



DEMENTIA CARE SPECIALIST

2016 ACTIVITY REPORT



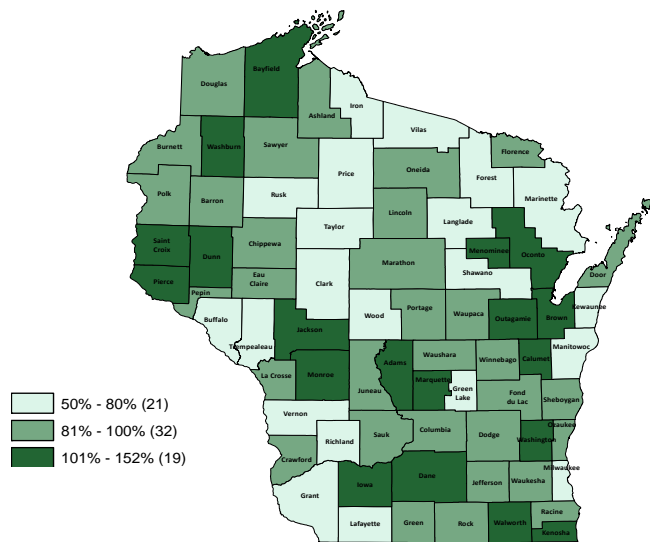
Wisconsin Department of Health Services
P-01775 (05/2017)

INTRODUCTION

In 2015, an estimated 115,000 individuals in Wisconsin were living with Alzheimer’s disease or a related dementia. By 2035, that number is expected to grow to 216,000.¹ Figure 1 represents the estimated percent increase in the number of people with dementia in each county from 2015 to 2035.² For 21 counties, the percentage is projected to increase by at least 50%. For the 19 counties in the darkest shade, the population with dementia is projected to increase by at least 100%, up to 152%.

Without a cure or effective treatment, Alzheimer’s disease is the only cause of death among the top 10 chronic illnesses that cannot be prevented, cured, or slowed in its progression. It is quickly becoming expensive for family caregivers and state-funded long-term care programs. In 2016 alone, Medicaid costs in Wisconsin totaled \$706 million for people over age 65 with Alzheimer’s disease and other dementias.³ In addition, family caregivers provided 219 million hours of unpaid care for people with dementia valued at \$2.7 billion in Wisconsin in 2015.⁴

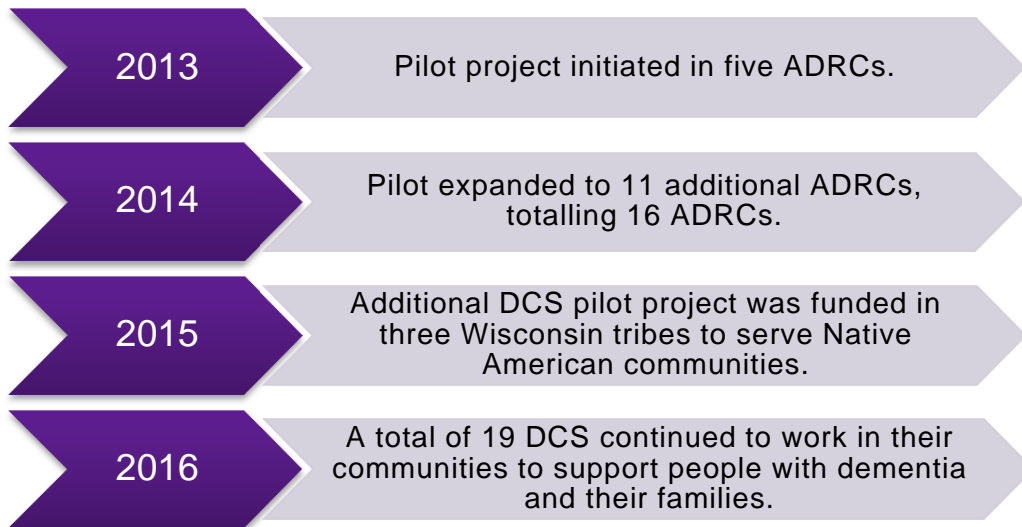
Figure 1 Projected Increase in Dementia 2015-2035



The large number of people affected, the personal impact on individuals with dementia and their families, and the cost of providing care are all compelling reasons for providing a community specialist as part of the dementia care system in Wisconsin. In 2013, the Wisconsin Department of Health Services piloted the Dementia Care Specialist (DCS) project in five aging and disability resource centers (ADRC). In 2014, the pilot expanded as part of the Dementia Care System Redesign. Since then, the pilot project has grown to 19 DCSs, including three at tribal agencies.

Dementia Care Specialists support individuals with dementia to remain active and able to stay in their homes in the community and provide support to family caregivers. DCSs also work with other professionals and throughout their community to develop dementia-friendly organizations, businesses, and communities.

PILOT TIMELINE

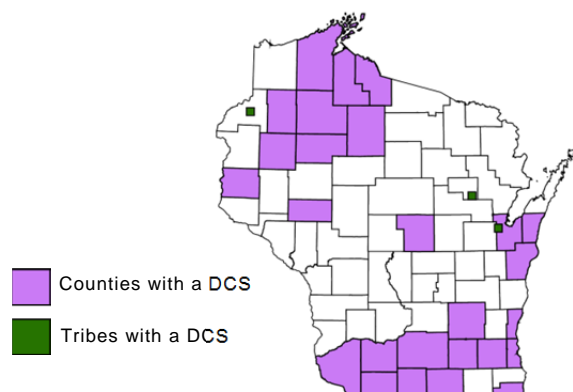


PILOT SERVICE AREAS

AGING AND DISABILITY RESOURCE CENTERS WITH A DEMENTIA CARE SPECIALIST			
Barron, Rusk, and Washburn Counties	Eau Claire County	Milwaukee County	Rock County
Brown County	Jefferson County	North (Ashland, Bayfield, Iron, Price, and Sawyer Counties)	Southwest (Grant, Green, Iowa, and Lafayette Counties)
Dane County	Kenosha County	Ozaukee County	St. Croix County
Dodge County	Lakeshore (Kewaunee, and Manitowoc Counties)	Portage County	Waukesha County

TRIBAL AGENCIES WITH A DEMENTIA CARE SPECIALIST
Menominee Department of Aging and Long Term Care
Oneida Tribe Elder Services
St. Croix Tribal Aging Unit

Figure 2 DCS Project Service Areas in 2016



PILOT GOALS

- 1 Support individuals with dementia to remain active and able to stay in their own homes in the community.**
- 2 Support family caregivers so that they can continue to help their loved ones with dementia remain in the least restrictive setting for as long as possible.**
- 3 Increase the dementia capability of the local ADRC as well as other county and tribal agencies.**
- 4 Facilitate local efforts to build dementia-friendly communities.**

FROM THE DESK OF A DCS ON CAREGIVER EDUCATION

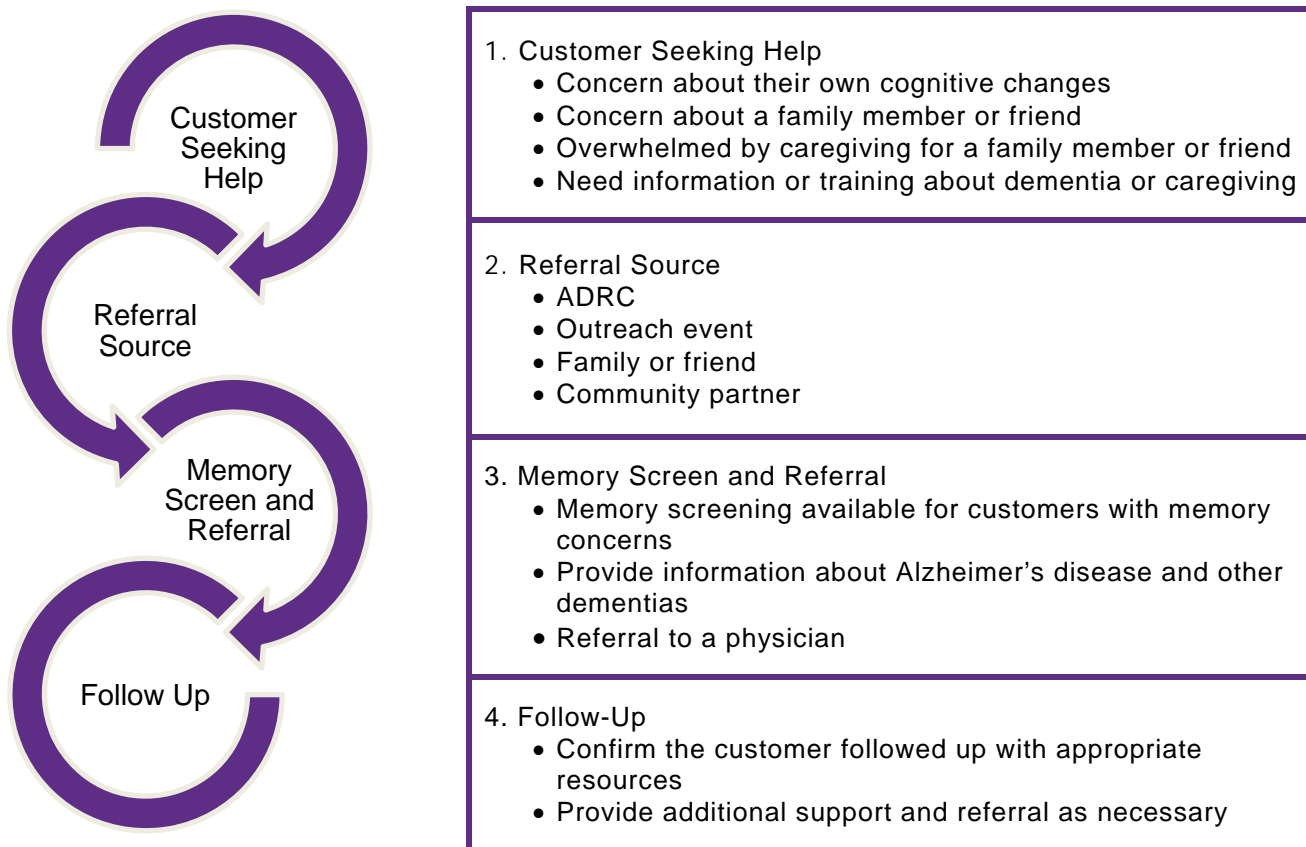
“It is surprising to me the amount of caregivers whose loved ones have been diagnosed (even a year or longer) and have received no education about the disease, progression, or other information to help plan for the future. So many people receive ‘dementia’ as a diagnosis along with a prescription...

“Education about getting a specific diagnosis is incredibly important to take the next step in educating about that diagnosis and help that individual/family understand the symptoms, management, communication, environment, activities, and services available. When that family understands these things and can implement strategies using this information, the person living with dementia has a greater chance of remaining at home longer.”

Nicolette Miller, Brown County DCS

PILOT IMPACT

The services that customers seek from a DCS vary from county to county and tribe to tribe. However, there is a general pattern to the way customers are served by ADRCs and tribal agencies to address their concerns about Alzheimer's disease and other dementias. Below is a diagram that illustrates this process. Each step in this process will be expanded in a section sequentially laid out in this report.



Much of the aggregate data that is in this report reflects reported data for all of 2016. However, due to a change in reporting tools, the indicated tables throughout the report only reflect data collected from April to December 2016. It should be noted that these data are an underrepresentation of the total impact that DCSs made in 2016. For more information regarding the change in reporting tools, please see the note at the end of the report.⁵

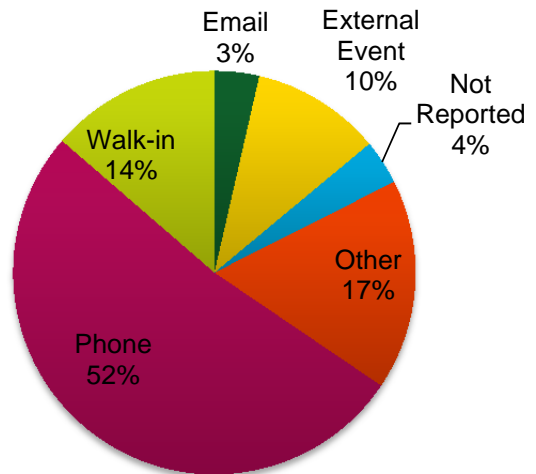
In addition to serving customers at ADRCs and tribal agencies, DCSs also work with businesses, law enforcement, local organizations, and the community to increase awareness of the unique needs of individuals with dementia and their caregivers. They attend numerous outreach events and provide their expertise to other professionals in their service areas.

CUSTOMER SEEKING HELP

DCSs provide information about a wide variety of topics related to Alzheimer's disease and other dementias, including but not limited to: signs and symptoms of the disease; cognitive screening and referral to a medical professional; family caregiving and respite; difficult conversations about safety and independence; and power of attorney for healthcare and finances. All information is provided to community members regardless of income level.

Customers can reach the DCSs through many different routes. In 2016, over half of contacts occurred via phone call. In some cases, these calls are routed through information and assistance specialists at the ADRC. In other counties, the DCS provides his or her direct number to customers on brochures and other educational materials. DCSs also see walk-in customers who may request a memory screen or need information about caring for a family member with dementia.

Figure 3 Customer's Mode of Initial Communication, May - December 2016, n=1,924



DCS CONTACT QUICK STATS

Total Contacts: 2,822
Minimum Age: 18
Maximum Age: 103
Average Age: 68.6

Male: 30%
Female: 69%
Not Reported: 1%

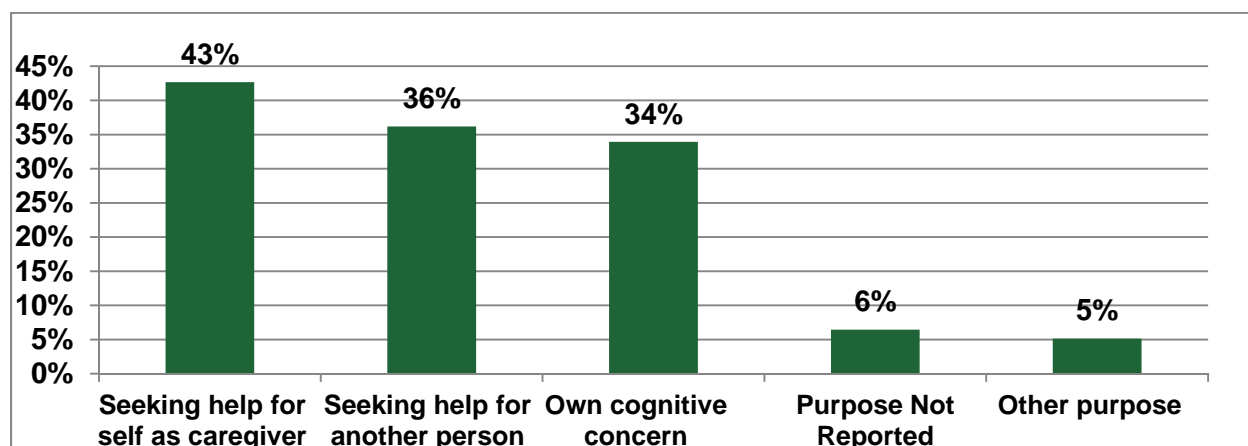
In 2016, 43% of people who contacted a DCS were seeking help for themselves as caregivers. According to the Alzheimer's Association, 83% of care provided to people with dementia living in the community is provided by unpaid caregivers, most often family members.⁶ Family caregivers often lack sufficient training to be able to appropriately respond to the needs of a family member with dementia or to recognize their own need for support.

FAMILY CAREGIVERS

- Are the most common people to call a DCS looking for resources and support.
- Provided 219 million hours of unpaid care for people with dementia valued at \$2.7 billion in Wisconsin in 2015.

Of those who were seeking help for themselves as a caregiver, 37% were a spouse or partner and 50% were an adult child.⁷ Many spouses and adult children whose parents develop dementia do not think of themselves as caregivers. They are often unaware of the physical and mental stress that being a caregiver has placed on them. DCSs provide necessary training and referrals for family caregivers to better support the person with dementia in the community. Half of contacts who were seeking help for another person were adult children, presumably looking to help a parent who was exhibiting memory concerns or for a parent who was overwhelmed by caregiving.⁸

Figure 4 Purposes of Contact's Initial Communication with DCSs*, May - December 2016, n=1,924



*More than one purpose may be selected

The most common age group to contact a DCS was 60-79 years of age. This trend was consistent across all purposes for initial communication. People in this age group were the most likely to contact a DCS related to their own cognitive concern, seeking help for themselves as a caregiver, seeking help for another person, and for all other purposes. By 2030, this age group is projected to increase 38%, making them over 22% of the population.⁹ The concerns and needs of this population regarding dementia and caregiving are going to continue to grow and become more critical in the coming decades. DCSs are poised in their communities to be a resource for all as the need for this type of resource grows.

COMMUNITY REFERRAL NETWORK

DCSs develop strong connections with community partners to foster a referral network, in order to achieve better outcomes for people with dementia and their family caregivers. In 2016, DCSs received 1,924 referrals from the community and they made 5,600 referrals to community resources and programs.¹⁰

In 2016, ADRCs and tribal agencies received over 18,000 calls statewide regarding Alzheimer’s disease and other dementias.¹¹ The DCSs provide a high level of expertise in ADRCs and invaluable services to individuals with dementia, their caregivers, professionals and other community members. The location of DCSs in ADRCs and tribal agencies helps provide seamless mutual referrals to additional supportive services. ADRCs, county or tribal aging units, and independent living centers provide a wide variety of services and supports for people with dementia and their caregivers, including, but not limited to: home-delivered meals, family caregiver training and support, legal advice and services, information and assistance, options counseling, intergenerational volunteer programs, transportation services, chronic disease self-management programs, long-term care programs, and independent living services.

TOP FIVE REFERRAL SOURCE TO DCS		
Source	Number	Percent
County and Tribal Agencies	678	35%
Friends and Family	276	14%
Outreach Event	276	14%
Health Care Professional	115	6%
Community Services	92	5%
Total	1,924	*
*Note: Total percent will not equal 100%		

Family members and friends are the second most common source to refer to a DCS. This is significant because it illustrates that people in the community are talking about dementia and related resources. Unfortunately, a diagnosis of Alzheimer’s disease or other dementias often carries stigma. Misconceptions about these diseases and lack of awareness impacts quality of life and how people seek help. If family and friends are referring their loved-ones to a DCS, this would seem to indicate that they understand that the DCSs will provide education, support, and resources in a safe, judgment-free environment.

TOP FIVE REFERRALS FROM DCS		
Source	Number	Percent
Caregiver Support Program	484	21%
County and Tribal Agencies	587	15%
Alzheimer’s or Dementia Agency	450	11%
Memory Café	351	9%
Health Care Professional	278	7%
Total	4,031	*
*Note: Total percent will not equal 100%		

FROM THE DESK OF A DCS ON PROVIDING SOLUTIONS

“We have learned that families often have limited time and frequently need short-term assistance through difficult situations. They come for information and resolutions to a short-term problem and will then return later when new problems arise. The role of the dementia care specialist has been crucial in helping families find the resources and tools that allow them to continue to care for their family members at home.”

Joy Schmidt, Dane County DCS

DCSs collaborate with many partners around the state and receive referrals from all over the community. There is a strong collaborative effort between the DCSs and many local Alzheimer’s advocacy and support agencies. Additionally, DCSs receive referrals from the 36 memory clinics that are affiliated with the Wisconsin Alzheimer’s Institute to facilitate early diagnosis. These clinics and others refer to a DCS for appropriate services and supports. DCSs work closely with adult protective services agencies and crisis response units. DCSs also work with local coffee shops, restaurants, senior centers, and libraries to develop memory cafes, which are social gatherings for those with early

stage dementia or mild cognitive impairment and a caregiver.

DCSs also provide opportunities for individuals and family caregivers to participate in programs to improve the experience and outcomes of both caregivers and people with dementia such as, memory cafes, Memory Care Connections (MCC), Language-Enriched Exercise Plus Socialization (LEEPS) programs, SPARK!, and Music & Memory.

Memory cafes are social gatherings for those with early stage dementia or mild cognitive impairment and a caregiver. People with dementia and their caregivers often become isolated due to behavioral symptoms of dementia. Memory cafes are safe, accessible events that are held where people naturally gather to enjoy social activities such as coffee shops, restaurants, libraries, and community centers. Activities are geared to a wide range of cognitive abilities and help attendees to stay active and engaged. Although information about dementia is often available, the time is focused on having fun and not on the disease.

Memory Care Connections (MCC) is an evidence-based program (known elsewhere as the New York University Caregiver Intervention program) that provides family caregivers with the tools to care for their loved ones. The MCC program has been shown to help families care for loved ones at home an average of 18 months longer than without the support of the program. In 2016, there were 109 individuals referred to an MCC program.¹² Evidence-based expectations for this program’s outcomes predict a collective 163 additional years of living at home for participants.





The LEEPS program provides opportunities for people in the early stages of Alzheimer’s disease or mild dementia to engage in exercise and social opportunities. LEEPS has been shown to help individuals with dementia improve their physical fitness and mood as well as maintain functional ability.

Music & Memory was originally established to improve the care and quality of life for dementia patients in nursing homes by providing them with personalized music on an iPod. The project has been expanded to the community, where family caregivers are able to provide personalized playlists to their loved one to reduce caregiver stress and burden.



SPARK! provides an opportunity for those with early to mid-stage memory loss and their care partners to enjoy art, artifacts, and nature in comfortable settings. The project is based on the Meet Me at MoMA project at the Museum of Modern Art in New York.

FROM THE DESK OF A DCS ON ENCOURAGING ENGAGEMENT

“We have seen the number of participants increase dramatically at memory cafes and more importantly, the level of engagement and comfort people show in being there and interacting with others is fabulous to see. We have people coming with their spouses or adult children, paid caregivers or by themselves. Many have verbalized hesitancy at attending something like this as they haven’t been involved in any organized activities related to their memory changes or diagnosis.”

Kathy Glaser, Ozaukee County DCS

MEMORY SCREENS

DCSs are trained to perform memory screens for individuals in the community to determine a need for clinical follow-up with a primary physician or other health care professional. DCSs also train other ADRC and tribal staff on the use of the memory screen tools. A memory screen program manual is available to provide guidance on offering memory screens in the community. In 2016, ADRCs and tribal agencies received 16,356 calls regarding Alzheimer’s disease or other dementias. Out of those calls, 11% resulted in a memory screen.¹³

Memory screening is one way ADRCs and tribal agencies are meeting the challenge of becoming dementia-capable. Individuals are offered the opportunity to participate in a memory screen that assesses whether cognitive impairment may be present. The screen typically consists of two brief exercises—the Animal Naming screen and the Mini-cog screen. The screens require a few minutes to administer and each indicates whether an issue may exist that requires further clinical screening or diagnostic tests. These exercises do not indicate a reason for the memory issues and do not constitute a medical diagnosis.

If the results of the screen indicate that clinical follow-up is recommended, the DCSs will offer to send the screening results, along with a letter, to the individual’s physician. For this process to be successful, it is important for the DCSs to collaborate closely with local clinicians to ensure that they understand the screening and referral process. It is also important that the physician be prepared to make a correct diagnosis, since available treatments and resources can be specific to the type of dementia.

Memory screening is an important aspect of the DCS role in ADRCs and tribal agencies. DCSs not only perform memory screens for any customer who requests one, but they also offer memory screens in the community at various outreach events. In fact, nearly half of the memory screens performed by a DCS were completed at an outreach event.¹⁴

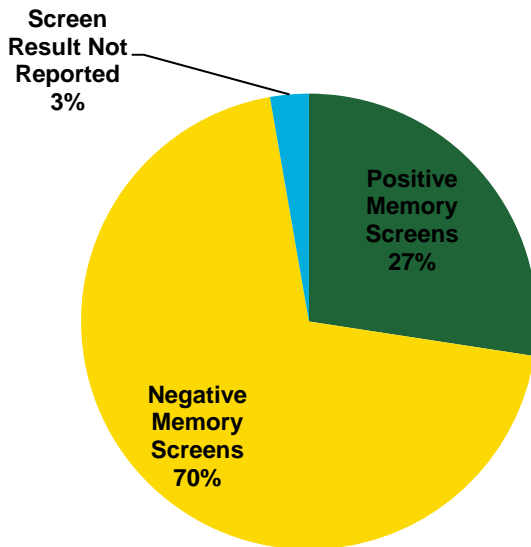
MEMORY SCREEN QUICK STATS
Total Memory Screens by DCSs: 620
Total Memory Screens by ADRCs: 1,952
Average Age: 72.7

**FROM THE DESK OF A DCS
ON BUILDING TRUST**

“They need to feel empowered to contact their physician about these changes and to advocate for a diagnosis or a referral for further testing if the primary physician is unable to provide one. We also want to encourage our consumers to build and expect to have a good and trusting relationship with their physician.”

Judy Wiese, Dodge County DCS

Figure 5 Result of Memory Screens Conducted by DCSs, 2016, n=620



In 2016, more than one in four individuals who participated in a memory screen with a DCS were referred to a doctor for clinical follow-up.¹⁵ Memory screens and appropriate referral result in early detection of dementia.

Early detection of dementia:

- Allows individuals to work with their doctors to determine what lifestyle changes they can make or what treatment options may be available to address the progression of the disease or ease symptoms.
 - Allows individuals and families to make plans for the future such as making health care and financial decisions when the person with dementia can still participate.
- Allows time for families to learn about caregiving, and arrange support and respite, which can help avoid potential crisis situations.

FROM THE DESK OF A DCS ON STARTING CONVERSATIONS

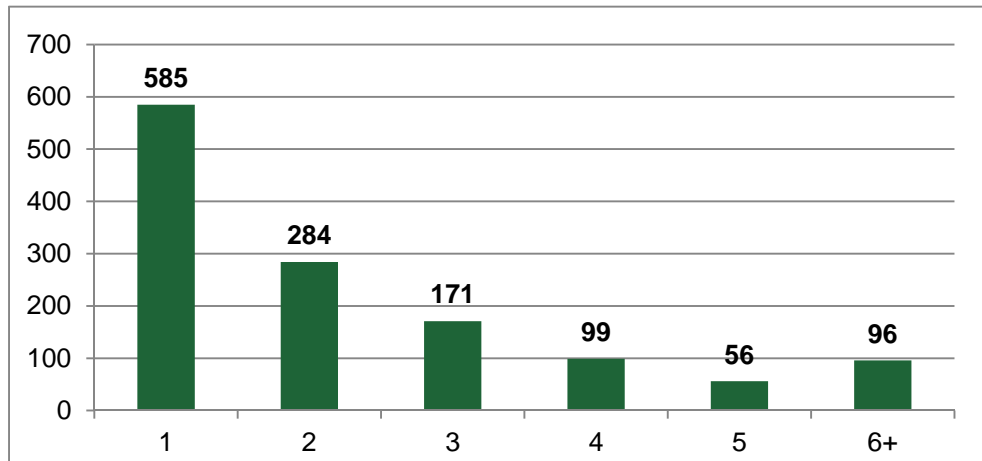
“I have found memory screens to be a vehicle to encourage the conversation early on. The one-on-one interchanges allow individuals a place to safely ask their questions. Several consumers have already returned for a retest and even more have followed up with me when they noticed accelerating or problematic changes. Screens have provided a bridge to open conversation for couples. They are taken back-to-back, and then we discuss results together without pointing fingers. Adult children have proactively followed up on their concerns by scheduling a screen for their parent. Often, they take one too and then next steps are discussed in a palatable manner making implementation of a plan more successful.”

Judy Wiese, Dodge County DCS

FOLLOW-UP

After providing referrals to people with dementia or their family caregivers, DCSs often conduct follow-up to ensure the family received the information and resources needed. For two-thirds of contacts, a DCS had at least one follow-up. DCSs conducted six or more follow-up conversations with 5% of contacts.¹⁶

Figure 6 Number of Follow-Up Conversations with Unique Customers, May - December 2016, n=1291



When a DCS first meets with or talks to a customer, the family is often in a crisis situation or beginning their journey with dementia. It is important for the DCSs to address the immediate concern of the family without overwhelming them with information or resources. It becomes necessary for the DCSs to regularly check in with the family to provide information in “bite sized” pieces. It is not just a question of what information is needed, but also of the best time to present this to the family so that it will be received and incorporated effectively. Showing compassion and understanding while providing follow-up helps to establish a trusting relationship, which results in a better outcome for the person with dementia and the caregiver.

FROM THE DESK OF A DCS ON ADDRESSING CRISIS

“Families are often already in crisis when the DCS is engaged. It is important to not inundate them with too much information. It is best to provide them with a list of support groups, ADRC contact information, and local resources they may be seeking. We need to be careful of standing at the ‘brochure wall’ and pulling out everything we think they may need.”

Cori Marsh, Rock County DCS

OUTREACH

In support of fostering dementia-friendly communities, DCSs work with businesses, employers, local organizations, and the community to increase awareness of the unique needs of individuals with dementia and their caregivers. Initiatives like the Toolkit for Building Dementia-Friendly Communities (P-01000), Purple Angel Dementia Awareness Campaign and Dementia Friendly America provide DCSs with tools and resources to provide training to businesses and other community partners.

DCS OUTREACH QUICK STATS

Total Outreach Events in 2016: 1,870

Total Attendees at Outreach Events in 2016: 40,361

Total Outreach Events 2015 and 2016: 3,115

Total Attendees at Outreach Events 2015 and 2016: 71,493

DCSs provide community education, mobilize community resources, and consult with law enforcement, adult protective services, crisis response teams, medical providers, and others who need information regarding dementia-related issues. The sweeping scope of DCS outreach is necessary to reach all community services and providers that may serve people with dementia and family caregivers. DCSs facilitate and lead efforts to make local communities safe and welcoming for people with dementia.



FROM THE DESK OF A DCS ON FACILITATING INCLUSIVITY

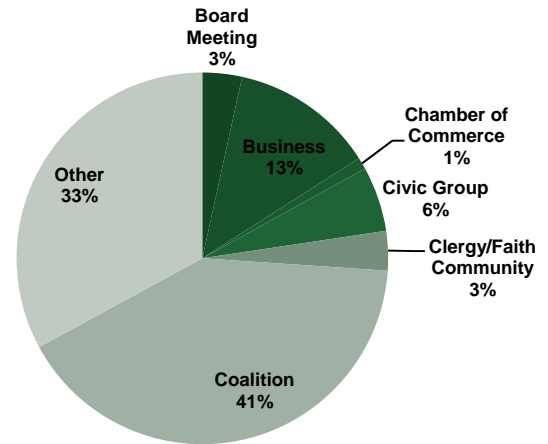
“We believe that the ongoing role of the ADRC as a facilitator is vital to the dementia-friendly initiatives. Creating an environment that is respectful, supportive, and all-inclusive for the many agencies and volunteers allows for a cohesive and consistent message to be shared across the county. We hear from consumers that they appreciate living in communities that understand their needs.”

Joy Schmidt, Dane County DCS

**TOP 10 OUTREACH EVENTS
BY TYPE:**

1. Meetings
2. Community Education
3. Professional Education
4. Memory Café Facilitator
5. Vendor Booth at Fair
6. Support Group
7. Conference or Workshop
8. Press Conference or Media Interview
9. Roundtables or Forums
10. Hearing or Listening Sessions

**Figure 7 Types of Meetings, May - December 2016,
n=495**

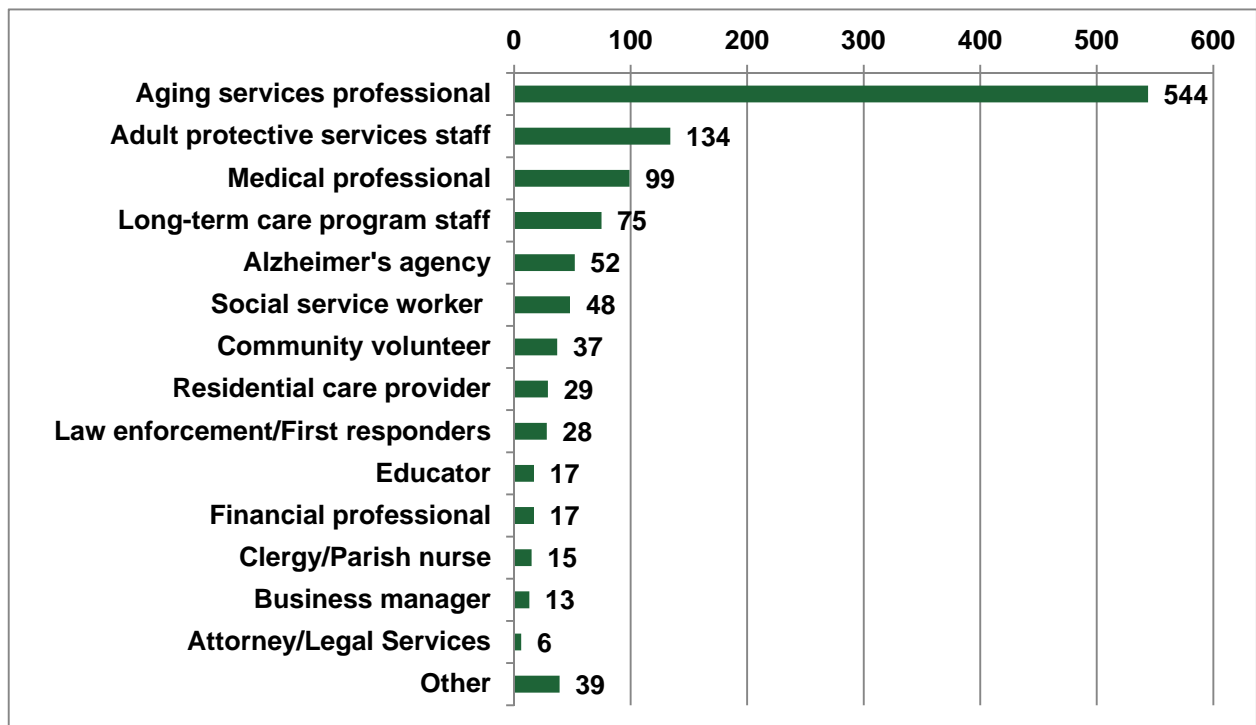


Meetings are a fairly common activity for professionals in any business sector. For DCSs, meetings are not only a place to share ideas and make decisions, but also to make community-wide system changes. Many counties have dementia coalitions that meet regularly to discuss initiatives. DCSs act as catalysts promoting local initiatives and encouraging coalition members to conduct community outreach. DCSs also meet with members of the faith community, civic groups such as Kiwanis, a variety of businesses, and others.

PROFESSIONAL EXPERTISE

DCSs are experts in their field. They have a variety of backgrounds and experience, but the common attribute that brings them all together is that they are extremely knowledgeable and passionate about working with people with dementia and their caregivers. DCSs are a valuable resource for all organizations in their local community and for other professionals. In 2016, DCSs documented 1,153 consultations with professionals.

Figure 8 Number of Consultations by Type of Professional, May - December 2016, n=1153



LOOKING FORWARD

As a leading state in innovative dementia practices, Wisconsin looks forward to building on the solid foundation that DCSs have built. When referring to the Dementia Care System Redesign project, former Department of Health Services Secretary Kitty Rhoades would say, “We are all in this together!” Every day DCSs bring people and communities together across the state to build better systems of care and community engagement to serve people with dementia and their family caregivers.

RESOURCES

Wisconsin's Family Caregiver Support Programs: <http://wisconsincaregiver.org/>

Wisconsin Alzheimer's Institute Memory Clinics:

<http://www.wai.wisc.edu/clinics/overview.html>

Wisconsin Alzheimer's Institute: <http://www.wai.wisc.edu/>

Wisconsin's Crisis Response System: Capacity for Serving Persons with Dementia:

<https://www.dhs.wisconsin.gov/publications/p01072.pdf>

Wisconsin Memory Cafe Directory: <http://www.memorycafedirectory.com/memory-cafes-in-wisconsin>

Memory Screening in the Community Manual:

<https://www.dhs.wisconsin.gov/dementia/memoriescreening.htm>

Wisconsin Music & Memory Program: <https://www.dhs.wisconsin.gov/music-memory/index.htm>

Meet Me at MoMA project: <https://www.moma.org/meetme/>

Toolkit for Building Dementia-Friendly Communities:

<https://www.dhs.wisconsin.gov/publications/p01000.pdf>

Purple Angel Dementia Awareness Campaign: <http://www.purpleangel-global.com/>

Dementia Friendly America: <http://www.dfamerica.org/>

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FOOTNOTES

¹ <https://www.dhs.wisconsin.gov/publications/p01159.pdf>

² This is based on a linear projection of those with dementia in household population based on 2013 national prevalence rates by age group being held constant over time. These data do not account for prevalence in non-household, institutional settings such as nursing homes. Assisted living facilities are enumerated as household population by the U.S. Census. As such, there are no specific assisted living facility population estimates via the U.S. Census from which to confidently estimate prevalence. These estimates are intended for communities' planning purposes only.

³ Alzheimer's Association "2016 Alzheimer's Association Facts and Figures," pg 52.

⁴ Alzheimer's Association "2016 Alzheimer's Association Facts and Figures," pg 39.

⁵ When the Dementia Care Specialist Program expanded to a total of 16 DCSs in 2014, the Bureau of Aging and Disability Resources (BADR) created a data collection tool in order to routinely record activity and the impact of the program. After several months of use, BADR received a plethora of feedback from DCSs and conducted its own analysis that illustrated that the tool needed to be improved. After drafting and testing, the editing process was completed in April 2016 and resulted in significant changes, yielding a more effective and descriptive tool. The new tool has a number of newly introduced field offerings and some fields from the old tool were discontinued. Some fields can be compared between both tools, but only at an aggregate level and not at a more detailed selection level.

⁶ Alzheimer's Association "2016 Alzheimer's Association Facts and Figures," pg 32.

⁷ Aging and Disability Resource Center Dementia Care Specialist Reporting System submissions as of 12/31/16

⁸ Aging and Disability Resource Center Dementia Care Specialist Reporting System submissions as of 12/31/16

⁹ Wisconsin Department of Administration, Demographic Services Center, Vintage 2013 Population Projections

¹⁰ Aging and Disability Resource Center Dementia Care Specialist Reporting System submissions as of 12/31/16

¹¹ Client Tracking Data as of 12/31/16

¹² Aging and Disability Resource Center Dementia Care Specialist Reporting System submissions as of 12/31/16

¹³ Client Tracking Data as of 12/31/16

¹⁴ Aging and Disability Resource Center Dementia Care Specialist Reporting System submissions as of 12/31/16

¹⁵ Aging and Disability Resource Center Dementia Care Specialist Reporting System submissions as of 12/31/16

¹⁶ Aging and Disability Resource Center Dementia Care Specialist Reporting System submissions as of 12/31/16