



Center *for* Rural Health

Assessment of the North Dakota Dementia Care Services Program

January 2010 to June 2013



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July 2013

Funded by

North Dakota Department of Human Services, Aging Services Division
This report may also be found at ruralhealth.und.edu/publications/reports

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EXECUTIVE SUMMARY

The North Dakota Department of Human Services, Aging Services Division has funded, and the Alzheimer's Association of MN-ND has administered the Dementia Care Services Program (DCSP) in North Dakota since January 2010. The DCSP provides service to all counties and legislative districts in North Dakota. Two project staff provide supervision and oversight to five regional care consultants.

Caregivers interact with the DCSP either through an information help line or a care consultation. The care consultants decide if the caregiver needs are a level 1 (i.e., focuses on one specific topic or objective for the caregiver) or a level 2 (i.e., addresses multiple issues encountered by the caregiver) consultation, either in person or by phone. Follow-up care consultations are provided to determine if the caregivers have completed their objectives and if they need further help. The DCSP strives to complete the care plan action steps within three visits, usually within a time period of six months. However, there is no formal discharge from the program and a caregiver can return to the DCSP for additional care plans at any time.

The DCSP has steadily grown over its 42-month course in the number of visits (current total=2,985), caregivers (current total=1,750), and persons with dementia (PWDs) (current total=951). Participation among PWDs and caregivers was across all regions of North Dakota, including sparsely populated areas. Increasing numbers of caregivers are contacting the DCSP multiple times; currently, about one-half of all caregivers have had two or more DCSP contacts. Most caregivers (73%) were female or a family member of the PWD (68%). The median travel distance for those caregivers not living in the same city as the PWD (29%) was 86 miles. We found that 72% of PWDs still live at home, 22% live home alone. About 74% of DCSP PWDs had been provided a diagnosis of dementia/Alzheimer's Disease (AD). Comorbidities occurred in 39% of the PWDs. The DCSP has provided level 1 and level 2 visits 37% and 18% of the time respectively, in person visits 22%, and follow-up visits 28%.

Participation in the DCSP was associated with an increased likelihood that caregivers and their PWDs acquired needed health care objectives in the 42-month program period. Acquisition of Medic Alert + Safe Return[®] had the highest percentage increase (215%), followed by educational classes (71%), health care directives (29%), and power of attorney (24%). The PWD's rural status, with whom they lived, the severity of their condition, more care consultations, and receiving referrals were associated with increases in meeting health care objectives.

DCSP participation has continued to coincide with substantial estimated health care cost savings, such as those incurred through hospital or emergency related services. The total

estimated health care cost savings for 867 PWDs was \$833,516 over the 42-month period. Total cost savings estimates by health service type were \$731,743 for hospital, \$51,658 for emergency room, \$43,645 for ambulance, and \$6,470 for 911 calls. Estimated health care cost savings per PWD were associated with PWDs' rural status and living arrangement, caregiver travel, severity of the PWD and long term care (LTC) placement. DCSP actions that increased cost savings per PWD included number of care consultations; follow-up, in person, and action level 2 consultations; and referral or resource provision. Having health care objectives was also associated with increased cost savings per PWD. Estimated LTC cost savings totaled \$39,206,232 over the 42-month program period for 106 PWDs. Delays in LTC placement were associated with less severity, more care consultations, and more referrals.

Empowerment, increased access to support, and improved knowledge were behavioral health measures reported by the caregivers. These were related to the PWD living at home, the caregiver being from a less rural area, and having follow-up visits and health care directives. Caregivers also reported the DCSP was convenient and were very satisfied with the service, especially if they were a daughter of the PWD, younger, traveled, or had health care objectives.

Suggestions for DCSP improvement include increasing efforts for: more public awareness campaigns to increase participation from PWDs in early stages, focus on PWDs in isolated situations, emphasis on providing level 1 and level 2 care consultations, promotion of health care objective completion, assessment of behavioral health, encouragement of preventive health care, and study of how caregiver needs change and DCSP actions change as the disease progresses.

Finally, it is suggested that additional grant funding be sought to (1) increase promotional awareness of the DCSP, (2) assessment of behavioral health of the caregiver; (3) the development, pilot testing, and implementation of educational interventions for stressing the importance and appropriate use of preventive, acute, and long-term care; (4) increase understanding of dementia caregivers' changing needs as the PWD's dementia progresses.

INTRODUCTION

Alzheimer's disease (AD), the most common type of dementia, is a progressive, degenerative, neurological disorder with no known cure and high social and economic costs. Health and Long Term Care (LTC) costs for persons with AD or other dementias are massive and continue to grow at an alarming rate. In 2012, the total amount spent on health care, LTC, and hospice for persons with AD or other dementias was approximately \$200 billion, which is projected to increase to \$1.1 trillion in 2050 (Alzheimer's Association, 2012). In response to these projections, many states are starting to take measures for reducing dementia related health and LTC costs. One method is to increase efforts to provide support to dementia caregivers in hopes of increasing their efficacy, easing the burden of dementia care, and thus reducing health and LTC costs.

Caregiving for persons with dementia (PWDs), typically provided by a spouse or other family member, can be very difficult, costly, and time-intensive (Shriver, 2010; Alzheimer's Association, 2012). It is associated with poorer emotional, mental, and physical health among caregivers (Rose-Rego et al., 1998; Dunkin & Anderson-Hanley, 1998). Other factors that exacerbate the dementia caregiver crisis in the U.S. include the discontinuous and fragmented nature of health care services, shorter hospital stays for patients, and discharged patients having increasingly complex health needs (Levine et al., 2010). Caregiving in rural areas is even more difficult due to social isolation, poorer access to health and social services, and long travel times (Butler et al., 2005).

There are several important issues for caregivers and families to consider after discussing the truth about the diagnosis with the PWD (Alzheimer's Association, 2011). Advance directives specify a person's preferences for care when they are in the latter stages of their terminal disease (Rocker et al., 2000). The establishment of Power of Attorney is an advance directive which designates a specific person to make health care decisions for the patient if they are unable to make or convey these decisions themselves (Alzheimer's Association, 2011; Baker, 2002). Advance directives, although greatly underutilized (Porock et al., 2003), can reduce stress and anxiety among patients, caregivers, and families and helps to ensure the patient receives their preferred type and extent of care during their disease course (Prendergast, 2001; Singer et al., 1998). As previous studies have found, caregivers' and family members' beliefs and predictions about patients' care wishes can often be contradictory (Shalowitz et al., 2006). It is important for caregivers to work with their PWDs to establish their preferred care instructions in the form of written advance directives.

Receiving education about dementia is another important goal for caregivers. Understanding the disease, its stages, and its effects on people can help to relieve stress and gain empowerment for the caregiver and PWD (Devor & Renvall, 2008). Also, implementing a Medic

Alert + Safe Return[®] system for a PWD, particularly for those living alone and/or located in rural areas, is an important consideration for increasing personal safety (Patel et al., 2012). This system entails wearable devices (often in the form of a watch or pendant) with a button that when depressed transmits an alarm message to operators at a remote call center. These operators can then take action to have immediate assistance provided to the person at their residence (Patel et al., 2012).

Starting in 2008, there has been a momentous rise in oil drilling and processing activity in the Bakken Oil Formation in western North Dakota. These increased oil-related activities are due in part to rising petroleum prices, improved oil exploration and extraction technology, and substantial gains in oil recovery (Bangsund & Leistritz, 2010). The oil boom coincided with a 28% annual increase in mining employment within North Dakota during 2005 through 2008, and an increase in the share of mining jobs in the region's basic industry mix (from 28% in 2000 to 55% in 2008; Seifert, 2009). The increased mining activity also corresponded with a 33% average annual continuous growth in North Dakota petroleum extraction tax revenues (Seifert, 2009). Nearly one-quarter of all petroleum extraction tax revenue collected in North Dakota since 1981 occurred in fiscal years 2008 and 2009 (Seifert, 2009). The state is expected to collect \$2 billion in oil tax revenue in the next two years (Winter, 2012).

Although there are many positive aspects to the influx in oil work, economic activity, and population, there are some notable, serious, and negative consequences including a housing shortage, marked increases in the cost of living, skilled and service labor under-supply, and unfavorable impacts to the area's infrastructure (e.g., damaged, insufficient, and increasingly unsafe roadways; Seifert, 2009; Winter, 2012). There is also anecdotal information regarding possible increased air, land, and water contamination in western North Dakota due to the oil drilling and processing activities (Winter, 2012). The oil boom will require North Dakota to spend an additional \$113 million on Medicaid and other human services program to maintain present levels of service to the poor (Wetzel, 2012). North Dakota Dementia Care Service Program's (DCSP) evaluation efforts indicated that Regions I (Williston area) and VIII (Dickinson area), representing the heart of the Bakken oil boom region, have had the greatest challenges. PWDs may have to leave their homes as rents drastically increase. Office space for care-workers can be difficult to obtain as their rent has also drastically increased. There can be further difficulty retaining care-workers as wages for oil related jobs are much higher.

In many rural areas, access to hospital and emergency care resources is constrained by outdated facilities, health provider recruitment/retention difficulties, poor access to continuing medical education, and other challenges (Ricketts, 2000; Doty et al., 2008; Casey et al., 2008). The Bakken oil activity and its accompanying population boom may be having deleterious effects on access to hospital and emergency room care in affected regions, especially for older persons who have a serious chronic health condition such as dementia/AD.

Program Background

In North Dakota, the DCSP was created by Dementia Care Services Bill (ND House Bill 1043) in 2009. The DCSP's aim is to inform persons with dementia (approximately 8,000 in North Dakota residing outside of LTC facilities) and their caregivers about dementia care issues which, in turn, may lead to increased family support, decreased depression, delays in nursing home placement, and reductions in acute health service use. The DCSP provides care consultations to caregivers. These consultations consist of assessing needs, identifying issues, concerns, and resources, developing care plans and referrals, and providing education and follow-up. These services were provided by phone, email, or in person through individual and family meetings. The target population for this program included North Dakota residents with a diagnosis and/or symptoms of dementia and their caregivers.

Assessment Approach and Methods

The assessment of the DCSP's assistance intervention for care providers followed the principles of the utilization-focused evaluation framework: a focus on program improvement and accountability, examining intended use by intended users (i.e., program administrators, staff, and funders) which informed evaluation design decisions. Assessment questions were:

1. What are the outputs and outcomes of the program?
2. How much are services being utilized?
3. In what ways could program implementation be modified to enhance effectiveness?

The assessment has been an evolving and responsive process in which the DCSP leadership/implementation team provided collaborative feedback throughout the planning, implementation, and reporting stages of the assessment. Based on this feedback, the assessment work plan has been refined to more effectively guide the measurement of program outcomes.

Outcome assessment included systematic collection of information on the program's short-term and long-term outcomes. Quantitative methods of data collection and analysis were utilized to enable triangulation. Process and outcome assessment methods consisted of document analysis (DCSP's proposal, reports, and other documentation) and interviews with the DCSP staff members. The data were collected to determine the ongoing status of program development and its effectiveness, and included quantitative information (numbers of clients served, assistance requests, consultations, and target audiences reached as well as their demographics). This information was collected through surveys and intake forms completed by program clients and DCSP staff providing services and/or undertaking promotion efforts (see Appendix A for the intake form and Appendix B for the survey used). Utilizing specially-developed intake and follow-up forms, the customized DCSP tracking system has been

monitoring the amount of time that caregivers have delayed placing PWDs in LTC and the numbers of PWDs having advanced care directives in place for the future (health care, financial, legal), and the numbers of inpatient hospital stays, ambulance runs, emergency room visits, and 911 calls.

Figure 1 shows the conceptual model used to assess the DCSP. Inputs were measured regarding the amount and type of services provided by the DCSP. These were tempered by aspects of the caregiver and the PWD. Outcomes measured included healthcare objectives, reduction in health care utilization (hospital, emergency room, ambulance, and 911 services with estimated cost savings), LTC placement delays (with estimated cost avoidance), and behavioral health of the caregiver. The services provided by the DCSP were associated with outcomes while controlling for aspects of the caregiver and PWD.

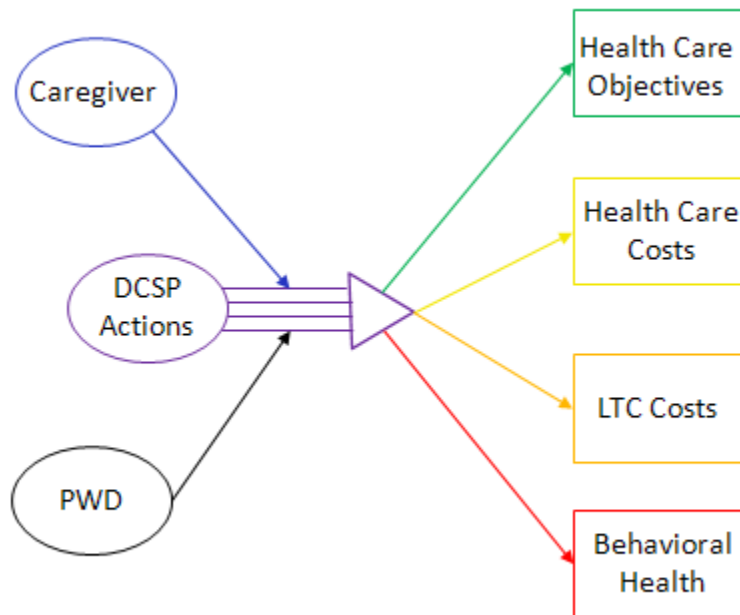


Figure 1. Conceptual model used to assess the actions of the DCSP regarding outcomes.

DATA ANALYSIS

Description of Participants and DCSP Actions

Aspects of caregivers included demographics, relationship to the PWD, location, and how they were referred to the DCSP. These were shown by eight DHS regions of ND (see figure 2) relative to the population in each region. Aspects of the PWDs measured included demographics, location, diagnoses, and severity of disease. They were also shown by DHS region relative to the population aged 65 and older in North Dakota.

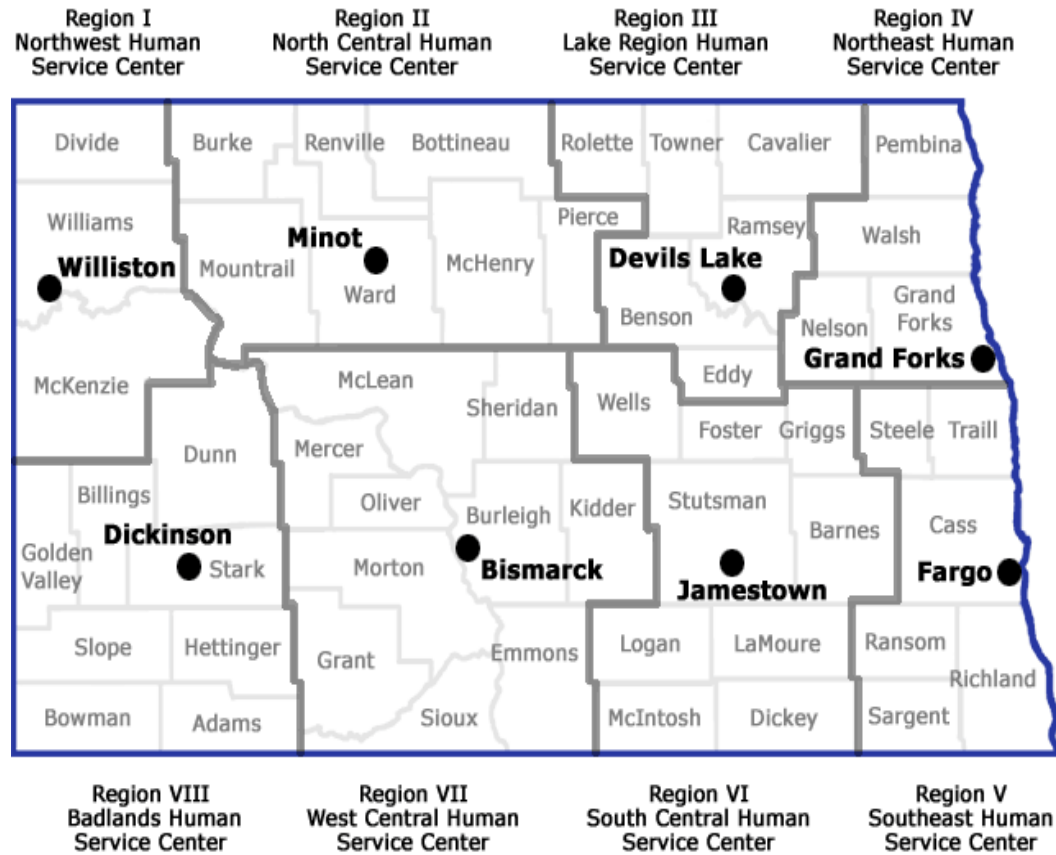


Figure 2. North Dakota’s Human Service Regions.

Visits by the DCSP to caregivers were recorded as care consultations or help line, action levels 1 (a specific topic was covered) or 2 (more than one topic was covered), in person or by phone, and initial visit or follow-up. The number of resources and referrals--including referrals to Family Caregiver Support Programs (FCSP)--given to caregivers were also recorded.

Assessment of Health Care Objective Obtainment

The following four health care objectives were recorded: whether and when a client has established power of attorney, obtained health care directives, attended health education classes, and implemented Medic Alert + Safe Return[®] systems. The number of PWDs still needing the health care objectives and the number that obtained them after working with the DCSP were noted. These were also tested for association with region, location, living arrangement, diagnoses and severity of the PWD, distance the caregiver travels to see the PWD, and type of visits by the DCSP using Chi-Square analyses.

Assessment of Hospital and Emergency Services Cost Reductions

As visits with caregivers were irregular over time and no control group was available, a cross-time model was utilized to estimate changes in utilization patterns of PWDs and estimate cost savings (Klug et al., 2012a). Caregivers were asked about their hospital, emergency room, ambulance, and 911 service utilization during the prior 3 months. 867 caregivers reported at their first DCSP visit the number of days that the PWD had been hospitalized, as well as the number of times that the PWD needed to use the emergency room, ambulance, or 911 call services for the past 3 months (Time Period 1 or “T1”), which is the baseline of their DCSP participation. 283 caregivers reported this information for 4 to 6 months after working with the program (Time Period 2 or “T2”), 189 reporting from 7 to 9 months (Time Period 3 or “T3”), 133 reporting after 9 months (Time Period 4 or “T4”) 106 reporting after 12 months (Time Period 5 or “T5”) and 70 reporting after 15 months (Time Period 6 or “T6”). The prevalence of each of the 4 events for the 867 people during T1 was compared to the prevalences for the 283 people during T2, 189 people during T3, 133 people for T4, 106 people for T5, and 70 people for T6. The differences in these prevalences represented the change in the number of events per person after working with the DCSP.

To estimate health care costs, ‘typical’ cost estimates were derived from the medical literature for use of each health service. Whenever possible, cost estimates were utilized that directly pertained to the care of persons with Alzheimer’s or dementia. In some cases, however, these costs were unavailable (e.g., North Dakota 911 call data does not contain information about the caller or the person(s) who is in need of emergency assistance), so estimates were utilized that included costs-of-care for patients with other types of health conditions. The utilized cost figures include the following: \$82 per 911 call; \$617 per urban ambulance transport; \$927 per rural ambulance transport (rural ambulance runs are more expensive due in part to their longer average response and transport times); \$568 per emergency room visit; and \$1,977 per day for hospital stays.

To estimate cost savings due to reduced PWD health care use that coincided with DCSP participation, costs-per-event (e.g., 1 day in the hospital, 1 911 call) were applied to the change

in the number of occurring events per PWD between T1 and T2, T1 and T3, T1 and T4, T1 and T5, and between T1 and T6. It is important to note that most of the costs corresponding to PWD health care usage in T1 actually occurred *before* initiating DCSP participation. Consequently, confidence is increased in associating any derived cost savings to DCSP participation.

Associations between region, location, living arrangement, diagnoses and severity of the PWD, distance the caregiver travels to see the PWD, and type of visits by the DCSP and cost savings were tested using Chi-Square analyses.

Long-Term Care Cost Avoidance

Cost analyses were conducted to estimate potential LTC cost reductions that coincided with program participation. Changes in reported length of time of LTC placement were estimated using reported likelihood to place (Klug et al., 2012b). This is an important measure since improving caregiver well-being and support is linked to delays in nursing home placement for persons with AD (Mittelman et al., 2006). These potential cost avoidances and savings were further analyzed according to region, location, living arrangement, diagnoses and severity of the PWD, distance the caregiver travels to see the PWD, and type of visits by the DCSP.

Caregivers were asked to rate the likelihood of placing the PWD in LTC using a 1 to 5 Likert scale. Responses to the question were interpreted using a scale representing the number of years until placement based on the probability of when the PWD would be placed in LTC. For example, it was estimated that a caregiver who indicated "1," or very unlikely to place would probably not place the PWD in LTC for 15 years. If the caregiver indicated "3," (the midpoint of the scale) it was estimated that 5 years would elapse before they placed the PWD in LTC, since the literature indicates that 5 years is the median number of years for placing a PWD in LTC. A choice of "5," indicating a desire to place the PWD in LTC as soon as possible, was estimated as 6 months.

Because the first question was based on 6-month increments, caregivers were identified who had answered the question more than once over at least a 6 month period, making it possible to identify changes in LTC placement responses. These criteria identified 106 people who had decreased their likelihood of LTC placement if time to place was not available. The number of years their placement plans changed was then calculated according to their change in survey responses.

The median daily cost of LTC for the county of residence of the PWD multiplied by 365 days was used as a yearly LTC cost estimate. The yearly LTC cost avoided by the caregiver changing their intentions for LTC placement was estimated by multiplying this cost by the number of years that reflected the change in their LTC placement plans. Since costs vary by facilities within

counties and different types of care provided within these facilities due to severity, upper and lower cost estimates were also provided. If no LTC facilities existed in the county the PWD resided in, median costs from adjacent counties were used. Associations between delay in placement and PWD demographics, health, travel by the caregiver, and actions of the DCSP were tested using Chi-Square analyses.

Behavioral Health

A survey was administered to caregivers that had a care consultation with the DCSP more than one time. This survey measured the caregiver's behavioral health and satisfaction using nine Likert-type questions on a one to five scale. These questions were entered into a principal component factor analysis with varimax rotation. Two subscales were clearly identified regarding access to support and empowerment of the caregiver. The two subscales and two other variables were compared between different levels of PWD demographics, health severity, and actions of the DCSP using correlations, independent t-tests, and one-way analyses of variance (ANOVAs).

Limitations

There were a number of limitations to the program assessment process. First, due to the nature of the program (particularly, the ethical reason for not excluding any interested individuals and families to form a treatment group), no control or comparison groups were feasible. This limited the ability to optimally measure the direct and indirect impacts of program participation on outcomes. Second, challenges were encountered with missing data for PWDs and their caregivers which somewhat limited the ability to analyze the information. A large part of the missing data was due to data taken from information help lines where the intake form did not have all the questions used for care consultations (e.g., questions on LTC placement). Other reasons for missing data was due in part to respondent refusals, their lack of time for completing surveys and interviews, or misunderstanding the question. Third, some of the earlier versions of the surveys and data collections instruments did not contain potentially important items for measuring characteristics/outcomes of PWDs or their caregivers. One example is PWDs' health condition severity; this factor is not optimally accounted in our analysis due to its absence from the survey and interview data for approximately the first 18-24 months of the program. This factor, while very important in assessing data and outcomes for PWD and their caregivers, is difficult to measure/capture in self-reported data due to its reliance on clinical indicators. Fourth, while analyses used health care cost data for persons with Alzheimer's or dementia that were derived from the literature, some costs were unavailable or were not specific to North Dakota; therefore, some estimates were derived using national mean costs.

RESULTS

DCSP Contacts with Caregivers

Caregivers of persons with dementia (PWDs) in North Dakota had a total of 2,985 contacts with the DCSP during the 42 program months (Figure 3). These contacts took a variety of forms, with 1,641 being care consultations (either initial or follow-up). Of the 1,641 care consultations, 657 were conducted in person. Also, 1,092 were action Level 1, and 549 were action Level 2. There were 844 follow-up visits (393 action Level 1 and 258 action level 2).

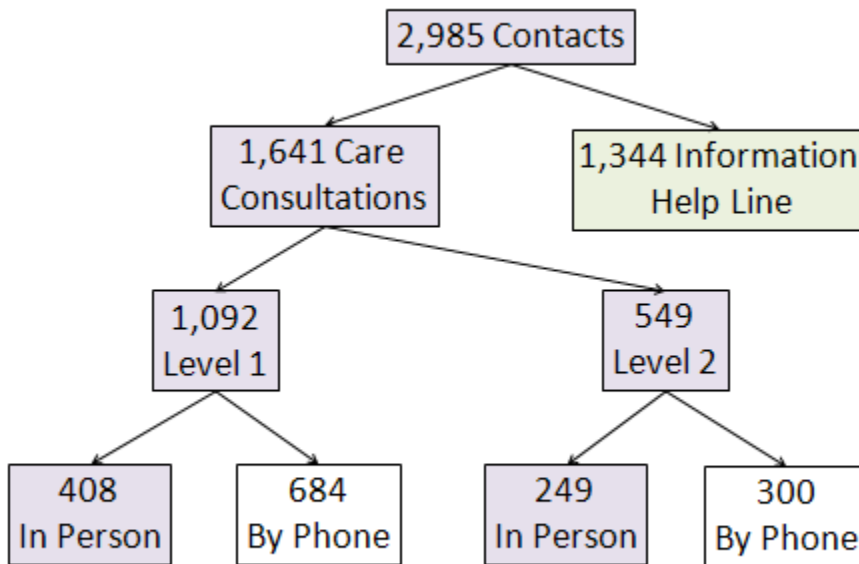


Figure 3. Types of DCSP contacts, Jan. 2010-June 2013

Figure 4 shows the distribution of care consultations (as level 1 and level 2) across the regions of the state relative to the population of those regions. Regions II (10.9%), III (5.1%) and IV (10.2%) had fewer care consultations than the population of that region suggests. Region VI (14.1%) and VII (20.5%) had more care consultations. All but region II had more level 1 visits than level 2 visits.

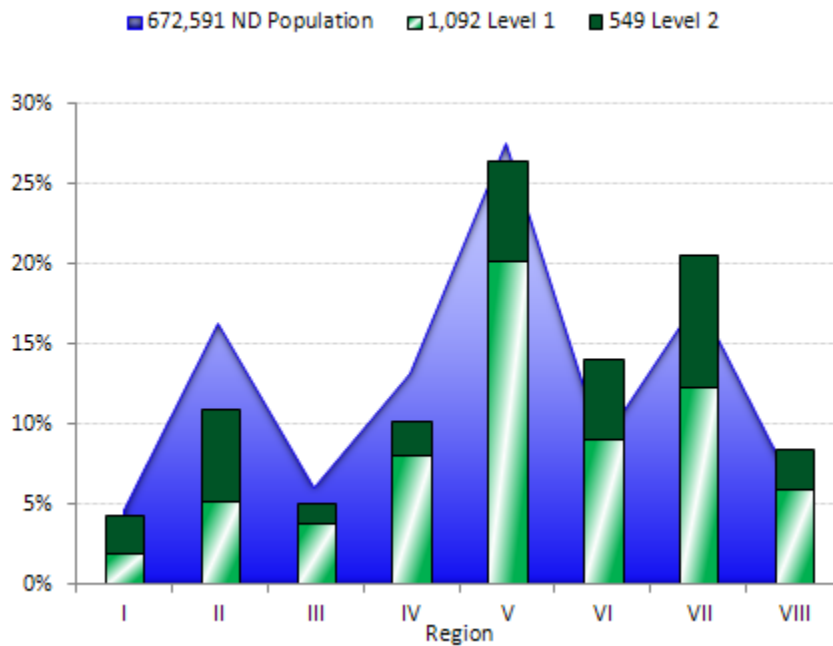


Figure 4. Percent of level 1 and level 2 care consultation by ND region relative to population, January 2010-June 2013

Resources were provided to caregivers 1,170 times. Figure 5 depicts the percent distribution of resources given to DCSP participants during the 42-month period of DCSP operation (January 2010-June 2013) by North Dakota region in relation to each region’s percent of population. Results indicated that caregivers residing in all regions of North Dakota had received DCSP resources.

Comparison between each region’s percent population and percent of DCSP resource acquisition provides a means for assessing the extent to which dementia care resource needs are being addressed in each region. Regions whose resource acquisition percentage was significantly lower (i.e., unmet resource needs are higher) than their population percentage were III (Devils Lake area) and IV (Grand Forks area) (Figure 5). Alternatively, regions whose resource acquisition percentage was significantly higher (i.e., unmet resource needs are lower) than their population percentage were VII (Bismarck area) and VIII (Dickinson area).

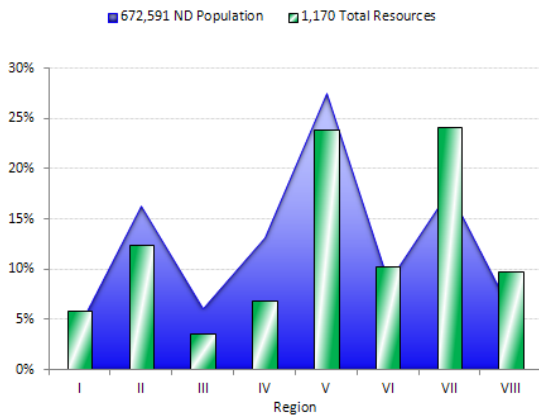


Figure 5. Percent of resources provided at DCSP visits by ND region relative to population, January 2010-June 2013

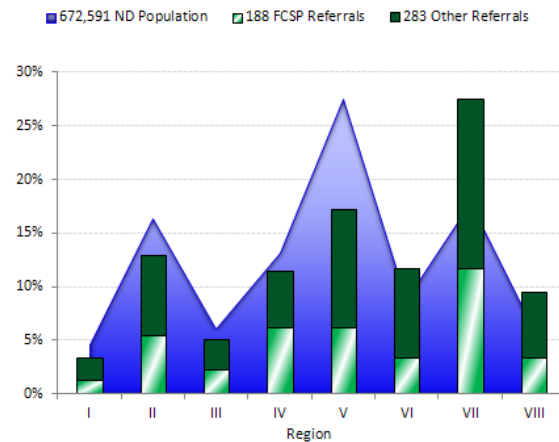


Figure 6. Percent of referrals to other agencies including the FCSP from the DCSP by ND region relative to population, January 2010-June 2013

Referrals were made by DCSP staff 471 times, and 188 (40%) of those referrals were to the Family Care Support Program (FCSP). Figure 6 depicts the percent distribution of referrals made for DCSP participants during the 42-month program period (January 2010-June 2013) by North Dakota region in relation to each region’s percent of population. Results indicated that caregivers residing in all regions of North Dakota had received DCSP referrals. The one region whose referral percentage was significantly lower than their population percentage was region V (Fargo area). Alternatively, two regions whose referral percentage was higher than their population percentage were regions VI (Jamestown area), VII (Bismarck area), and VIII (Dickinson area).

Figure 6 also depicts the 42-month percent distribution of 188 FCSP referrals made for DCSP participants by North Dakota region in relation to each region’s percent of population. Results indicated that caregiver residing in all regions of North Dakota had received FCSP referrals. Regions whose FCSP referral percentage was low relative to the other referrals were regions I (Williston area), VI (Jamestown area), and VIII (Dickinson area). Alternatively, regions whose FCSP referral percentage was about the same as other referrals were Regions III (Devils Lake area), and IV (Grand Forks area).

Caregivers

The 1,750 caregivers served during the past 42 months were primarily females (73%) and typically a wife (13%) or daughter (32%) of the PWD. Caregivers' ages ranged from 20 to 96 years with a mean of 61.2 years. Most of the caregivers were white (81.0%) while 1.0% were American Indian. About one half of these caregivers (49.8%) resided in rural areas. About one fourth (29%) of the caregivers had to travel to see the PWD. The median travel distance was 87 miles, with the furthest travel incurred by a caregiver from Great Britain. The most common reason for contacting the DCSP was to find care resource information or to receive check-in support.

Just under one third of all caregivers (32.2%) received a follow-up care consultation with DCSP staff. Over time, increasing numbers of caregivers are contacting DCSP multiple times. Currently, nearly one half (47.2%) of caregivers have had multiple DCSP contacts, and the number of DCSP contacts per caregiver ranged from 1 to 27. Health care or service professionals comprised 222 (12.7%) of the caregivers, some of which had multiple contacts with DCSP. The number of DCSP contacts per professional ranged from 1 to 6, and 61 professionals had multiple contacts. These professionals were likely contacting DCSP regarding multiple PWDs.

Information on the various sources who referred caregivers and PWDs to the DCSP is important for increased understanding of what is (and what is not) working for promoting DCSP service awareness among its target population. Table 1 indicates the use prevalence of various referral sources by North Dakota and the caregiver's relationship to the PWD during the 42-month program period. The first row in Table 1 shows the Alzheimer's Association was the most common referral source (55%), followed by friend/family (24%), other source (10%), contact center (6%), and health care professional (5%). Other source includes media/advertising, internet, unknown, and other responses not provided on this list.

Table 1. Caregivers' Sources of Referral to the DCSP by ND Region and Relationship to PWD, Jan. 2010-June 2013

	Referred to DCSP by:									
	Alz. Assoc.		Cont. Cent.		Friend/Fam.		H.C. Pro.		Other	
	N	%	N	%	N	%	N	%	N	%
Total	956	54.63	109	6.23	426	24.34	84	4.80	175	10.00
Region										
I (Williston)	46	58.23	1	1.27	27	34.18	2	2.53	3	3.80
II (Minot)	102	52.04	17	8.67	51	26.02	6	3.06	20	10.20
III (Devils Lake)	40	57.14	3	4.29	18	25.71	7	10.00	2	2.86
IV (Grand Forks)	72	55.38	13	10.00	23	17.69	8	6.15	14	10.77
V (Fargo)	267	55.74	22	4.59	124	25.89	28	5.85	38	7.93
VI (Jamestown)	102	58.62	10	5.75	37	21.26	8	4.60	17	9.77
VII (Bismarck)	221	57.25	14	3.63	98	25.39	13	3.37	40	10.36
VIII (Dickinson)	67	46.85	2	1.40	47	32.87	9	6.29	18	12.59
Missing	39	41.94	27	29.03	1	1.08	3	3.23	23	24.73
Caregiver's Relationship to PWD										
Spouse	256	73.35	9	2.58	38	10.89	21	6.02	25	7.16
Family	444	52.98	47	5.61	228	27.21	41	4.89	78	9.31
Other	138	40.47	27	7.92	132	38.71	11	3.23	33	9.68
Professional	118	53.15	26	11.71	28	12.61	11	4.95	39	17.57

By region, the Alzheimer's Association was most commonly used in regions VI (Jamestown area; 59%), III (Devils Lake area; 57%), and VII (Bismarck; 57%) and least utilized in region VIII (Dickinson area; 47%) (Table 1). Friends/family were most commonly used as referral sources in Regions I (Williston area; 34%), and VIII (Dickinson area; 33%), and least used in regions IV (Grand Forks area; 18%) and VI (Jamestown area; 21%). Contact centers were most frequently utilized in Regions IV (Grand Forks area; 10%) and II (Minot area; 9%) and least utilized in regions I (Williston area; 1%) and VIII (Dickinson area; 1%). Health professionals were most

often used as DCSP referral sources in region III (Devils Lake area; 10%) and least used in regions I (Williston area; 3%), II (Minot area; 3%), and VII (Bismarck area; 3%).

By relationship to the PWD, spouses were more likely to be referred to the DCSP by the Alzheimer's Association (73%) and less likely to have been referred by contact centers (3%) (Table 1). Health care professionals were more likely to use the contact centers (12%) as a referral source. Family members were more likely to have been referred by other family members (13%).

Persons with Dementia

There were 951 PWDs served by the DCSP in the past 42 months. These are uniquely identified people and thus do not include contacts by caregivers (such as professionals) who were contacting DCSP regarding groups of people. PWDs' ages ranged from 30 to 100 years with a mean of 78.7 years; 54% were female and 19% were veterans. Regarding residence, 398 PWDs lived in urban counties and 479 lived in rural counties; 778 PWDs lived in towns and 84 lived in the country. Also, about three-fourths (N=684) of the PWDs lived in the community at their home, of which 210 lived home alone (i.e., without a spouse or family member).

Having a formal diagnosis and receiving it early versus late in the disease process is associated with increased access to pharmacologic treatment and increased cost efficiencies for affected families and the health care system (Weimer & Sager, 2009). DCSP data were evaluated for the prevalence of dementia/AD diagnosis by North Dakota region for the 42 month program period. Alternative categories to having a diagnosis were suspected dementia/AD, other diagnosis, and unknown. DCSP participants were asked whether the person being provided care had been diagnosed by a health care provider as having dementia/AD. About three-fourths (N=707) had a diagnosis of AD or dementia (56 reporting young onset).

Figure 7 shows the prevalence of diagnoses in PWDs by region relative to the population in that region age 65 and older (as this age group is most relevant to PWDs). Regions with the highest prevalence of a diagnosis relative to their population were regions V (Fargo area; 31%) and region VII (Bismarck area; 23%). The lowest diagnosis prevalence figures were found in regions II (Minot area; 11%) and region III (Devils Lake area; 4%).

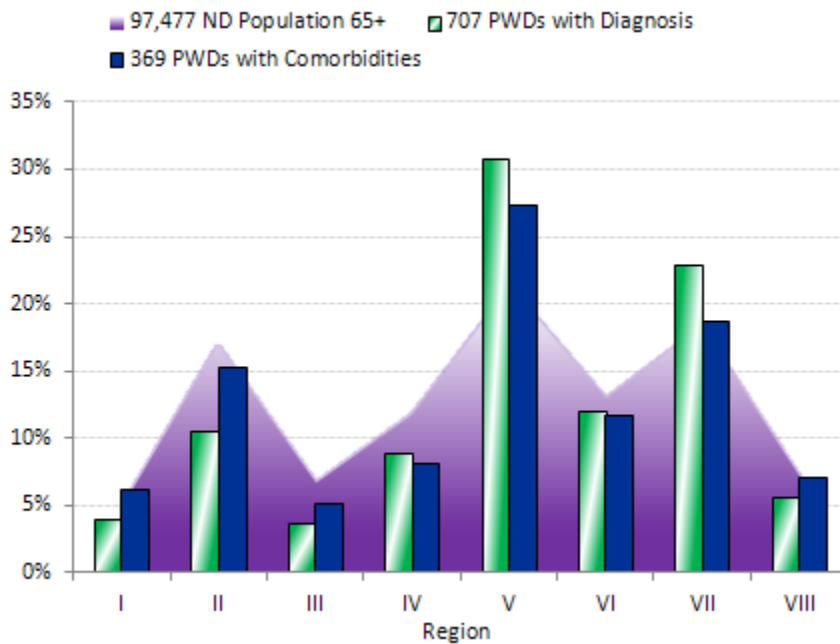


Figure 7. Dementia/AD diagnosis and comorbid diagnoses prevalences by ND region and population 65 and older, January 2010-June 2013.

Figure 7 also shows the regional prevalence of the 513 PWDs who reported at least one comorbid health condition. Persons with dementia/AD can often have one or more comorbidities (i.e., other health conditions) which can adversely affect one’s health status, functional ability, and cognitive state (Maslow, 2004). Comorbid conditions are thus a measure of severity of the general health of the PWD. Region V (Fargo area; 27%) had the highest proportions of PWDs with comorbid conditions relative to the population, suggesting more complicated situations.

Stage and severity of the AD/dementia in the PWD were measured by 1) recording the reported stage of disease (early, middle, or late), 2) a five point Likert type scale of the DCSP’s evaluation of the severity of the disease, and 3) a five point Likert type scale of the caregiver’s perception of the stage of the disease. Disease stage information is important for assessing the relative severity of the disease state and determining the level of needed care and assistance by the PWD and their caregiver. The caregiver’s perception was measured as it also reflects the stress and urgency they feel regarding the PWD’s disease. Table 2 shows the reported measures. Missing values are high as these measures were not taken until after 18-24 months of the DCSP.

Table 2. Stage and severity measures for 951 PWDs

Variable	Level	N	%	Variable	Level	N	%
Rated Severity	Minor	31	3.3	Perceived Severity	Minor	100	10.5
	Moderate	341	25.9		Moderate	202	21.2
	Severe	33	3.5		Severe	113	11.9
	Missing	546	57.4		Missing	536	56.4
Stage of Dementia	Early	67	7.1	Total Severity	Mild	180	18.9
	Middle	170	17.9		Moderate	237	24.9
	Late	28	2.9		Severe	171	18.0
	Missing	686	72.1		Missing	363	38.2

Most of the PWDs being served are middle stage (18%), and of moderate severity on both rated and perceived measures (26% and 21% respectively). The correlation between the two severity measures and stage of disease was significant (all $p < .05$). These three measures were combined into one severity measure (Total Severity, based on the average scores of the 3 measures) to decrease the number of missing values and then be used in further comparisons.

Acquisition of Health Care Objectives

The designation of power of attorney (PoA) for persons with a potentially debilitating and lethal disease (such as dementia/AD) is viewed as a helpful step for addressing any future legal and/or health related issues or decisions in the event the PWD is unable to tend to such issues due to worsening health. Having health care directives (HCDs) in place for PWDs is helpful for the same reasons. Of the 951 PWDs, 182 did not provide information on PoAs and 197 provided no information on HCDs. Figure 8 shows the number of PWDs who after the 42 month DCSP do not have a PoA ($n=162$) or HCD ($n=205$) relative to the population of ND 65 and older for each region.

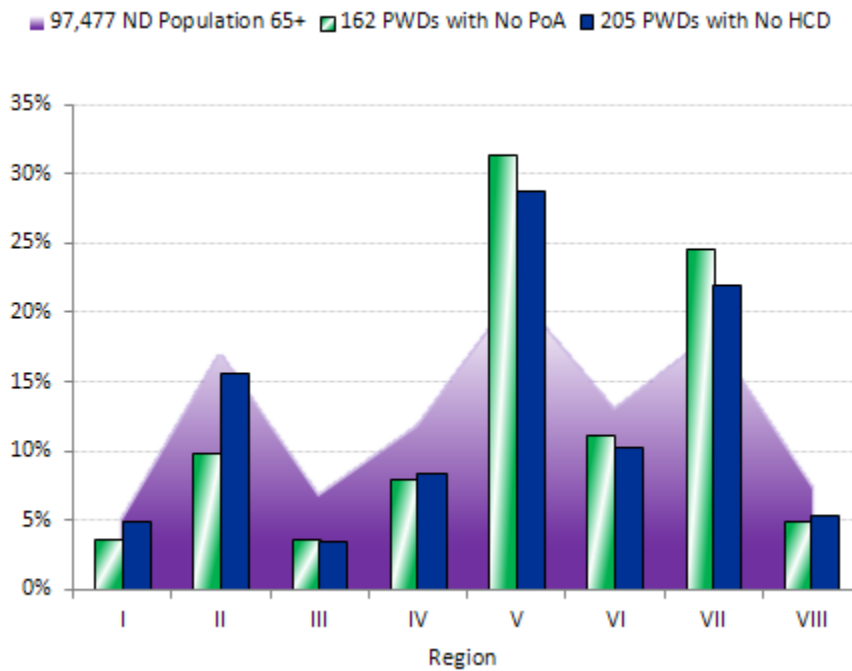


Figure 8. PWDs without PoAs or HCDs at DCSP initiation relative to age 65+ population by ND region, January 2010-June 2013

Regions whose percentage of PoA absence was significantly lower than their age 65+ percentage were regions II (Minot area; 10%) and III (Devils Lake area; 4%) (Figure 8). Alternatively, regions whose percentage of PoA absence was higher than their age 65+ percentage were regions V (Fargo area; 31%) and VII (Bismarck area; 25%). Regions whose percentage of HCD absence was lower than their age 65+ percentage were regions III (Devils Lake area; 3%), IV (Grand Forks area; 8%), and VI (Jamestown area; 10%). Alternatively, regions whose percentage of HCD absence was higher than their age 65+ percentage were again regions V (Fargo area; 29%) and VII (Bismarck area 22%).

Receiving education about dementia is another important goal for caregivers. Understanding the disease, its stages, and its effects on people can help to relieve stress and gain empowerment for the caregiver and PWD (Devor & Renvall, 2008). Implementing a Medic Alert + Safe Return[®] system for a PWD, particularly for those living alone and/or located in rural areas, is an important consideration when trying to increase personal safety of the patient (Patel et al., 2012). This system entails utilizing a wearable device with a button that when depressed transmits an alarm message to an operator at a remote call center, who then summons immediate assistance for the person in need. Of the 951 PWDs, 61 did not provide information on education classes and 152 provided no information on Medic Alert + Safe Return[®] systems. Figure 9 depicts the percent distribution of 658 DCSP PWDs whose caregiver

had not completed a dementia care-related educational class and the 717 PWDs without a Medic Alert + Safe Return[®] system during the 42-month program period relative to percent of population aged 65 years or older by North Dakota region.

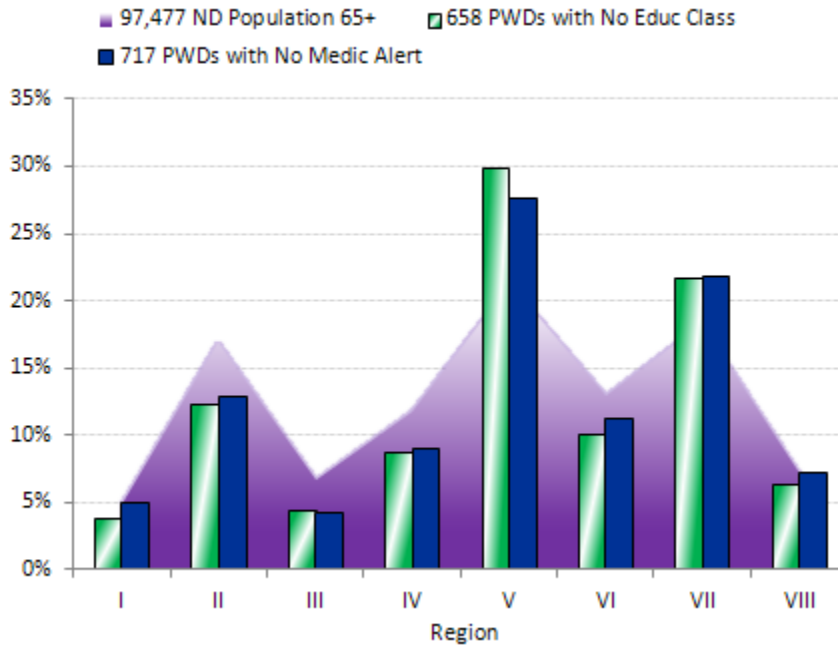


Figure 9. PWDs whose caregivers had no education class and who had no Medic Alert + Safe Return[®] system relative to Age 65+ population by ND region, January 2010-June 2013

Comparison between each region’s population percentage over the age of 65 and percent of DCSP caregivers without dementia care class completion or without Medic Alert + Safe Return[®] provides means for assessing the extent to which dementia care informational needs are being addressed in each region. Regions whose percentage of dementia care class non-completion was lower than their age 65+ percentage were regions II (Minot area; 12%), III (Devils Lake area; 4%) and IV (Grand Forks area; 9%), and VI (Jamestown area; 10%) (Figure 9). Alternatively, regions whose percentage of dementia care class non-completion was higher than their age 65+ percentage were regions V (Fargo area; 30%) and VII (Bismarck area; 22%). Regions whose percentage of Medic Alert + Safe Return[®] absence was lower than their age 65+ percentage were Regions II (Minot area; 17%), III (Devils Lake area; 4%), IV (Grand Forks area; 11%), and VI (Jamestown area; 10%). Regions whose percentage of Medic Alert + Safe Return[®] absence was higher than their age 65+ percentage were again regions V (Fargo area; 22%) and VII (Bismarck area; 16%).

Analyses were conducted to determine whether DCSP participation coincided with increases in obtaining PoA, establishing HCD, completing a dementia care related class, and implementing a Medic Alert + Safe Return[®] system among the 951 caregivers of PWDs in the 42-month program period (Figure 10). Comparisons were made between the prevalence of PWDs with health care objectives when they started working with the DCSP at intake, and the prevalence of those who now have them after working with the DCSP. Substantial increases were noted among DCSP participants for all four endeavors: Medic Alert + Safe Return[®] (215%); education class (71%); HCD (29%); and PoA (24%).

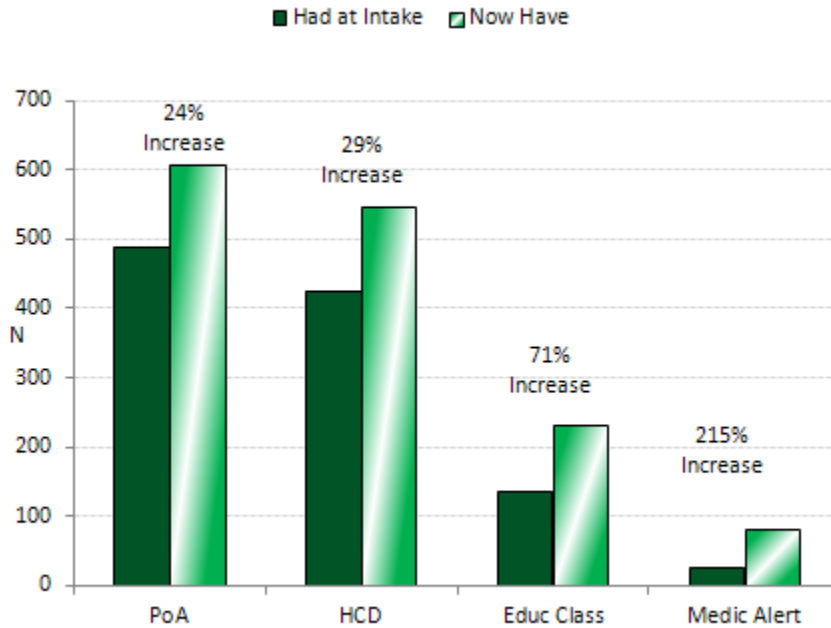


Figure 10. DCSP impact on acquisition of health care objectives, January 2010-June 2013

Attributes of PWDs and caregivers were tested for associations with obtaining health care objectives. Figure 11 shows that PWDs who live in urban areas or have no comorbidities were more likely to obtain a PoA. No comorbidities are also associated with obtaining HCDs. Figure 12 shows that PWDs who lived with someone at home were more likely to have the health care objectives of PoA, HCD, education class, and Medic Alert + Safe Return[®] system.

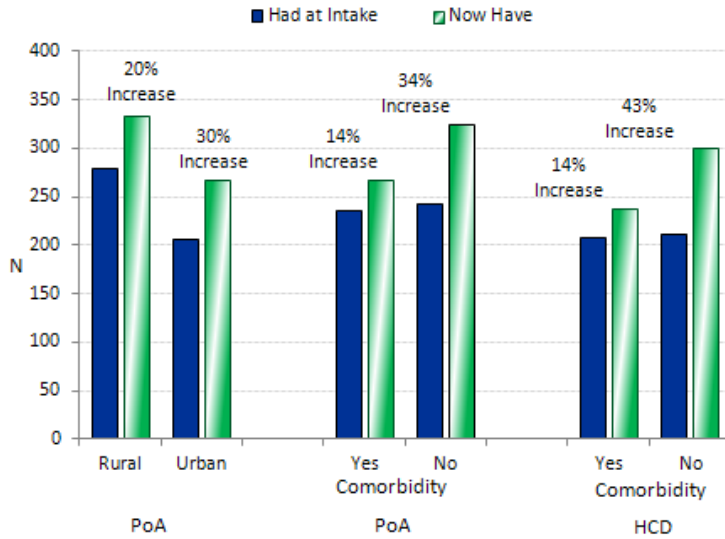


Figure 11. Association of PWD's rural status with obtaining PoA, and PWD's comorbidities with obtaining PoA and HCD

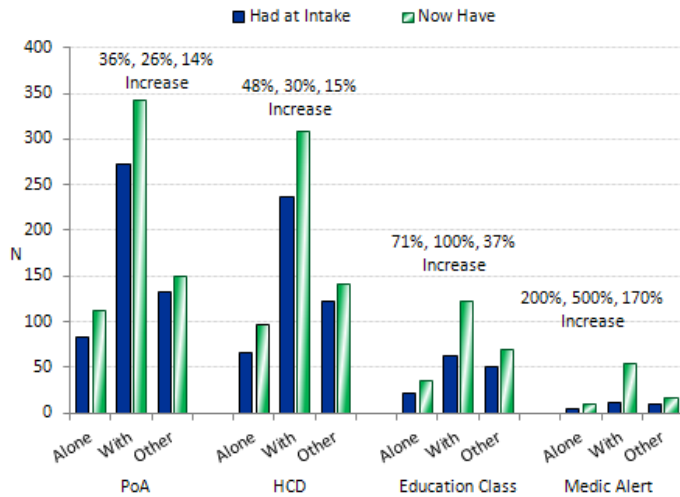


Figure 12. Association of PWD's living arrangement with obtaining health care objectives

The actions of the DCSP were tested for associations with obtaining health care objectives. Figures 13 and 14 show that the more care consultations a PWD had, the greater their likelihood of obtaining all health care objectives.

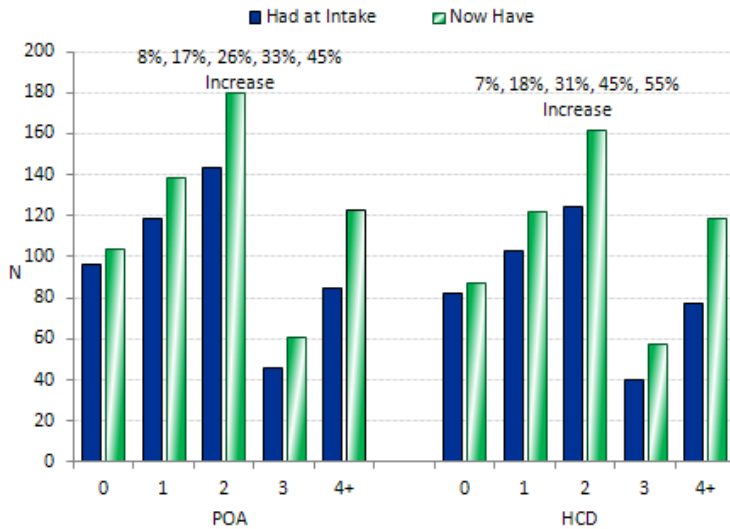


Figure 13. Association of number of care consultations and with obtaining PoAs and HCDs

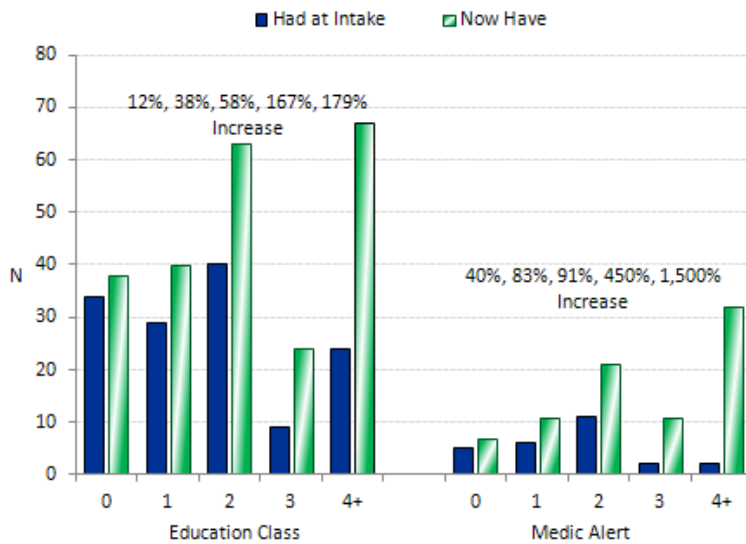


Figure 14. Association of number of care consultations with obtaining an education class and Medic Alert + Safe Return[®] system

As with having multiple care consultations, having follow-up visits (Figure 15) and receiving a referral (Figure 16) were also associated with increased likelihood of obtaining all health care objectives.

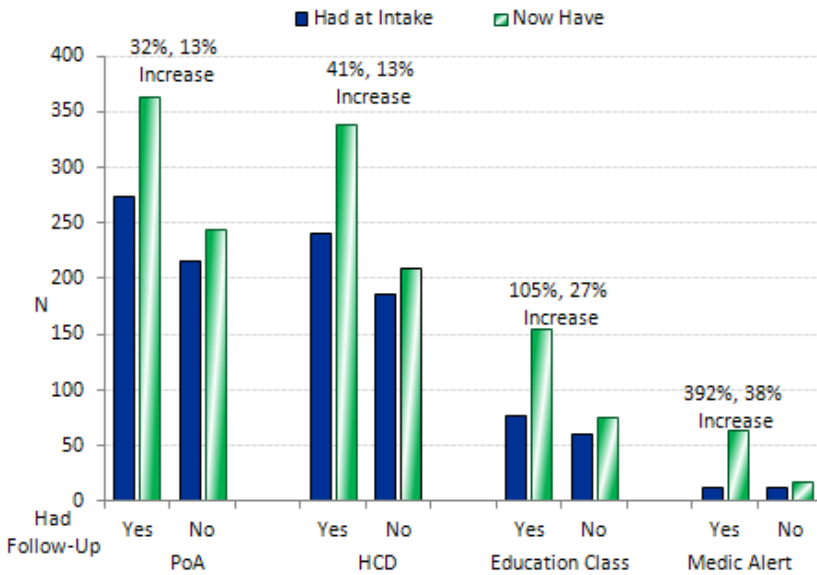


Figure 15. Association of having follow-up visits with obtaining health care objectives

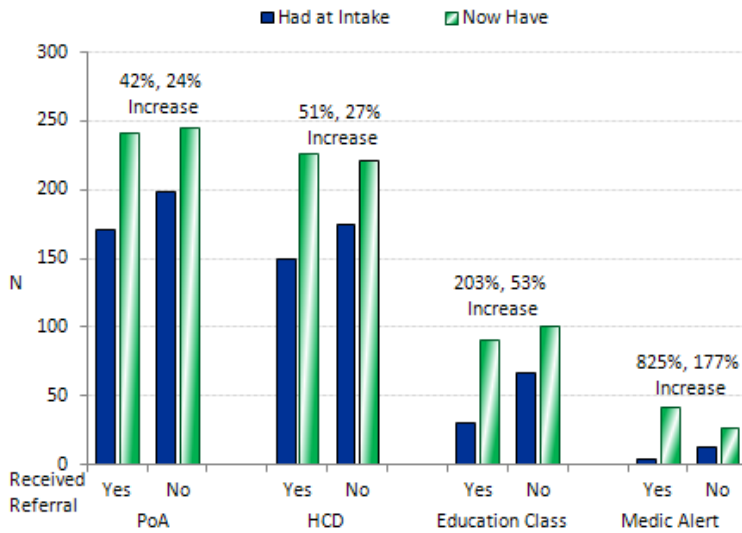


Figure 16. Association of having received a referral with obtaining health care objectives

Estimated Health Care Cost Savings

Health care cost savings coinciding with DCSP participation over time were estimated based on changes in PWDs' use of hospital, emergency room, ambulance, and 911 services during the 42 month program period. Use of these services for each PWD was tracked during their DCSP tenure and grouped into three month time intervals. Frequency of use for these time intervals was compared to the baseline period (i.e., 1-3 months). Estimated costs per health service use (i.e., event) were derived from the medical literature and available North Dakota-based reports. Estimated costs savings were noted for all four health service types.

Table 3 shows the estimation of cost savings. The rate of events per PWD is the number of times an event happened during the three month period (i.e., days hospitalized, ambulance uses, ER visits, 911 calls) relative to the number of PWDs reporting in that time frame. The change in event rate is the difference in rates between later rates and the baseline rate from 1-3 months. Cost per event is the estimated mean or median cost for that event. Amounts saved relative to the first three months is the rate change multiplied by the number of PWDs in that time period (the estimated utilization change is applied to each PWD to obtain the total utilization change in that time frame), then multiplied by the cost of one event.

Total estimated cost savings coinciding with DCSP participation included the following: hospital (\$731,743); emergency room (\$51,658), ambulance (\$43,645); and 911 calls (\$6,470) for a total of \$833,516 (Table 3). Estimated total cost savings were higher in time intervals closer to (i.e., 4-6 months) rather than farther from (i.e., more than 12 months) the baseline period for use of all four health service types, but especially for hospital care. This was primarily due to there being more PWDs in earlier time frames, hence more total savings. Figure 17 shows how the cost savings per PWD, which controls for the number of PWDs in each time frame, do not decrease over time but show some indications of increasing. Hospital cost savings are shown using the right axis due to the much higher savings amounts.

Table 3. Estimated \$833,516 health care cost savings in the DCSP for hospital, ambulance, emergency room, and 911 calls, January 2010-June 2013.

	N PWD	Rate of Events per PWD	Change in Event Rate	Cost per Event	Amount Saved Relative to First 3 Months
Days in Hospital					\$731,743
1 – 3 Months	867	.754			
4 – 6 Months	283	.272	.482	\$1,977	\$269,809
7 – 9 Months	189	.328	.426	\$1,977	\$159,282
10 - 12 Months	133	.241	.514	\$1,977	\$135,079
13 - 15 Months	106	.406	.349	\$1,977	\$73,067
16 - 18 Months	70	.071	.683	\$1,977	\$94,506
Urban Ambulance					\$16,917
1 – 3 Months	423	.092			
4 – 6 Months	140	.021	.071	\$617	\$6,113
7 – 9 Months	99	.010	.082	\$617	\$5,015
10 - 12 Months	67	.045	.047	\$617	\$1,960
13 - 15 Months	55	.036	.056	\$617	\$1,895
16 - 18 Months	34	0	.092	\$617	\$1,934
Rural Ambulance					\$26,728
1 – 3 Months	437	.124			
4 – 6 Months	141	.071	.053	\$927	\$6,881
7 – 9 Months	88	.045	.078	\$927	\$6,372
10 - 12 Months	64	.031	.092	\$927	\$5,477
13 - 15 Months	50	.040	.084	\$927	\$3,873
16 - 18 Months	36	0	.124	\$927	\$4,124
Emergency Use					\$51,658
1 – 3 Months	867	.210			
4 – 6 Months	283	.117	.093	\$568	\$14,999
7 – 9 Months	189	.079	.131	\$568	\$14,015
10 - 12 Months	133	.105	.105	\$568	\$7,906
13 - 15 Months	106	.094	.116	\$568	\$6,959
16 - 18 Months	70	.014	.196	\$568	\$7,778
911 Calls					\$6,470
1 – 3 Months	867	.141			
4 – 6 Months	283	.046	.095	\$82	\$2,199
7 – 9 Months	189	.053	.088	\$82	\$1,361
10 - 12 Months	133	.030	.111	\$82	\$1,207
13 - 15 Months	106	.038	.103	\$82	\$895
16 - 18 Months	70	0	.141	\$82	\$808

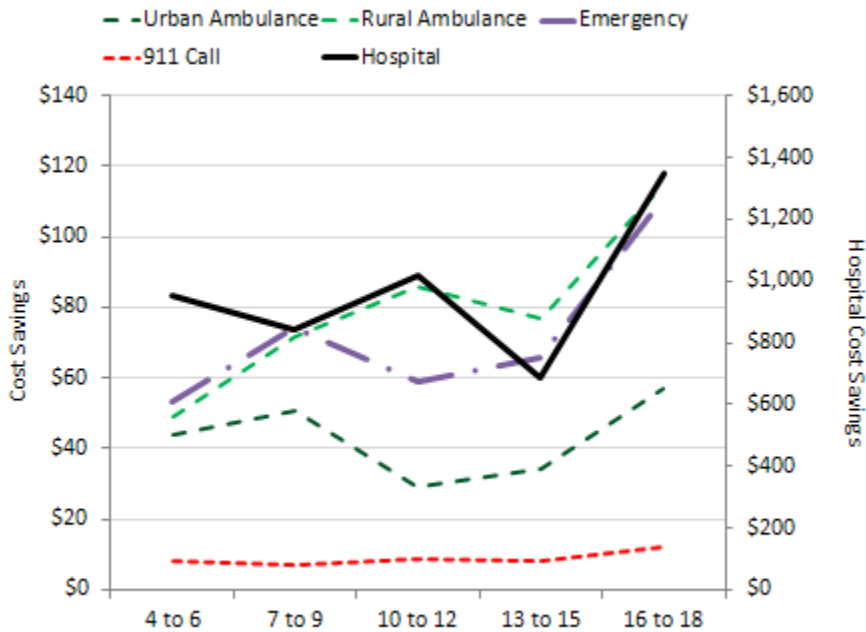


Figure 17. Estimated cost savings per PWD over time

Total estimated cost savings per PWD over the time period were compared between different levels of demographics and DCSP actions for each cost type. Table 4 shows which groups had higher estimated hospital cost savings per PWD. Having a comorbid disease had the greatest increase in cost savings (\$601 per PWD). Having two or three care consultations created the greatest increase (\$604 and \$438 per PWD respectively). Having follow-up consultations (\$752 per PWD) or receiving referrals (\$743 per PWD) were the strongest DCSP actions to increase cost savings.

Table 5 shows estimated ambulance cost savings per PWD. PWDs who didn't live at home had higher cost savings (\$44 per PWD). Having three to four care consultations increased savings \$50 and \$74 per PWD. DCSP actions of follow-up (\$54 per PWD) and action level 2 (\$58 per PWD) care consultations created the highest savings. Having a PoA also increase cost savings by \$57.

Table 4. Estimated hospital cost savings per PWD by demographics and DCSP actions

Group	N	Cost Savings per PWD	Group	N	Cost Savings per PWD	Increase in Cost Savings per PWD
Rural	379	\$729	Urban	395	\$1,083	\$354
Lives at Home	687	\$752	Lives Other	90	\$2,111	\$1,359
No Travel	559	\$513	Caregiver Travels	206	\$2,004	\$1,491
No Comorbidity	583	\$691	Comorbidity	192	\$1,292	\$601
Mild Severity	143	\$892	Moderate Severity	121	\$2,249	\$1,357
LTC Place Sooner	273	\$876	LTC Place Delayed	289	\$1,239	\$363
0 or 1 Care Consultations	92	\$906	2 Care Consultations	181	\$1,510	\$604
			3 Care Consultations	142	\$1,344	\$438
			4 Care Consultations	366	\$585	-\$321
No Follow-Up	118	\$498	Follow-Up	663	\$1,250	\$752
No Action Level 2	377	\$875	Action Level 2	404	\$1,073	\$198
No Referral	304	\$556	Referral	477	\$1,299	\$743
No HCD	111	\$840	HCD	670	\$1,168	\$328

Table 5. Estimated ambulance cost savings per PWD by demographics and DCSP actions

Group	N	Cost Savings per PWD	Group	N	Cost Savings per PWD	Increase in Cost Savings per PWD
Urban	395	\$47	Rural	379	\$71	\$24
Lives at Home	680	\$55	Lives Other	90	\$99	\$44
No Travel	552	\$54	Caregiver Travels	206	\$74	\$20
No Comorbidity	576	\$49	Comorbidity	192	\$68	\$19
Mild Severity	136	\$54	High Severity	422	\$83	\$29
0 or 1 Care Consultations	92	\$46	2 Care Consultations	174	\$44	-\$2
			3 Care Consultations	142	\$96	\$50
			4 Care Consultations	366	\$120	\$74
No Follow-Up	118	\$33	Follow-Up	656	\$87	\$54
No In Person	132	\$42	In Person	642	\$78	\$36
No Action Level 2	373	\$47	Action Level 2	401	\$105	\$58
No Resource	87	\$34	Resource	687	\$78	\$35
No Referral	297	\$43	Referral	477	\$63	\$20
No PoA	82	\$18	PoA	692	\$75	\$57
No HCD	107	\$51	HCD	667	\$71	\$20

Table 6 shows estimated emergency room cost savings per PWD. As with ambulance savings, PWDs not living at home had greater emergency cost savings (\$51 per PWD) than those at home. PWDs whose placement was delayed had very high emergency room savings of \$73 per PWD. For emergency room savings, having only two care consultations produced higher cost savings (\$67 per PWD). DCSP action of having a follow-up visit increased cost savings by \$81 per PWD. Having a PoA established also increase cost savings by \$72 per PWD.

Table 7 shows estimated 911 call cost savings per PWD. Demographics had weaker cost savings, while severity measures and delays in LTC placement had higher cost savings (\$13 and \$12 per PWD respectively). 911 call cost savings only increased when the number of care consultations was four or more (\$20 per PWD). Most actions of the DCSP showed modest increases in cost savings (\$6 to \$9 per PWD). Health care objectives of having a PoA, HCD, and education class increased cost savings by \$10 to \$11 per PWD.

Table 6. Estimated emergency room cost savings per PWD by demographics and DCSP actions

Group	N	Cost Savings per PWD	Group	N	Cost Savings per PWD	Increase in Cost Savings per PWD
Lives at Home	687	\$65	Lives Other	90	\$116	\$51
No Travel	559	\$61	Caregiver Travels	206	\$90	\$29
Comorbidity	192	\$46	No Comorbidity	583	\$73	\$27
Mild Severity	143	\$69	Moderate Severity	121	\$109	\$40
LTC Place Sooner	273	\$90	LTC Place Delayed	289	\$163	\$73
0 or 1 Care Consultations	92	\$56	2 Care Consultations	181	\$123	\$67
			3 Care Consultations	142	\$79	\$23
			4 Care Consultations	366	\$94	\$38
No Follow-Up	118	\$30	Follow-Up	663	\$111	\$81
No In Person	139	\$54	In Person	642	\$88	\$34
No Action Level 2	377	\$64	Action Level 2	404	\$91	\$27
No Resource	87	\$25	Resource	694	\$84	\$59
No Referral	304	\$49	Referral	477	\$86	\$37
No PoA	82	\$30	PoA	699	\$102	\$72
No HCD	111	\$53	HCD	670	\$99	\$46
No Med Alert Sys	607	\$76	Med Alert Sys	174	\$120	\$44

Table 7. Estimated 911 call cost savings per PWD by demographics and DCSP actions

Group	N	Cost Savings per PWD	Group	N	Cost Savings per PWD	Increase in Cost Savings per PWD
Urban	395	\$7	Rural	379	\$10	\$3
Lives at Home	687	\$8	Lives Other	90	\$15	\$7
No Travel	559	\$7	Caregiver Travels	206	\$13	\$6
Mild Severity	143	\$3	High Severity	422	\$16	\$13
LTC Place Sooner	273	\$14	LTC Place Delayed	289	\$26	\$12
0 or 1 Care Consultations	92	\$7	2 Care Consultations	181	\$8	\$1
			3 Care Consultations	142	\$3	-\$4
			4 Care Consultations	366	\$27	\$20
No Follow-Up	118	\$5	Follow-Up	663	\$13	\$8
No Action Level 2	377	\$8	Action Level 2	404	\$14	\$6
No Resource	87	\$2	Resource	694	\$11	\$9
No PoA	82	\$1	PoA	699	\$12	\$11
No HCD	111	\$2	HCD	670	\$13	\$11
No Educ Class	444	\$6	Educ Class	337	\$16	\$10

Some patterns emerged over the four types of cost savings estimated. Rural PWDs had higher ambulance and 911 call cost savings per PWD, while urban PWDs had higher hospital cost savings per PWD. Rural status did not affect emergency room cost savings. Caregivers who traveled had more cost savings per PWD after working with the DCSP than those who didn't travel for all four costs. Delays in LTC placement was associated with higher cost savings per PWD for hospital, emergency room, and ambulance costs, but not 911 calls. Having a follow-up or action level 2 care consultation increased savings per PWD in all costs. Having HCDs also increased cost savings per PWD for all costs. Having an education class increased 911 call savings, while having a Medic Alert + Safe Return[®] system increased emergency room savings.

Estimated Long Term Care Costs Avoided

Over the entire course of the DCSP implementation period or 42 months, decreases in caregivers' likelihood to place their PWD in LTC has generated an estimated cost savings of \$39,206,232 in North Dakota. This was based on 372 PWDs who had worked with the DCSP for two weeks or more and their caregivers had given two or more answers regarding likelihood to place them in LTC. LTC cost was based on LTC facilities that were closest to the caregivers of the PWD. 105 PWDs had their likelihood of LTC placement delayed, 151 had no change, and 115 had their placement changed to sooner.

Analysis by geographical region indicated substantial estimated savings in all areas of North Dakota (Figure 18). Regions with the highest estimated LTC cost savings were VII (Bismarck area; \$14.5 million), II (Minot area; \$6.12 million), and V (Fargo area; \$5.95 million). Regions with the lowest estimated LTC cost savings were IV (Grand Forks area; \$0.46 million), III (Devils Lake area; \$1.01 million), and I (Williston; 1.41 million).

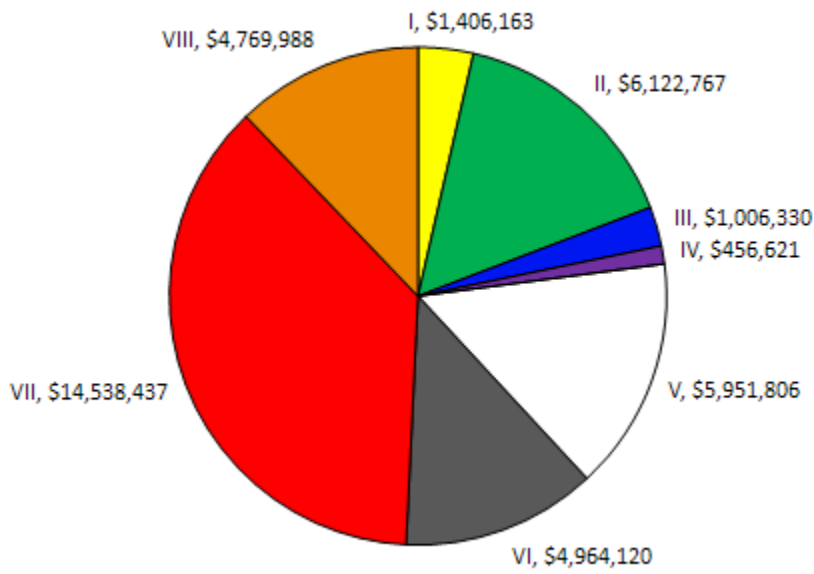


Figure 18. Total long-term care cost savings by ND region, January 2010-June 2013

Figure 19 shows what percent of PWDs in each region had a delayed LTC placement after working with the DCSP relative to the population of North Dakota 65 and older. Regions I (Williston; 2%), III (Devils Lake; 4%), and IV (Grand Forks; 6%) had few PWDs with delayed placement relative to the population. Regions VII (Bismarck; 31%) and V (Fargo; 24%) had the highest relative number of delays.

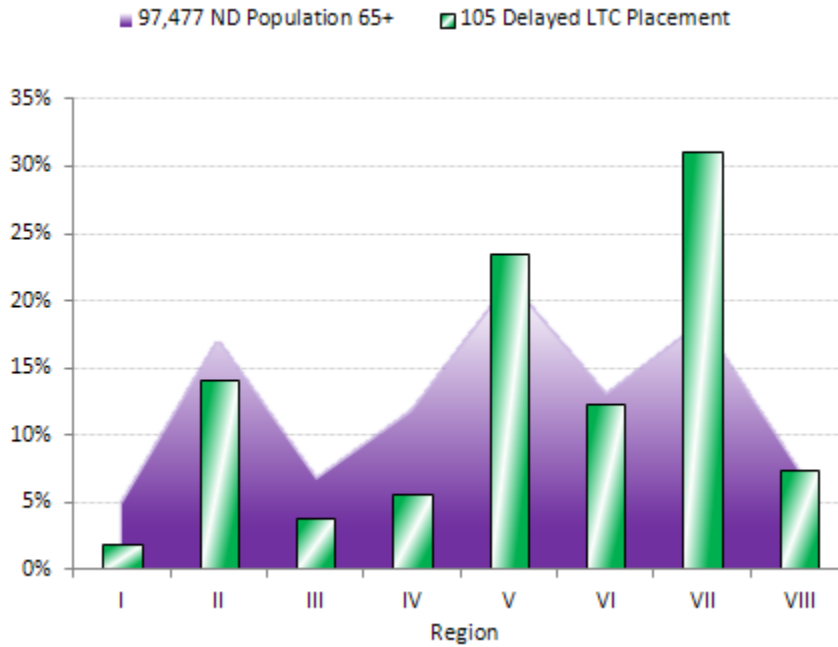


Figure 19. Percent of long-term care delays in placement by ND region relative to population, January 2010-June 2013

Days of LTC that were potentially avoided by working with the DCSP by region are shown in Table 8. The first column (N) refers to the number of PWDs who had their LTC placement delayed (105). LTC Days Saved is the total number of days LTC placement was delayed (191,325) and how many days per person that was (1,822). Number Visits is the total number of visits or contacts they had with the DCSP (646) and how many per person that was (6). Number Care Consultations is the total number of care consultations they had of any type (438) and the average number per person (4). Days Saved per Visit is the total number of days LTC placement was delayed for a single visit (296). Days Saved per CC is the total number of days LTC placement was delayed for a single care consultation (437).

Region I (Williston) had the highest number of days saved per visit (1,217) or per care consultation (1,825) (Table 8). Region IV (Grand Forks) had the lowest (34 and 49) days saved per visit and care consultation respectively. Region III (Devils Lake) was also low for both numbers (129 and 149).

Table 8. Estimated LTC days that were potentially avoided relative to the number of visits with the DCSP and number of care consultations

	N	LTC Days Saved		Number Visits		Number Care Consultations		Days Saved per Visit	Days Saved per CC
		Total	per person	Total	per person	Total	per person	Total	Total
All	105	191,325	1,822.14	646	6.09	438	4.13	296.17	436.82
Regn 1	2	7,300	3,650.00	6	3.00	4	2.00	1,216.67	1,825.00
Regn 2	15	31,427	2,095.13	63	4.20	42	2.80	498.84	748.26
Regn 3	4	4,773	1,193.25	37	9.25	32	8.00	129.00	149.16
Regn 4	6	2,134	355.67	63	10.5	44	7.33	33.87	48.50
Regn 5	25	28,164	1,126.56	124	4.96	70	2.80	227.13	402.34
Regn 6	12	26,733	2,227.75	110	8.46	77	5.92	243.03	347.18
Regn 7	33	66,785	2,023.79	194	5.88	133	4.03	344.25	502.14
Regn 8	8	24,009	3,001.13	49	6.13	36	4.50	489.98	666.92

Figure 20 shows variables that are associated with delayed LTC placement. PWDs with comorbidities had a greater prevalence of delayed placements (33%) compared to those without (23%). There were 35% of the PWDs' caregivers who received a referral and decreased the likelihood of placement compared to 25% of the caregivers not receiving referrals. Multiple care consultations also increased the likelihood of placement delay, especially one (30%), three (27%), and four (39%) consultations. PWD demographics and health care objectives were not associated with delays in likelihood to place in LTC.

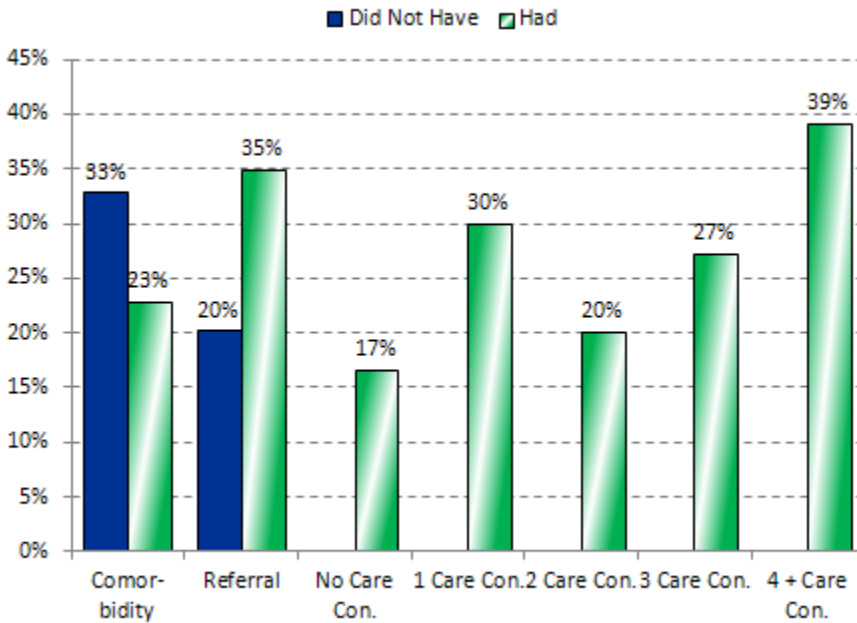


Figure 20. Percent of long-term care delays in placement by actions of the DCSP, January 2010-June 2013

Behavioral Health in Caregivers

There were 101 caregivers who had care consultations and responded to a survey regarding their behavioral health and medical situation of the PWD. The caregivers' behavioral health was assessed through three measures, 1) if the DCSP improved the caregivers' knowledge of dementia, 2) a scale measuring empowerment of the caregiver (based on four questions which ask: if they feel better equipped, if they have improved knowledge of resources, if they have improved health, and if they feel less stressed), and 3) a scale measuring access to support (based on questions regarding their improved knowledge of support, improved access to health care, and improved access to information). Satisfaction with the DCSP was measured through one question about convenience of the program and one question directly asking about satisfaction. All questions were measured with a five point Likert scale. The average responses for these variables are in Table 9. All show very high values (above four).

Table 9. Average responses to survey questions regarding caregiver's behavioral health

	N	Mean	Min	Max
Improved Knowledge of Dementia	97	4.32	1	5
Empowerment	97	4.06	2.5	5
Access to Support	97	4.28	3	5
Convenience	95	4.63	4	5
Satisfaction	94	4.40	1	5

Table 10 shows aspects of the PWD or caregiver and actions by the DCSP that were related to the behavioral health questions and satisfaction with the DCSP. Independent t-tests with one-tail p-values or one-way ANOVAs with F statistics were used to compare average behavioral health scores between groups.

The PWD not living at home ($p = .021$), the caregiver being from a more urban area ($p = .031$) and having HCDs in place were all related to higher empowerment scores for the caregiver (Table 1). Increased access to support was higher for caregivers who had a follow-up visit ($p = .040$) or had HCDs ($p = .004$). The number of contacts the caregiver had with the DCSP was also positively correlated with the access to support measure ($r = .198$; $p = .039$).

Caregivers who thought the program was convenient were more likely to be daughters of the PWD ($p = .020$), have to travel to see the PWD ($p = .004$), and be under 75 years old ($p < .001$). Satisfaction with the DCSP was higher for caregivers who had a PoA ($p = .043$) or an HCD ($p = .040$).

Table 10. Relationship of demographics and DCSP actions to caregivers' behavioral health

Variable	Level	N	Mean	St. D.	t	p
Empowerment						
Lives at Home	No	8	4.50	0.39	2.10	.021
	Yes	34	4.05	0.57		
Rural Status	Urban	43	4.25	0.58	*3.65	.031
	Large Rural	16	4.02	0.51		
	Small/Isolated Rural	21	3.87	0.51		
Has HCD	Yes	32	4.24	0.54	2.32	.017
	No	10	3.79	0.53		
Access to Support						
Had Follow-Up	Yes	38	4.41	.058	1.77	.040
	No	42	4.18	.056		
Has HCD	Yes	32	4.55	0.57	2.83	.004
	No	10	3.97	0.55		
Convenience						
Caregiver a Daughter	Yes	28	4.86	0.36	2.94	.002
	No	50	4.54	0.50		
Caregiver Travels	Yes	22	4.91	.029	2.75	.004
	No	31	4.58	0.50		
Caregiver Under 75	Yes	58	4.74	0.44	3.35	<.001
	No	18	4.33	.049		
Satisfaction						
Have PoA	Yes	37	4.54	0.51	1.77	.043
	No	4	4.00	1.15		
Have HCD	Yes	31	4.58	0.50	1.80	.040
	No	10	4.20	0.79		

* F statistic

SUMMARY AND CONCLUSION

The DCSP has steadily grown over its 42 month course in the number of program contacts (current total=2,985; average increase of 71 per month), caregivers (current total=1,750; average increase of 42 per month), and PWDs (current total=951; average increase of 23 per month). Participation among PWDs and caregivers was unequal across all regions, relative to region populations. Regions I, II, III, and IV, the northern half of the state, consistently lagged relative to the population of those areas. The DCSP does care consultations for about 55% of the contacts, 33% are level 2 care consultations, 40% are in person, and 32% are follow-up. The DCSP provides resources 33% of the time, referrals 16%, and FCSP referrals 6% of the time.

Increasing numbers of caregivers (about one half) are contacting the DCSP multiple times. The highest number of visits is 27, and the longest time spent working with the DCSP is 42 months. About half of the caregivers and PWDs live in rural areas. The DCSP has worked with caregivers from many states, as well as from Great Britain. Health care professionals make up about 13% of all caregivers. American Indians make up 1% of the caregivers. Veterans make up 19% of the PWDs, about three fourths have a diagnosis of dementia or Alzheimer's, and 54% have a comorbidity. Most of those reporting severity are moderate.

Outcomes have been consistently produced over this 42 month period. Obtainment of health care objectives has occurred each month, gradually reducing the percent of PWDs without them (Figure 10). PoAs and HCDs are the most prevalent health care objectives. Education classes, an important part of increasing the knowledge of dementia, have shown a moderate increase in the number of attendees. Medic Alert + Safe Return[®] systems are new and were almost non-existent in this population before the DCSP began working with them. Thus, though the numbers are small, they have made great gains. As with having multiple care consultations (Figures 13 and 14), having follow-up visits (Figure 15) and receiving a referral (Figure 16) are associated with increases in obtaining all health care objectives.

Estimated total health care cost savings has grown steadily through this time frame and is currently \$833,516 (Table 3). Total health care savings are highest in the first 3-6 months after intake, then savings decline somewhat. Estimated cost savings per PWD are steady or increase over time (Figure 17). Demographics such as living arrangement and severity affect cost savings (Tables 4, 5, 6, and 7). Delay in LTC placement is associated with more cost savings. DCSP actions such as multiple care consultations, follow-up, in person, and action level 2 visits, along with receiving resources and referrals were associated with greater estimated health care cost savings. Also, obtaining HCDs, and education classes (for 911 calls) and Medic Alert + Safe Return[®] systems (for emergency room visits) were associated with higher cost savings.

LTC cost avoidances only increase as time progresses and more caregivers delay placement of PWDs. Currently an estimated \$39,206,232 in LTC costs has been avoided. An estimated 296 days are avoided for each DCSP visit, and 437 days for each care consultation (Table 8). Again, regions I, II, III, and IV are lagging relative to their populations (Figure 19). These estimated cost avoidances are associated with no comorbidities in the PWD, more care consultations, and getting referrals from the DCSP (Figure 20).

The behavioral health of the caregiver survey is a recent addition to the data gathering instruments (as are measures of severity of the PWD). Thus, the number of observations available for analysis was small. However, there were sufficient numbers to begin to describe the behavioral health of the caregiver and understand how it may affect other outcomes. Overall the caregivers reported positive outcomes, especially in satisfaction with the DCSP and what the DCSP has done for them. Behavioral health was associated with the PWD not being at home, the caregiver being in a less rural area, having follow-up visits, and having an HCD in place (Table 10). Satisfaction was associated with the caregiver being a daughter of the PWD, or the caregiver having to travel to see the PWD, or the caregiver being younger. Having a PoA or HCD also increased satisfaction.

The DCSP has done an excellent job reaching out to caregivers of PWDs with multiple visits in a very rural state. They have provided caregivers with assistance such as resources and referrals that have empowered the caregiver, reducing their stress, and saving them money. It is understandable why the satisfaction with the DCSP was rated so highly by caregivers.

RECOMMENDATIONS

The DCSP has made vast strides toward achieving their outcomes. However, there are a number of areas that were found to be weak. The northern regions of North Dakota were consistently lagging in many areas from actions done by the DCSP to outcome measures. Multiple care consultations and follow-up visits were common actions that were related to improved outcomes. Also, though the prevalence of American Indians caregivers was somewhat low (1% compared to 1.9% of the North Dakota population 65 and older), this is actually a strong number considering difficulties working on reservations and cultural differences. How caregivers hear about the DCSP is usually through the Alzheimer's Association or by word of mouth. Advertising is lacking and needs to be increased to promote awareness of the DCSP. Finally, it must always be kept in mind that North Dakota is a very rural state and PWDs who live alone will have special challenges.

Outcomes such as education classes and Medic Alert + Safe Return[®] systems had strong increases but low numbers. Classes are regularly offered and advertised, so this may be in part due to caregivers not feeling they need the class or not having time. Total health care costs appear to decrease over time. This is likely due to 1) fewer PWDs that have worked with the DCSP longer than six months, and 2) dementia is a progressive disease and the PWD's severity will increase with time, increasing health care utilization. However the cost per PWD is consistent or increasing over time so this is not a large concern. The behavioral health survey was done only on 101 caregivers and though it may be an accurate report, its generalizability is questionable and more caregivers are needed, especially tracking them across time.

Based on these findings, here are suggestions for DCSP improvement:

- Increase efforts for participant recruitment including public awareness campaigns, billboards, and television ads.
- Increased focus on persons providing care to PWDs living alone and in isolated or rural areas.
- Increased promotion and encouragement of participation in Level 1 and 2 care consultations.
- Promotion of health care objective completion, especially education classes and Medic Alert + Safe Return[®] systems.
- Increase assessment of behavior health of the caregiver, especially depression and mechanisms caregivers use to improve their behavioral health.

- Encourage use of preventive health care such as primary care providers.
- Better understand how needs of caregivers change as the disease progresses.

Increased promotion of the DCSP would likely increase the number of caregivers of PWDs who are in early stages of dementia. Advertising takes the DCSP to the caregiver, not the caregiver searching for the DCSP. Working with PWDs who are in early, not middle or late stages of dementia, potentially increases cost savings and delays in LTC placement. Health care objective completions are also best accomplished in the early or middle stages of dementia. With this the DCSP needs to work more to reach PWDs that live alone, in rural areas, or on reservations and thus may have fewer resources readily available to them. The caregivers of these PWDs may need different aid than those in more populated areas and the care consultants need to adjust their plans accordingly. More care consultants would aid in reaching these caregivers, especially in the northern regions.

Level 1 and level 2 care consultations are strongly associated with increased health care objectives and cost savings. It is important for the care consultant to work with the caregiver to provide these services, whichever level is felt most appropriate. Further, the completion of health care objectives is more than an outcome measure; it is also associated with cost savings and behavioral health of the caregiver. Currently there has been an estimated (\$731,743) in hospital cost savings. Approximately 10% of hospital costs in North Dakota are billed to Medicaid. This represents a Medicaid cost savings of \$73,174. Approximately 75% of LTC costs are billed to Medicaid. The DCSP has potentially avoided \$39,206,232 in LTC costs, representing approximately \$29,404,674 in Medicaid savings. More care consultants would again aid in accomplishing these goals by being able to increase care consultations.

Behavioral health of the caregiver needs to be more consistently measured, especially depression scales. Also, due to the culture of the caregivers in North Dakota, many do not report behavioral health problems and/or have established coping systems, (e.g., neighbors, family, churches, community). It is also recommended that DCSP staff measure participants' preventive health care use. Such new information would shed additional light on a more complete picture of health care receipt. Using the previously established model for estimating cost savings (Klug et al., 2012a), preventive care use could be examined for its level of association to acute and emergency care use (and associated costs). Increased funding would help to identify what strategies work for these caregivers.

More data regarding caregiver behavioral health and quality of life benchmarks could be measured and assessed at early stages of dementia and compared over the course of the caregivers' DCSP tenure. Further funding would allow these data to be tested to determine if it

is associated with changes in health care and LTC cost savings. This could also provide information as to how the DCSP's actions need to change with the changes in caregiver needs.

Estimations of population changes in the oil patch are, at best, educated guesses. Much of the added population is transient and will not appear in census data. Attempts have been made to count population in man camps, but the camps continually change and many camps are unregistered. Rental population is difficult to measure as many homes are not declaring they have rented out space and the number of renters occupying one residence is much higher than single-family occupancy. Some cities in the oil patch have even taken to estimating their population by changes in water and sewer usage. They know approximately how much utility usage one person had before the oil boom, and thus can estimate the number of people in their city after the boom by measuring the increases. None of these estimates can provide an accurate picture of the population changes and thus these changes are not reflected in this report.

However, it is recognized that the oil boom is affecting the DCSP. Recently the DCSP has been asking caregivers if the oil patch is causing problems. Two caregivers reported that their PWDs had to relocate, one reported problem with transportation, and one reported difficulties in receiving timely medical care. Care consultants in the western part of North Dakota need to be aware these and other problems may be occurring, and care consultants in the eastern part of North Dakota also need to be aware of PWDs and caregivers migrating from the west. These caregivers and PWDs affected by the oil patch will have unique needs. A qualitative study of caregivers and PWDs affected by the oil boom would help in the understanding of these needs and the ways the DCSP can best fulfill them.

The Future of the DCSP

The importance of more funding to implement the recommendations can be summarized as follows: (1) increased promotional awareness and outreach of the DCSP, (2) assessment of behavioral health; (3) the development, pilot testing, and implementation of educational interventions for encouraging the importance and appropriate use of preventive, acute, and long-term care; (4) increased understanding of dementia caregivers' changing needs as the dementia progresses.

The DCSP is unique in the United States for providing assistance to caregivers of PWDs. It has become a nationally recognized leader for its methods and contributions. The state of Michigan has begun a program patterned after the DCSP, and other states are also seeking funding to do so. The collaboration the DCSP is apparent with hundreds of organizations to which it refers

caregivers, as well as health care personnel (e.g., physicians, nurses), which in turn illustrates the strength of this program.

The DCSP has made great strides in providing assistance leading to improved physical and behavioral health of the caregiver and PWD in a difficult to reach environment. Provided that additional funding can be secured and the above recommendations heeded, it is expected that DCSP participants who are exposed to the newly implemented interventions will have increased use and costs of preventive health care services leading to reduced use and costs of the more expensive and invasive acute/urgent health and LTC. Also, DCSP participants will have improved behavioral health and increased quality of life over the course of their program tenure, and this will positively relate to preventive healthcare use and costs, and acute health and LTC cost savings for the caregivers, insurance companies, Medicaid, and Medicare.

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APPENDIX A: Intake Form

<p>Caller Contact Information</p> <p>Raiser's Edge Number: _____</p> <p>Name: _____ Date of Birth _____</p> <p>Address (Home/Business): _____</p> <p>City: _____ State: _____ Zip: _____</p> <p>H): _____ B): _____</p> <p>Cell): _____ Email: _____</p> <p>Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown <input type="checkbox"/> Refused <input type="checkbox"/> Not Appropriate County: _____</p> <p>Have you attended an Alzheimer's Association education session since Jan 2011? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Highest level of education completed: <input type="checkbox"/> Less than high school <input type="checkbox"/> High School graduate <input type="checkbox"/> Some college <input type="checkbox"/> Bachelor's degree <input type="checkbox"/> Post/Professional degree <input type="checkbox"/> Refused <input type="checkbox"/> Not appropriate for call</p> <p>Race/Ethnicity: <input type="checkbox"/> White <input type="checkbox"/> Black/African American <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> American Indian/Alaskan Native <input type="checkbox"/> Native Hawaiian/Other Pacific Islander <input type="checkbox"/> Asian <input type="checkbox"/> Other race <input type="checkbox"/> 2 or more races <input type="checkbox"/> Unknown <input type="checkbox"/> Not appropriate for call</p> <p>In general my health is: <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very Good <input type="checkbox"/> Excellent</p> <hr/> <p>PWD Information</p> <p>Name: _____ City PWD Lives: _____</p> <p>Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Refused <input type="checkbox"/> Not Appropriate</p> <p>Region: 1 2 3 4 5 6 7 8 Town Country: (Circle)</p> <p>Date of Birth: _____ Veteran: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown County: _____</p> <p>Date of Diagnosis (if unknown, ask for estimate of month and year of dx): _____</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; vertical-align: top; border: none;"> <p>Dementia Diagnosis (check all that apply):</p> <input type="checkbox"/> Alzheimer's Disease <input type="checkbox"/> Vascular Dementia <input type="checkbox"/> Mixed Dementia <input type="checkbox"/> Mild Cognitive Impairment <input type="checkbox"/> Parkinson's Disease <input type="checkbox"/> Frontotemporal dementia <input type="checkbox"/> Creutzfeldt-Jakob Disease <input type="checkbox"/> Normal Pressure Hydrocephalus <input type="checkbox"/> Huntington's Disease <input type="checkbox"/> Lewy Body dementia <input type="checkbox"/> Wernicke-Korsakoff syndrome <input type="checkbox"/> Unspecified dementia <input type="checkbox"/> Alzheimer's Disease suspected <input type="checkbox"/> Other <input type="checkbox"/> Unknown <input type="checkbox"/> Refused <input type="checkbox"/> Not appropriate for call </td> <td style="width: 50%; vertical-align: top; border: none;"> <p>Other comorbid conditions:</p> <input type="checkbox"/> Diabetes <input type="checkbox"/> Heart <input type="checkbox"/> Arthritis <input type="checkbox"/> Autoimmune disorder <input type="checkbox"/> Depression <input type="checkbox"/> Other psychiatric condition <input type="checkbox"/> Other (please list): _____ </td> </tr> </table> <p style="text-align: center;">On a scale of 1 (minor) to 5 (severe), how do you perceive the current level of dementia/Alzheimer's severity for the person you are calling about:</p> <table style="width: 100%; border: none; text-align: center;"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>Minor</td> <td></td> <td>Moderate</td> <td></td> <td>Severe</td> </tr> </table> <p style="text-align: center;">Current stage of dementia severity (as determined by Care Consultant)</p> <table style="width: 100%; border: none; text-align: center;"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> <td>6</td> <td>7</td> </tr> <tr> <td>None</td> <td>Very Mild</td> <td>Mild</td> <td>Moderate</td> <td>Moderately Severe</td> <td>Severe</td> <td>Very Severe</td> </tr> </table> <p>In general, the health of the person I am calling about is: <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very Good <input type="checkbox"/> Excellent</p> <p>Nursing home: In the past three months, how many days have you (or the person you are calling about) been in a nursing home or rehab center for physical health problems? _____ If placed, is this a permanent placement? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Emergency Services: In the past three months, how many days have you or the person you are calling about been:</p> <p>In the hospital: You _____ PWD _____ In ER: You _____ PWD _____ Used Ambulance: You _____ PWD _____ Called 911: You _____ PWD _____</p> <p>Likelihood to place: On a scale of 1-5 (with 5 bring placed ASAP), how likely are you to place the person you are calling about? 1 2 3 4 5</p> <p>Does the PWD have a POA? Yes No Unknown (Circle) Does the PWD have Health Care Directives? Yes No Unknown (Circle)</p> <p>Does the PWD have Medic Alert & Safe Return? Yes No Unknown (Circle) Is the PWD driving? Yes No Unknown (Circle)</p> <p>Does the PWD have long-term care insurance? Yes No Unknown (Circle)</p>	<p>Dementia Diagnosis (check all that apply):</p> <input type="checkbox"/> Alzheimer's Disease <input type="checkbox"/> Vascular Dementia <input type="checkbox"/> Mixed Dementia <input type="checkbox"/> Mild Cognitive Impairment <input type="checkbox"/> Parkinson's Disease <input type="checkbox"/> Frontotemporal dementia <input type="checkbox"/> Creutzfeldt-Jakob Disease <input type="checkbox"/> Normal Pressure Hydrocephalus <input type="checkbox"/> Huntington's Disease <input type="checkbox"/> Lewy Body dementia <input type="checkbox"/> Wernicke-Korsakoff syndrome <input type="checkbox"/> Unspecified dementia <input type="checkbox"/> Alzheimer's Disease suspected <input type="checkbox"/> Other <input type="checkbox"/> Unknown <input type="checkbox"/> Refused <input type="checkbox"/> Not appropriate for call	<p>Other comorbid conditions:</p> <input type="checkbox"/> Diabetes <input type="checkbox"/> Heart <input type="checkbox"/> Arthritis <input type="checkbox"/> Autoimmune disorder <input type="checkbox"/> Depression <input type="checkbox"/> Other psychiatric condition <input type="checkbox"/> Other (please list): _____	1	2	3	4	5	Minor		Moderate		Severe	1	2	3	4	5	6	7	None	Very Mild	Mild	Moderate	Moderately Severe	Severe	Very Severe	<p><input type="checkbox"/> Phone <input type="checkbox"/> In Person</p> <p><input type="checkbox"/> Follow Up <input type="checkbox"/> Information Helpline <input type="checkbox"/> Level 1 <input type="checkbox"/> Level 2 <input type="checkbox"/> Early Stage <input type="checkbox"/> Report of Contact</p> <p>Caller's Relationship to PWD:</p> <p>Caller is PWD: _____</p> <p>Caller's Profession: for professionals: _____</p> <hr/> <p>PWD Living Arrangement: (Check 2)</p> <input type="checkbox"/> Assisted Living/Basic Care <input type="checkbox"/> Group Home <input type="checkbox"/> In community <input type="checkbox"/> Skilled Nursing Facility <input type="checkbox"/> Family <input type="checkbox"/> Lives alone <input type="checkbox"/> With Spouse <input type="checkbox"/> Other(Specify below) <p>Referral Source</p> <input type="checkbox"/> AA Mailing <input type="checkbox"/> AA Staff or Program <input type="checkbox"/> Billboard/Sign <input type="checkbox"/> Contact Center <input type="checkbox"/> Co-worker <input type="checkbox"/> County Staff <input type="checkbox"/> Don't recall <input type="checkbox"/> Email <input type="checkbox"/> Friend <input type="checkbox"/> Flyer/brochure <input type="checkbox"/> Health Fair <input type="checkbox"/> MD Toolkit <input type="checkbox"/> Magazine <input type="checkbox"/> Newspaper <input type="checkbox"/> Other <input type="checkbox"/> Radio <input type="checkbox"/> Relative <input type="checkbox"/> Television <input type="checkbox"/> Website <input type="checkbox"/> NH/Res Care Staff <input type="checkbox"/> Parish Nurse <input type="checkbox"/> Other Health Prof <input type="checkbox"/> Refused/Declined <input type="checkbox"/> Family CG Prog <input type="checkbox"/> Senior Linkage Line <input type="checkbox"/> Yellow Pgs/Ph. Bk <input type="checkbox"/> APP-MD (office), PA or NP <p>Has the oil boom in ND caused: (Check any or all that apply)</p> <input type="checkbox"/> Relocation in housing? <input type="checkbox"/> Problems with transportation? <input type="checkbox"/> Increased wait time for medical care?
<p>Dementia Diagnosis (check all that apply):</p> <input type="checkbox"/> Alzheimer's Disease <input type="checkbox"/> Vascular Dementia <input type="checkbox"/> Mixed Dementia <input type="checkbox"/> Mild Cognitive Impairment <input type="checkbox"/> Parkinson's Disease <input type="checkbox"/> Frontotemporal dementia <input type="checkbox"/> Creutzfeldt-Jakob Disease <input type="checkbox"/> Normal Pressure Hydrocephalus <input type="checkbox"/> Huntington's Disease <input type="checkbox"/> Lewy Body dementia <input type="checkbox"/> Wernicke-Korsakoff syndrome <input type="checkbox"/> Unspecified dementia <input type="checkbox"/> Alzheimer's Disease suspected <input type="checkbox"/> Other <input type="checkbox"/> Unknown <input type="checkbox"/> Refused <input type="checkbox"/> Not appropriate for call	<p>Other comorbid conditions:</p> <input type="checkbox"/> Diabetes <input type="checkbox"/> Heart <input type="checkbox"/> Arthritis <input type="checkbox"/> Autoimmune disorder <input type="checkbox"/> Depression <input type="checkbox"/> Other psychiatric condition <input type="checkbox"/> Other (please list): _____																										
1	2	3	4	5																							
Minor		Moderate		Severe																							
1	2	3	4	5	6	7																					
None	Very Mild	Mild	Moderate	Moderately Severe	Severe	Very Severe																					

Primary Concern or request: _____

Confidentiality Request or Permission: Ok to call Ok to mail Ok to refer (If no, please explain caller's preference): _____

Name of direct and indirect referrals (no abbreviations): _____

Staff Name & Date: _____ Total time spent: (Include phone/prep/RE): _____

Information Request Form

Name:

Quick Information:

- SG Listings Coach Caregiver Playbook
 Driving: Cross Roads and Topic Sheet
 Long term Care Consultation (add phone #)
 Online Resources (in Development)
 Message Board EZ CG Guide

Activities: (brochure)

- Activities for Men with dementia
 Care Partner Tips: Activities
 101 Ways to spend time with a pwd

Adult Day Programs:

- Care Options listing of Adult Day services
 Encour. Participation in Adult Day Services
 Helping your loved one Adjust to Adult Day Services
 Introduction to Adult Day Services

Behaviors: (brochure)

- Agitation
 Behavioral and Psychiatric symptoms
 Difficult Behaviors: Validate, Join and Distract
 Overcoming Resistance
 Sundowning, coping with

Caregiving Concerns/Stress: (brochure)

- Advice from a person with AD
 Are you a healthy caregiver?
 Avoiding care partner stress
 Care Partner Stress: Signs to watch for
 Caring for yourself
 Caring Techniques for people with AD
 Coping Tips for Care Partners
 Long Distance Care Partners
 LDCP Booklet
 Tips for New Care Partners
 12 Steps for Care Partners
 Visiting the doctor with a person with AD

Communication: (brochure)

- Communicating with person with AD
 Communication tips from persons with memory loss
 Responding to Denial
 Telling others about the diagnosis
 What to say or do when there is nothing to say and do
 What to say when...

Companion Services:

- Care Options listing of Companion Services
 How to arrange for outside assistance
 Respite Care Resources List

Dementia Clinics/Diagnosis/Disease Info.:

- AD and Dementia: Accepting the Diagnosis
 AD & Related Dementias
 Choosing a Primary Care Physician
 Dementia Clinic Listing
 Diagnosis of AD topic sheet
 FDA Approved Treatments
 Partnering With Your Doctor (brochure)
 Principles for a dignified DX (brochure)
 Stages of AD
 10 Warning Signs

Address:

Packets to be Sent:

- General Memory Loss (copy Youa)
 Legal&Financial Early Stage
 Professional Suspected
 Early/Young Onset
 MD Toolkit (copy Youa)

Family Issues:

- Changes in relationships: Family and Friends
 Families sharing the care
 How to hold a family meeting
 Tips for Adult Children
 When Care Partners Disagree
 When the caregiver parent resists help

Home Health Care/In Home Help:

- Care Options listing of Home Health Care
 Hiring a Home Health Care Employee
 How to arrange for outside assistance

Hospice:

- Care Options listing of Hospice providers
 Hospice and AD
 Hospice Readiness Assessment – Alzheimer's patients

Planning Ahead/Decision Making:

- Legal Plans (brochure) Money Matters (brochure)
 How to make tough decisions
 Planning Ahead: questions to consider
 Planning for the future: Legal & Financial Issues

Residential Care: Carefinder Guide booklet (brochure)

- Assisted Living Uniform Consumer Instruction Guide
 Care Options listing of Memory Care Providers
 Dementia Training Law-MN
 How to make the move to residential care
 Making the Decision: When is the right time for facility care
 Special Care Disclosure Law-MN
 To move or not to move
 Tips on visiting residential care facilities
 Visiting a Loved one with Dementia
 Website listing when looking for care in MN
 Working with Staff in a NH or AL facility
 Questions to consider when looking for residential care

Respite: Respite Care Guide (brochure)

- How to arrange for Outside Assistance
 Respite Care Resource List

Safety: (brochure)

- Helping PWD be safe and successful
 Home Safety Tips
 Medic Alert & Safe Return (brochure)
 Wandering Behavior: Preparing For and Preventing it

Other:

APPENDIX B: Dementia Care Survey

Dementia Care Service Care Consultation Client Survey

To help us improve the program’s ability to assist you and other families, please answer a few questions about your experience using the Care Consultation service administered by the Alzheimer’s Association’s staff. The survey will take 5-10 minutes. Your responses will be analyzed by independent researchers from UND, will not be presented in a way that would identify you, and will not influence in any way your relationship with the Alzheimer’s Association. Your feedback is highly appreciated!

SECTION 1

1. For each item, circle the response that best reflects your experience with the Care Consultation program.

Please indicate the extent to which you agree or disagree with the following statements about the program:	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree	N/A
The Care Consultation service was convenient.	1	2	3	4	5	0
Overall, the Care Consultation service was of high quality.	1	2	3	4	5	0
The Care Consultation program helped me improve my knowledge about dementia.	1	2	3	4	5	0
This program helped me improve my knowledge about how to manage the symptoms of dementia.	1	2	3	4	5	0
This program made me feel better equipped to manage this disease.	1	2	3	4	5	0
This program helped me have better access to dementia care information.	1	2	3	4	5	0
This program helped me improve my knowledge about dementia related resources and supports.	1	2	3	4	5	0
The Care Consultation program helped me feel less stressed.	1	2	3	4	5	0
The program helped me improve my health.	1	2	3	4	5	0
The program helped me to learn where to find more help and support.	1	2	3	4	5	0
The program helped me cope better with my role as caregiver for a person with dementia.	1	2	3	4	5	0
The program had a positive influence on my caregiving.	1	2	3	4	5	0

2. Following your Care Consultation, you received a follow-up letter. What steps from that letter were you able to complete?

3. Were there any you couldn't complete? What kept you from completing them?

4. How satisfied are you with the overall service provided by this program? Please circle or underline:
Very dissatisfied-1 Dissatisfied-2 Neither satisfied nor dissatisfied-3 Satisfied-4 Very satisfied-5

PLEASE ANSWER QUESTIONS IN SECTION 2 IF YOU WERE IN THE PROGRAM FOR AT LEAST **6 MONTHS**. IF LESS THAN 6 MONTHS, SKIP TO SECTION 3.

Please Go to Next Page

SECTION 2

The following questions are about the person you first contacted the Alzheimer's Association about because you had concern for them.

1. Has this person you were concerned about been provided a Dementia diagnosis by a physician?
Yes___ No___ If Yes, what was the diagnosis?

IF "NO", SKIP TO #3

2. Was this diagnosis received before you participated in a Care Consultation? Yes___ No___

3. Does this person you were concerned about have one person you think of as their personal doctor or health care provider? Yes___ No___

IF "NO", SKIP TO #5

4. Did they have a personal doctor or health care provider before you started participating in the Dementia Care Services project? Yes___ No___

5. Does this person you were concerned about currently take Alzheimer's or Dementia related medication(s)?

Yes___ No___

IF "NO", SKIP TO #7

6. Did they take Alzheimer's or Dementia related medication(s) before you started participating in Care Consultation? Yes___ No___

7. About how long has it been since this person you were concerned about last visited a doctor for a routine checkup?

<1 year___ 1-2 years___ 2-5 years___ 5+ years___ Never___

8. Have they visited a doctor for a routine checkup since you contacted the Alzheimer's Association?

Yes___ No___

9. During the past 6 months, did your participation in this program contribute to your decision NOT to use any of the following for this person you were concerned about?

Calling 911 Yes No If yes, what's your estimate of how many potential calls were avoided?

'Urgent care' clinic visit Yes No If yes, how many visits avoided? _____

Emergency room visit Yes No If yes, how many visits avoided? _____

Hospital stay Yes No If yes, how many stays avoided? _____

Other non-routine visit with health care provider Y N If yes, how many visits avoided? _____

10. Did your participation in the Care Consultation program change the likelihood of placing this person you were concerned about in long term care facility (for example, nursing home)? Yes ____ No ____

If "Yes", how?

SECTION 3 (FOR ALL RESPONDENTS)

1. What would you suggest to improve the Care Consultation program?

2. Finally, please share any other thoughts you have regarding your experiences with the Care Consultation program.

Thank you for your time and cooperation in completing this survey!