



Wisconsin's Aging and Disability Resource Center Dementia Care Specialist Program

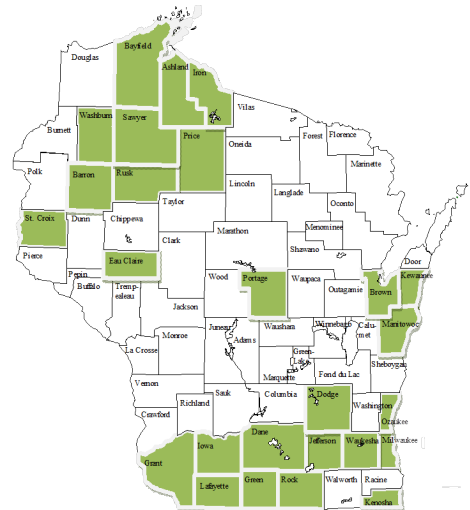
Activity Report for the period December 1, 2014, through December 31, 2015

The Dementia Care Specialist (DCS) Program

Background: The Department of Health Services (DHS) Dementia Care Specialist program enhances the capacity of Aging and Disability Resource Centers (ADRCs) to work with individuals and families living with dementia. Beginning in 2013 as a pilot in five ADRCs, the project was expanded in 2014 to 11 additional ADRCs. In 2015, additional DCS projects were funded in three Wisconsin tribes to serve Native American communities and in two counties to serve the African-American communities.

Goals of the Dementia Care Specialist Program:

- To support individuals with dementia to remain active and able to stay in their own homes in the community and to help support their family caregivers.
- To facilitate local efforts to build dementia- friendly communities.
- To increase the dementia capability of local ADRCs as well as county and tribal programs, helping them to be better prepared with knowledge and resources.



Information, Assistance and Screening: To achieve the first goal, DCSs provide information about Alzheimer's disease and other dementias. They are trained to perform memory screens for individuals to determine a need for clinical follow-up with a primary physician or other health care professional. DCSs also provide assistance to individuals and their caregivers with needed programs and services. They can connect family caregivers with assistance, support, and options for home help, long-term care, and other needs. Like other ADRC staff, they are trained to provide impartial information and to assist in making plans of care.

Dementia-Friendly Communities: 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. DCSs provide community education, mobilize community resources, and consult with law enforcement, adult protective services (APS), crisis response teams, medical providers, and others who need information regarding dementia-related issues. Finally, DCSs facilitate and lead efforts to make local communities safe and welcoming for people with dementia.

Evidence-Based Interventions: The DCSs also provide opportunities for individuals and family caregivers to participate in evidence-based programs to improve the experience and outcomes of both caregivers and people with dementia. Two of these opportunities include the Memory Care Connections (MCC) and the Language-Enriched Exercise Plus Socialization (LEEPS) programs. Memory Care Connections is an evidenced-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 at home. 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. 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.

Dementia Care Specialist Activity Reporting

Purpose: On a quarterly basis, the DCSs submit activity reports to program managers at DHS. The purpose of this reporting is to track the activity of DCSs as a first step toward an evaluation of the program’s effectiveness. DCS activity data can help gauge whether the program is meeting the needs of the community for community-based health services and information, assistance, and resources related to dementia care. Evaluation will also include an assessment of program strengths and weaknesses, identification of opportunities for program expansion, and analysis of consumer characteristics.

Data Reporting Methods: An Excel workbook was created for each specialist to use to record facets of their activity. The workbook is divided into several categories:

- Client Contact Information and Memory Screen Activity
- Client Demographic Characteristics
- Memory Care Connections Program Enrollment
- LEEPS Program Enrollment
- Outreach Activities
- Consultation Activities
- Testimonials (unsolicited client comments about the specialist)

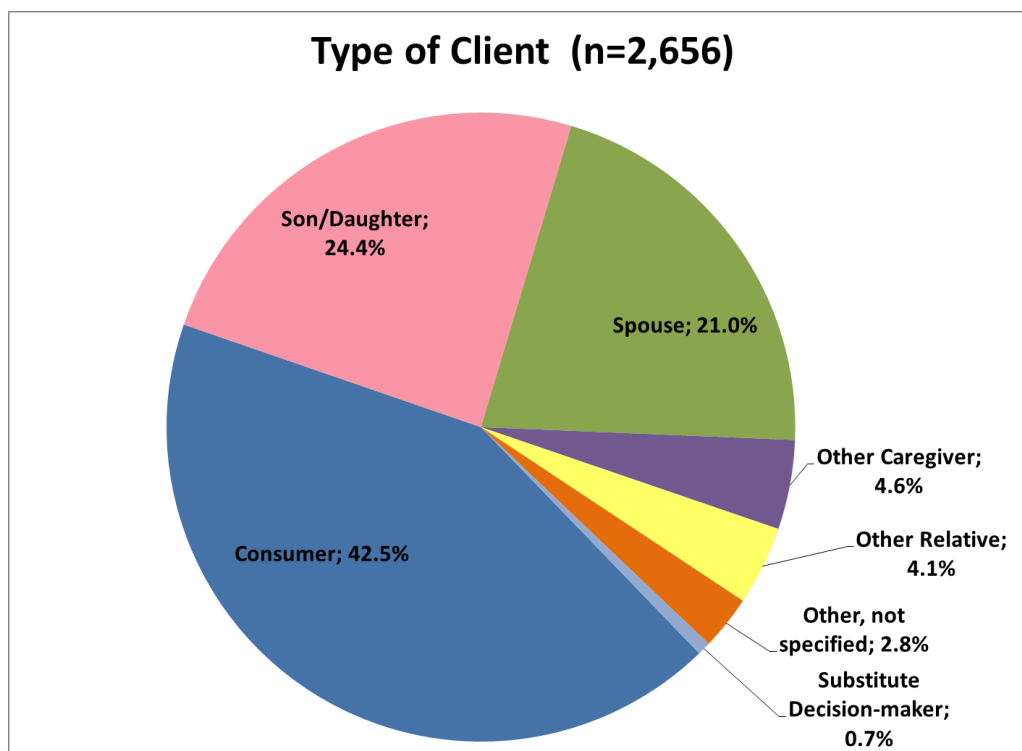
The Bureau of Aging and Disability Resources (BADR) collects the data from each specialist on a quarterly basis. To prepare each file for submission, the DCS removes all personally identifying information about clients. Data are then aggregated and integrated with information submitted in previous quarters to create a cumulative DCS activity database.

Dementia Care Specialist Activity Summary

Client Characteristics: For every contact with an individual seeking assistance or services, the DCSs record the type of client (a “customer” with concerns about him or herself, a caregiver, etc.), client age, and gender.

During 2015, DCSs recorded information about contacts with 2,656 clients. While about four in 10 people who reached out to a DCS did so because of a concern about their own cognitive health, care needs, or program or residential options, many clients made this contact because of a concern about someone they know or care for. About one in four clients made this contact in their role as a son or daughter, and another 21 percent made contact as a spouse. Other caregivers made up about 5 percent of contacts, and other relatives made up about 4 percent. In all, more than 85 percent of clients who made contact with a DCS were people concerned about their own cognitive health (called “consumers” in this report), or the spouses or children of people with cognitive concerns.





The average (median) age of consumers contacting a DCS with concerns about themselves was 76 years. More than four in 10 of these consumers were 80 years of age or older. People contacting the DCS as spouses averaged 75 years of age as well, while those making contact as a son or daughter averaged 59 years.

Six in 10 of all clients who contacted a DCS were women, and 26 percent were men. Another 14 percent chose not to report a gender. These percentages remained fairly consistent across the different types of clients, and correspond closely to the gender distribution of all Wisconsin residents age 75 and older (61 percent female and 39 percent male).

Memory Screens: DCS clients are offered the opportunity to participate in a memory screen, consisting of two brief exercises that assess whether cognitive impairment may be present. The “Mini-Cog” and the “Animal Naming” screens each require a few minutes to administer, and each indicate simply whether an issue may exist that requires further clinical screening or diagnostic tests. These exercises do not indicate a reason for the problem, and do not constitute medical diagnosis.

Anyone whose cognitive screen indicates a concern is urged to see a primary care physician for further evaluation. DCSs also offer to forward screen results to a primary care physician if the client wishes.

In addition to offering screenings during a visit, DCSs offer memory screens in the community at various outreach events. DCSs train other ADRC staff in use of the memory screen tools as part of their objective of increasing the dementia capability of the ADRC as a whole.

Nearly 600 memory screens were completed by DCSs in 2015, with 36% resulting in a recommendation for further evaluation by a health care provider. During 2015, DCSs were not asked to determine through follow-up contacts whether further evaluation was received. The number of memory screens completed by auxiliary ADRC staff is not known at this time, but will be the subject of future data collection.



Memory Screen Performed (All Client Types)	Number	Percent
Positive Results	213	35.6%
Negative Results	355	59.4%
Results Not Indicated	30	5.0%
Total	598	--

Memory screens are an important tool in expanding the early detection of dementia. With early detection, existing medications for Alzheimer's disease and dementia can be more effective; individuals and families can be proactive in planning for their future; and quality of life can be improved for individuals and families living with dementia. The earlier an individual or family connects with their health care provider and their ADRC, the more options they will have for programs, services, and other supports. In particular, when early detection results in planning that increases a family's capacity to support their loved one in living independently in the community, health and long-term care costs can be significantly reduced.

Source of Referrals: Individuals are referred to a DCS by a wide variety of other agencies and individuals. By far the most frequent source of referral is another staff person within an ADRC. Fellow ADRC staff members make more than one in four referrals (43 percent). Outreach events result in clients making contact in another 17 percent of cases, and families and friends make up another 12 percent of referrals. Aging services agencies, such as aging units, area agencies on aging, senior centers, or Alzheimer's advocacy agencies refer about 7 percent of clients. Other referrals come from community partners such as APS agencies, medical organizations, home health agencies, and faith-based organizations. It is likely that as DCSs become better known throughout their communities and develop their networks of contacts, the percent of referrals coming from sources outside the ADRC will increase.

Referral Sources	Number	Percent
ADRC	926	43.4%
Outreach Events	361	16.9%
Friend/Family	251	11.8%
Aging Services Agencies	158	7.4%
Media/Internet	103	4.8%
APS or Crisis	93	4.4%
Medical/Health Organization	86	4.0%
Home Health or Day Services	62	2.9%
Faith-based Organization	42	2.0%
Other	36	1.7%
Residential Facility	17	0.8%
Total	2135	

Outreach: Outreach events are among the most frequent sources of referral to the DCS, and they make up a significant share of DCS activity. During 2015, DCSs made a total of 1,669 appearances and presentations at outreach events. These events include community health fairs, educational seminars, dementia-friendly community meetings and trainings, regional and statewide conferences, and other opportunities for interaction with community members. In all, DCSs estimated that these activities reached more than 31,000 attendees during the year.



Type of Outreach Event	Number	Percent
Public Education	476	28.5%
Dementia Friendly Community Meeting	403	24.1%
Meeting with Healthcare Providers	121	7.2%
Training County Staff	70	4.2%
Health/Caregiver/Volunteer Fair	59	3.5%
Civic Group Meeting	43	2.6%
Conference	39	2.3%
Other Event, Unspecified	458	27.4%
Total	1,669	100.0%

In addition to outreach events, DCSs engaged both traditional and social media in an effort to get the word out about their programs and services. During 2015, DCSs reported 147 interactions with radio, television, or newspaper outlets and 181 social media postings. Combined with all of the events noted above, these outreach activities totaled nearly 2,000 for 2015.

Expert Consultations: DCSs are sought out as experts on both the conditions that underlie dementia and the programs, treatments, and services available to assist families. During this period, DCSs served as consultants to health care organizations, aging and social service organizations, residential facilities, workplaces, educational institutions, and a wide range of other organizations. In all, DCSs reported 1,330 consultations with community agencies or other organizations.

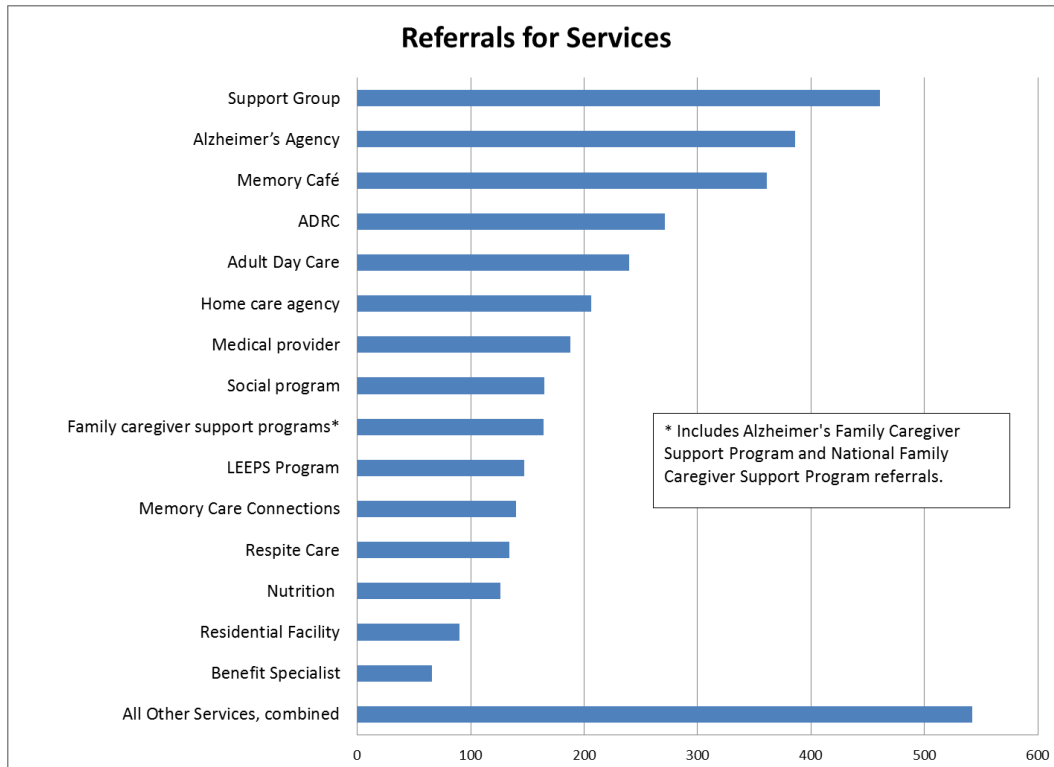
Type of Expert Consultation	Number	Percent
Health Care Organization	236	17.7%
Area Agency on Aging	175	13.2%
Social Services Agency	127	9.5%
County/Municipal Agency	101	7.6%
Residential Facility	85	6.4%
Workplace	47	3.5%
Educational Institution	38	2.9%
Library	21	1.6%
Faith-based Organization	17	1.3%
Recreational Organization	11	0.8%
Senior Center	6	0.5%
Tribal Center	6	0.5%
Other	460	34.6%
Total	1330	100.0%

Service Referrals: DCSs are positioned to connect people concerned about cognitive health with agencies and services that can help them successfully live active, engaged lives in the community. DCSs, as ADRC staff members, are well acquainted with the local service system and can provide both information and warm referrals to provider agencies. In 2015, DCSs made over 3,600 referrals for services. These include 188 referrals for medical consultation after a positive memory screen, as well as referrals for direct service or support (about 5 percent of all referrals).

The type of referrals made by DCSs range widely, with about one in five linking clients with direct services such as meals, transportation, and caregiver respite. Support groups followed with about 13 percent, and Alzheimer's disease support and advocacy agencies received 11 percent of referrals.



Programs like memory cafes (10 percent) and adult day care (7 percent) were also frequently referenced. With these types of relationships and referrals, DCSs contribute to better coordinated systems of care for individuals and their families living in the community with dementia.



Summary/Conclusions

During the first year of activity reporting, Wisconsin's DCSs demonstrated high levels of activity on behalf of achieving the program's goals. They met directly with more than 2,600 clients to talk about needs and service opportunities to help individuals and families. They reached out to 31,000 community members through events, media encounters, and other informational efforts, and reported over 1,300 expert consultations. They built relationships across local networks of organizations to create dementia-friendly communities and to ensure that local agencies, including ADRCs, health care providers, protective services, and others are fully apprised of the full range of opportunities and benefits available to individuals and families living with dementia.

ADRCs, and the DCS resources within them, are a growing source of information and assistance, education, resources, and support. Their work within local communities is building a strong foundation for a seamless system of support for consumers and families. Ultimately, the aim of these efforts is to enable persons with dementia to remain in their homes in the community longer with resources and supports in place, enjoying improved quality of life through DCS programs and ADRC services.

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

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