconsin with a population just over 163,000. This includes the two larger cities of Janesville and Beloit. My work involves 3 main pillars out in the community: 1) Creating a dementia-capable ADRC, 2) Providing dementia friendly community involvement, and 3) Supporting family caregivers and those living with dementia. We have the unique opportunity to work alongside families closely.

Cori (continued): I am one of the dementia care specialists in Wisconsin and I'm focused on one county, Rock County which is a blend of urban and rural areas in the very Southern part of Wisconsin with a population just over 163,000. This includes the two larger cities of Janesville and Beloit. My work involves 3 main pillars out in the community: 1) Creating a dementia-capable ADRC, 2) Providing dementia-friendly community involvement, and 3) Supporting family caregivers and those living with dementia. We have the unique opportunity to work alongside families closely.

What is the story behind why you're doing what you're doing?

Kristen: We tested the Cognistat screening tool for use in the community in a 2004 pilot in a few counties, and found that it was too long and too involved for ADRC staff to administer along with their other tasks. In our next pilot in 2009 with one county, the neuropsychologist at the Wisconsin Alzheimer's Institute, who we work closely with, selected the Mini-Cog and the Animal Naming Screen to be used in combination to help facilitate a conversation. The pilot was a great success. ADRC staff now use these to initiate a conversation about brain health for those whose screening results show no concerns, to discuss available resources with caregivers, and encourage people to connect with their doctor when appropriate to receive some type of diagnosis and treatment as needed. The screens are all voluntary and 96% of people who were offered screening in the pilot said that they wanted it. As a part of our BOLD Public Health Enhanced grant, we are creating an evaluation of this program to study more about what the impacts have been.

Cori: The Dementia Care Specialists program provides specialists the unique opportunity to work alongside families to create a safe place to discuss memory concerns, get memory screenings, and educate about the importance of maintaining brain health. Our program also provides individuals with the tools and strategies to seek care related to cognitive concerns with their primary care providers. Often, providers are reluctant to conduct memory screeners because there is no "cure", but we encourage people to strongly advocate for their health needs and concerns.

Cori (continued): We support people by giving them the language to have these conversations with their doctors. We also offer to contact their provider directly to express that they have concerns, or provide their doctor with the results of their memory screening with their consent. Dementia Care Specialists in Wisconsin have very unique backgrounds, varying from therapeutic recreation, mental health, social work, and nursing among other professions. We seek individuals who are comfortable doing programming like memory cafes and leading support groups, as well as those who are comfortable with public speaking to educate the community about dementia and the importance of brain health.

Tell us about some parts of your projects that you're working on now that you are really excited about.

Kristen: The evaluation we plan to conduct of the memory screening program will begin early in 2022. We plan to collect general demographics of those screened, living situation, reason for screening, screening outcome, whether a referral was made to the PCP, what types of education were provided, and a follow up call with those who were referred and agreed to receive a follow up call. With the disruption of the pandemic, the number of screens being completed has gone down, but we hope to collect data from several hundred community-based screens throughout the year from around the state. Analysis will be completed in 2023 for publication.

Cori: One project I'm leading is the Purple Tube Project. This project ensures that first responders can easily identify people living with ADRD. We do this by placing a purple dot in an inconspicuous place in a person's home. This then triggers first responders to go to this person's fridge, where they will find a purple tube containing vital information, such as this person's emergency contact, primary care provider, and medical conditions that would be relevant to their care. This program allows people living with ADRD to receive specialized care, without stigmatizing them, or calling too much public attention to their condition.

Cori (continued): We recently hosted a play about memory loss for our community. We had over 100 attendees. Following the event a woman pulled me aside and said her husband agreed to a memory screen if I would be the one doing it because he felt like he knew me from hosting the event. The screen was scheduled and the support for their journey was begun. The personal connections you build with the community goes a long way with building their trust and comfort level with you, which greatly incentivizes them to seek care.

For people who want to know more about your current work and programs, what are 1-2 pieces of information you think is important for them to know?

Kristen: The two screens (Minicog, Animal Naming Screen) are offered by the staff at the ADRCs when they suspect a person they are working with could benefit from a screen, or when people ask for it. People do want it enough that when they find out this service is available, they will request the screens themselves.

There are lots of ways that people find out screening is available, but one of my favorite ways is that the ADRCs have regular newsletters, and they've become very clever and put in a corner a coupon that says "Free Memory Screening with this Coupon" – and so people bring in these coupons to their county ADRC to receive free screening. Another place these are done is at health fairs, and that's a nice way that I think has helped to normalize memory screening, when it's offered together with bone density screening and falls risks assessments and whatever else is being offered. Helps to reduce the stigma somewhat of memory screening and normalize doing them.

Cori: Building connections with the community, and making them feel that they have an advocate in their corner goes a long way. Many of the consumers who have sought care with us, were referred by other consumers who viewed us an important resource.

Cori (continued): People need to feel like you're in their corner, listening to their needs, rather than telling them all of the important information you have that is related to dementia. Often, people are given too much information that they cannot sift through. It's important to tell people what they absolutely need and connect them to the appropriate resources, so they receive the information in smaller chunks, rather than all at once.

Our screening process emphasizes that some causes of memory loss are treatable. For instance, people starting a new medication or having a vitamin B12 deficiency can experience changes in their cognitive ability. Our screening process can be the first step to identifying a potential problem, and then referring them to a specialist to identify the cause of the problem. It is important that they have the tools they need to have the discussion with their primary care providers.

What would you tell someone who wanted to start a similar program like yours in their own setting (i.e., another state, county, or city)?

Kristen: One purpose of this program is to encourage people to have a discussion with their primary care doctor if they have any concerns about their memory or cognition, and to hopefully receive an appropriate evaluation and diagnosis. But there are other benefits as well. As a part of the screening, information is shared about what is normal aging, what is dementia, and how to maintain brain health. Information about programs and resources available in the local community are also shared. A simple 5 minute memory screening can take an entire hour-long home visit if there are lots of questions and discussion. This is also an opportunity to develop a relationship between the person and the resource center for the future. This program is similar to a blood pressure check at a health fair, and can be done anywhere there is private space for confidentiality. When the results of the screen are out of range, or other information has been shared that is of concern, a referral to a medical care provider is made and education and resources are provided.

Kristen (continued): It is critical for screeners to know these two tools do not cover all areas of cognition, are not a substitute for a clinical evaluation, and results that don't indicate a concern do not necessarily mean there is none. When screeners are talking with someone as a part of the program, possibly including family depending on setting such as in the person's home, they ask questions to try and ascertain if there have been any significant changes to the person's abilities or mood in addition to what is captured by the screens. Some types of dementia will not be captured in these screens, but a knowledgeable screener can ask those additional questions to inform whether talking to the physician should be recommended even if they "pass" the screens. There are also some limitations to these tools in cultural and physical accessibility.

Screeners also emphasize there are many causes of memory loss or confusion in older adults that are not a disease that causes dementia. Vitamin deficiencies, medication interactions and a host of other problems that can be treated can be the cause, and asking the doctor to check those things can lead to effective treatments and a "the fog has lifted" moment, as one woman put it after receiving a B12 injection. The screens are entirely voluntary. What is done with the results is entirely up to the individual. Some people are not ready to have a discussion with their PCP right away and may need time to become comfortable enough to do so. If the individual is not ready to take action on the screens, at least the aging and disability resource center screener has made the person aware of what the center can do, its resources and supports, and ways the person can be pro-active to reduce risk and take steps to maintain their brain health.

Cori: The ability to connect with people on a personal level is crucial to the success of any dementia detection program. The personal connection creates an environment that makes people comfortable to seek care with you. It also ensures that people are connected to the appropriate care and resources. There are similar programs that are done completely virtually, and while these programs are still valuable, there is no human connection.

Cori (continued): With virtual screenings, there is a higher likelihood that people will misunderstand the instructions leading to an incorrect screening. It also significantly less likely that people who test positive for cognitive impairment will seek the appropriate care afterwards in order to get a diagnosis, or any other follow-up care they may need. Education and outreach regarding dementia detection and maintaining brain health is equally important.

Where else can people look to find out more about all the great work that you're doing?

Kristen: The state of Wisconsin website includes information about the [Dementia Care Specialist \(DCS\) program](#), and the “Memory Screening in the Community” training manual. The DCS oversee the program at each aging and disability resource center location. The training manual is being revised and the updated version will be available in early 2022.

Cori: The work of the Dementia Care Specialists program varies from county to county, but all of the programming that we do can be found on the Wisconsin state website. Programs throughout the state might include memory cafes, including a drive-thru memory cafe, book clubs, support groups, educational programs and pizza nights. Many Dementia Care Specialists also offer evidenced based programs such as the Savvy Caregiver, Powerful Tools for Caregivers and Living Well Programs. Programs like pizza nights include minimal discussion about dementia from the organizers. Instead, it is an opportunity for families in the community to connect with each other and share their personal ADRD journey, or that of a loved one. The program in Rock County have had participants ranging in age from 12 to 87 with the focus on living the best life on the dementia journey. The pizza night was also the catalyst to hosting a day camp for kids who support someone in their family/community with dementia.

What is one thing that you wish people knew more about early detection of dementia?

Kristen: Knowledge is power. Walking through each day on the path with dementia is made more difficult for everyone when no one understands what is happening. The earlier on that path decisions can be made with some knowledge of what might be coming, the greater the impact those decisions can have on the quality of life for the person living with dementia, and their family and friends. Early detection puts the person in charge instead of the disease. Early detection allows for that big trip saved until after retirement to be taken now, while it's still possible. Early detection allows people the chance to mend relationships, and to say those things they want to say, before it is too late. Early detection is the opportunity of a lifetime.

Cori: There is a great need for the dementia screening to be more robust. The screening process needs to be enhanced, and the screening tool being implemented must fit the setting it is being utilized in. For instance, our community memory screenings use the Mini-cog and the Animal Naming Test for our first round of screening, because they are relatively easy to administer and can be completed in less than 20 minutes. In the event of a positive screen, we may schedule a follow-up appointment with a consumer using the MoCA, which is a longer cognitive screening test. We also spend a significant amount of time with consumers and families 1-on-1 to discuss the results of their screening, next steps, local resources they can access, and any other questions they may have.