

DEMENTIA CARE SPECIALIST PROGRAM

2017 ACTIVITY REPORT

The Dementia Care Specialist (DCS) Program is embedded within select aging and disability resource centers (ADRCs) and tribal agencies throughout Wisconsin. The DCS Program has four goals:

- 1. Support individuals with dementia to remain active and stay in their own homes in the community.
- 2. Support family caregivers so 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.

PROGRAM SERVICE AREAS

AGING AND DISABILITY RESOURCE CENTERS WITH A DEMENTIA CARE SPECIALIST						
Barron, Rusk, and Washburn counties Brown County Dane County Dodge County	Eau Claire County Jefferson County Kenosha County Lakeshore (Kewaunee, and Manitowoc counties)		Milwaukee County North (Ashland, Bayfield, Iron, Price, and Sawyer counties) Ozaukee County Portage County		Rock County Southwest (Grant, Green, Iowa, and Lafayette counties) St. Croix County Waukesha County	
TRIBAL AGENCIES WITH A DEMENTIA CARE SPECIALIST						
Menominee Department of Aging and Long Term Care			Elder Services St. Cr		roix Tribal Aging Unit	







Goals 1 and 2: Supporting People with Dementia and Their Family Caregivers

DCSs provide information about a 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; complex conversations about safety and independence; and power of attorney documents for health care and finances. All information is provided to community members regardless of income level.

In 2017, DCSs documented 2,615 contacts with customers. Customers can reach the DCSs through many different routes. In 2017, nearly 60% of contacts occurred via phone call. In many cases,

DCS Contact Quick Stats

- Total contacts: 2,615
 - Minimum age: 20
- Maximum age: 103
- Average age: 68.6

Male: 28%

Female: 72%





these calls are routed through the information and assistance specialists at the ADRC. DCSs also met with walk-in customers (8%) and customers at external outreach events (8%).

In 2017, 44% of DCS contacts were people seeking help for themselves as a caregiver. Within this group, the majority were aged 60-79 (48%) and were either the adult child (44%) or the spouse (41%) of the person with dementia.





As seen in the table below, the highest percentage of contacts with a DCS were aged 60-79 years. This trend was consistent across all reasons for initial communication. People in this age group were the most likely to contact a DCS seeking help related to their own cognitive concern, for themselves as a caregiver, for another person, and for all other purposes compared with the other age groups. This is consistent with data from the Alzheimer's Association's 2017 Facts and Figures, in which 60% of people with Alzheimer's disease were between the ages of 65 and 84.ⁱ Additionally, about one in three caregivers (34%) is age 65 or older.ⁱⁱ

By 2030, the 60-79 age group is projected to increase 38%, making them over 22% of the population.ⁱⁱⁱ 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 serve as a resource for all as the need for this type of resource grows.



^{*}More than one purpose may be selected



FROM THE DESK OF A DCS ON FAMILY EDUCATION

"The time you dedicate to individuals and families means everything to them. Dementia is not an issue that can be discussed and settled in an hour. Understand the importance of not overwhelming a person with information, and be mindful of the language you use so it is understandable. If you can give the time and balance the information at a dose and pace that works for that individual and family, you will be so much more effective."

Sheri Mealy, Brown County DCS

	Own cognitive concern	Seeking help for self as caregiver	Seeking help for another person	Other purpose	Total contacts by age
Under age 40	0%	2%	3%	4%	2%
Ages 40-59	7%	29%	34%	23%	23%
Ages 60-79	56%	48%	44%	40%	49%
Ages 80 and older	36%	21%	19%	33%	26%
Total	100%	100%	100%	100%	100%

Table 1 Age Distribution of Each Reason for Contacting a DCS*, n=2,615

*More than one purpose may be selected

DCSs develop strong connections with community partners to foster a referral network and achieve better outcomes for people with dementia and their family caregivers. In 2017, DCSs made 5,881 referrals to community resources and programs.

As seen in the table below, the majority of referrals received by a DCS are from an internal referral at the ADRC, or other county and tribal agencies. The placement 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: 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.





Source	Number	Percent		
County and tribal agencies	1,010	39%		
Friends and family	248	10%		
Outreach event	218	8%		
Health care professional	161	6%		
Library	116	4%		
Adult protective services	67	3%		
Alzheimer's or dementia agency	56	2%		
Newspaper, radio, or television	54	2%		
Internet web page	53	2%		
Other	227	9%		
Total	2,615	*		
*Note: Total percent will not equal 100%				

 Table 2 Top Ten Referral Sources to DCS, n=2,615

As seen in Table 3, 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 memory clinics to facilitate early diagnosis. These clinics and others refer to a DCS for appropriate services and supports. DCSs work closely with adult protective services and crisis response units. DCSs also work with local coffee shops, restaurants, senior centers, libraries, faith-based communities, and first responders.

Table 3 Top Ten Referral Sources from DCS, n=2,615

Source	Number	Percent		
Caregiver support programs	1,009	17%		
County and tribal agencies	845	14%		
Alzheimer's or dementia agency	669	11%		
Memory café	481	8%		
Health care professional	353	6%		
Legal services	249	4%		
Adult day care	245	4%		
Home health, visiting nurse, or community EMT	188	3%		
Residential care facility	169	3%		
Health promotion and prevention programs	164	3%		
All other referral types combined	1,509	26%		
Total	5,881	*		
*Note: Total percent will not equal 100% due to rounding				





FROM THE DESK OF A DCS ON BUILDING REFERRAL NETWORKS

"Relationship development with physicians/neurologists by providing simple packets for them to give to their patients at the time of diagnosis has led to a dramatic increase in referrals to the DCS. Because "a physician said so…," persons with a diagnosis, a family member, or spouse have contacted the DCS for information and an appointment. Through this referral process, we are able to connect people to programs and services early in the disease process."

Nancy Abrahamson, St. Croix County DCS

Goal 3: Increasing the Dementia Capability of County and Tribal Agencies

DCSs 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 2017, ADRCs and tribal agencies received nearly 20,000 calls regarding Alzheimer's disease or other dementias.^{iv} Of those calls, 17% resulted in a memory screen or a conversation about a memory screen.^v

Memory Screen Quick Stats

Total memory screens by DCSs: 494

Total memory screens by ADRCs: 3,434

Average age: 72.7

In addition to memory screening, DCSs provide the following information and resources to county and tribal agency staff to enhance dementia capability:

- Basic dementia education, communication strategies, and research updates
- Dementia resources and services available in the community (collected in a folder, binder, or electronic database)
- "Shadowing the DCS" opportunities for staff during home and office visits
- DCS assessment (through shadowing) of staff's dementia knowledge, memory screen skills, and ongoing training needs
- DCS support of staff on complex cases through consultation







In addition to consulting with county and tribal staff, DCSs also provide consultations to a variety of other professionals. According to Figure 2, in 2017 DCSs documented 1,298 consultations with professionals from many different organizations.



Figure 2 Number of Consultations DCSs had with Professionals by Professional Type, n=1,298





Goal 4: Facilitating Dementia-Friendly Community Efforts

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. Resources like the <u>Toolkit for Building</u> <u>Dementia-Friendly Communities</u> (P-01000), and initiatives such as the Purple Angel Dementia Awareness Campaign and Dementia Friendly America, provide DCSs with tools to train businesses and other community partners.

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. According to Table 4, DCSs participated in 1,651 outreach events and reached nearly 30,000 attendees. The sweeping scope of DCS outreach is necessary to reach all community services and providers that may serve people with dementia and their family caregivers. DCSs facilitate and lead efforts to make local communities safe and welcoming for people with dementia.

Number of in-person outreach events by type and number of attendees	# of In- person outreach	% of In- person outreach	Total attendees	% of Total attendees	Average Attendees per In- person outreach
Meeting	552	33.4%	6,186	20.9%	11
Community education and training	453	27.4%	7,911	26.7%	17
Memory café facilitator	166	10.1%	2,265	7.7%	14
Professional education and training	155	9.4%	2,867	9.7%	18
Other	96	5.8%	961	3.2%	10
Support group	79	4.8%	779	2.6%	10
Fair vendor booth	71	4.3%	4,803	16.2%	68
Conference or workshop	54	3.3%	3,201	10.8%	59
Press conference or media interview	15	0.9%	268	0.9%	18
Roundtables and forums	6	0.4%	156	0.5%	26
Hearings and listening Sessions	4	0.2%	185	0.6%	46
Total	1,651	100%	29,582	100%	18

Table 4 Number of In-Person Outreach by Type and Number of Attendees, n=1,651





More Information about the DCS Program and ADRCs

For more information about DCS services, including local agency contact information, visit the Wisconsin Department of Health Services website at:

https://www.dhs.wisconsin.gov/adrc/dementia-care-specialist-program.htm or contact the Bureau of Aging and Disability Resources at 608-266-2536.

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

Memory Screening in the Community Manual: <u>https://www.dhs.wisconsin.gov/dementia/memoryscreening.htm</u>

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/

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



ⁱ <u>https://www.alz.org/documents_custom/2018-facts-and-figures.pdf</u>

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^{iv} Client Tracking Data as of 12/31/17

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