

alzheimer's association®

House Appropriations Subcommittee on Health and Human Services
Alzheimer's Association: MI Choice Waiver and Michigan Dementia Care and Support Program

Dear Honorable Chairwoman Whiteford and members of the Committee,

Thank you for this opportunity. My name is Jen Hunt and I am the Director of Public Policy for the Alzheimer's Association and a member of the MI Caring Majority Steering Committee. I am here today to speak in support of two programs that are of great importance to our organization: MI Choice Waiver Program and the Michigan Dementia Care and Support Program.

Home and community-based services (HCBS) occupy a growing portion of the care continuum for people living with Alzheimer's and other dementias. People with Alzheimer's live an average of four to eight years following a diagnosis, though some live up to 20 years after diagnosis. There is currently no way to prevent, slow or cure Alzheimer's disease.

Increasing access to HCBS improves the quality of life for individuals and families affected by dementia, and reduces the financial and emotional burden on families.

The primary goal of HCBS is to enable people living with dementia to stay in their homes and active in their communities for as long as possible. The progressive nature of Alzheimer's demands different types of care throughout the different stages of the disease. While nursing homes and other inpatient facilities play a vital role in the later stages, services performed in the home and community may be more appropriate for the earlier and middle stages of the disease and those with younger-onset Alzheimer's.

This is why the Alzheimer's Association is speaking in support of increasing access to the MI Choice Waiver with a 5 percent increase over FY 19 appropriations levels.

As of January 2019, there were 3,013 individuals on the waitlist for the MI Choice Waiver Program.

Though Waiver services are not limited to individuals with Alzheimer's or dementia, we at the Alzheimer's Association know MI Choice is a lifeline for families facing this disease. 190,000 Michiganders age 65 and over are currently living with Alzheimer's disease and that number is expected to increase to 220,000 by 2025.

Our 2019 Alzheimer's Facts and Figures report showed that, nationwide, an estimated 70 percent of older adults with Alzheimer's or other dementias live in the community. (*Austrom*

MG, Carvell CA, Alder CA, Gao S, Boustani M, LaMantia M. Workforce development to provide person).

Michigan spends 40 percent of its Medicaid Long Term Services and Supports (LTSS) budget on home and community-based services, far less than the national average of 57 percent.

Molly DeLuca, an Alzheimer's Association volunteer and senior living center employee from Temperance said, "Without the Medicaid Waiver, folks with dementia have no choice but to enter a nursing home when funds or caregivers become exhausted. The reality is, nursing homes are significantly more expensive for the state of Michigan than assisted living. A move for someone with dementia is often so much more than a move; a decline in condition is a common occurrence. It's critical that folks have the opportunity to place somewhere safe and supportive that they can continue the aging process. "

Second, I am asking for an investment in a dementia-specific program: The Michigan Dementia Care and Support Program, which equips family caregivers to care for individuals with dementia in the home.

Alzheimer's and other forms of dementia are devastating to families – both financially and emotionally. Dementia also complicates chronic diseases such as cardiovascular disease, diabetes and cancer.

More than twice as many caregivers of persons with dementia suffer from depression, compared with non-caregivers of similar ages. Nearly half suffer with anxiety. These individuals are also twice as likely as caregivers of people without dementia to report that completing medical/nursing tasks was difficult, saying they often lack the information and resources to manage complex medical care.

The Michigan Dementia Care and Support Program (MDCSP) is modeled after a successful program that started in North Dakota in 2010. You have more information about this program in your packet.

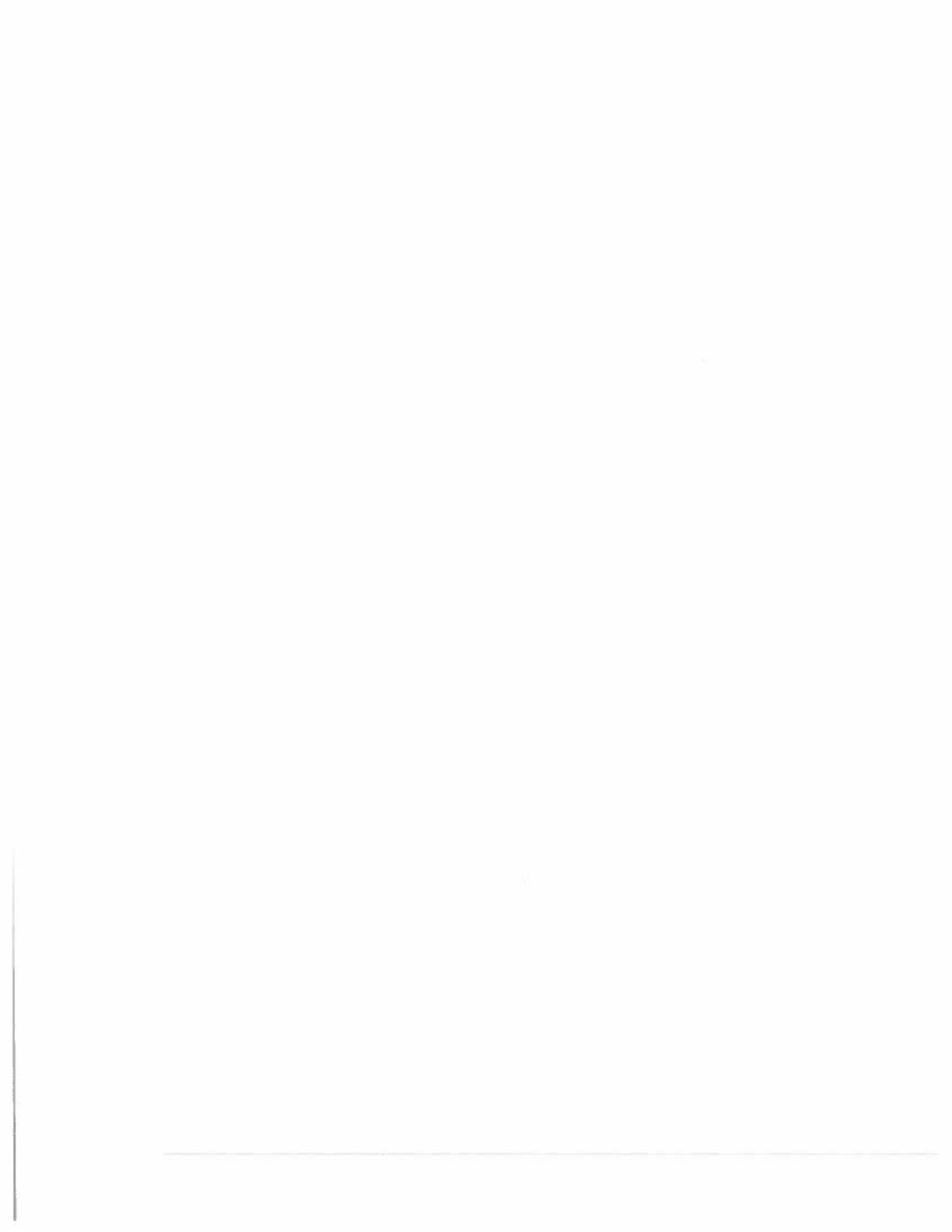
The program provides social work expertise, in-home care counseling, and person-centered planning to families affected by dementia. Additionally, the program connects people to resources in the local community. The ultimate goal of the program is to reduce/avert long term care placement.

155 families were enrolled in a small state-funded pilot from 2014-2017. The MDCSP averted 35 persons with dementia from being placed in long-term care over the course of three years. Evaluation by the University of Michigan said "the program is a cost-effective means of supporting caregivers." I've provided copies of the full program evaluation for your review.

Considering the landscape of older adults in our state and the looming crisis of caring for people with Alzheimer's and dementia, I urge you to include \$2 million in the FY 2020 budget to make this program available in all 83 Michigan counties.

I recognize you have difficult decisions to make with this year's budget, however, I am here today to ask for you to make an investment in our seniors. Both the MI Choice Waiver and the MDCSP will allow more seniors to age in a home or community setting.

Thank you, Chairwoman Whiteford and committee, for this opportunity. I would be happy to take any questions.



alzheimer's association®

MICHIGAN DEMENTIA CARE & SUPPORT PROGRAM (MDCSP)

Social work expertise is provided through in-home care counseling, person-centered planning, and supplies and resources for families affected by dementia. The goal of the program is to better serve all Michiganders facing Alzheimer's and other dementias by providing support and information for caregivers of PWD about dementia care issues. By supporting families at home, the need for skilled nursing care can be delayed and in some cases prevented.

RESULTS OF MDSCP

- ⇒11% of caregivers reported a reduction in family stress and conflict;
- ⇒38% of caregivers were more satisfied with their knowledge regarding dementia;
- ⇒47% of caregivers were more satisfied with their knowledge of providing care, particularly in helping their loved ones eat, bathe, and address incontinence;

Education and support have been shown to help reduce depression, increase family support, delay nursing home placement, and reduce redundant use of health services.

**PLEASE INCLUDE
\$2 MILLION IN THE FY 2020
BUDGET FOR THE
MICHIGAN DEMENTIA CARE &
SUPPORT PROGRAM**



SUPPORT MDSCP



“My wife Dawn didn’t become forgetful, she just stopped being who she was. I saw subtle changes when she was 34, The [MDCSP] program needs to be available to anyone that needs it - looking back, it is hard to imagine how we were able to handle each day. The turning point was reaching out to the Alzheimer’s Association. This disease will impact almost everyone at some point - be it a close relative or friend. This program is vital, it gives families hope and tools as we wait for a cure. We cannot sit back and hope that Alzheimer’s doesn’t happen - we need to prepare and do more to be ready for when it does happen to families.”

- Don Kowalski, Macomb County caregiver for his wife with early-onset dementia

**In 2018, 517,000 Michigan Caregivers Provided
589 Million Hours of Unpaid Care, Valued at \$7.44 Billion.**

THE TOLL OF CAREGIVING

Dementia is a relentless, progressive and fatal disease; it cannot be cured or even slowed. It is also a caregiver's disease - the plight of most families affected by dementia includes isolation, economic hardship and increasing physical and emotional demands.

Caring for a Person With Dementia (PWD) is a tremendous burden for the caregiver. As the dementia symptoms worsen, the care required can result in:



INCREASED STRESS AND DEPRESSION

- ◆ 59% of caregivers of PWD report the stress of caregiving is high or very high.¹
- ◆ More than twice as many caregivers of PWD (30-40%) suffer from depression, compared with 5-17% of non-caregivers of similar ages and nearly half suffer with anxiety.¹
- ◆ Caregivers of PWD are twice as likely as caregivers of people without dementia to report that completing medical/nursing related tasks (for example, injections and catheter/colostomy care) was difficult and they often lack the information and resources to manage complex medical regimens.³

- ◆ 74% of caregivers of PWD report that they are "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver.¹
- ◆ Spousal caregivers of PWD are more likely than married non-caregivers to experience changes in their health including high levels of stress hormones, impaired immune function, slow wound healing, cardiovascular disease, and increased incidence of hypertension.³
- ◆ Distress associated with caring for a PWD negatively influences the quality of caregivers' sleep, increasing the risk of anxiety, hypertension, heart disease, obesity and diabetes.³



NEW OR WORSENEED HEALTH PROBLEMS



DEPLETED INCOME AND FINANCES

- ◆ Caregivers of PWD suffer a reduction of wages as well as the loss of health insurance, retirement savings, and Social Security benefits which is extremely detrimental for the "career caregiver".²
- ◆ 18% of caregivers of PWD reduced their work hours due to caregiving responsibilities. 57% arrive at work late or leave early, 16% take a leave of absence, and 9% quit their jobs entirely in order to continue providing care.¹
- ◆ Caregivers of PWD provide 27 hours more care per month than caregivers of people without dementia (92 hours vs 65 hours) leaving less time for work. Nearly half provide 9 hours of care per day.¹

1. Alzheimer's Association. (2019). 2019 Alzheimer's Disease Facts and Figures.
2. AARP Public Policy Institute. (2008). Valuing the Invaluable: The Economic Value of Family Caregiving.
3. Alzheimer's Association. (2018). 2018 Alzheimer's Disease Facts and Figures.
4. Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and Figures.

alzheimer's association®

North Dakota Dementia Care Services Program



"My mom started showing symptoms of younger-onset Alzheimer's when she was 48 years old.

Our family didn't know what to do, so we turned to the Alzheimer's Association.



Their care consultant was my support system – she met me for coffee once a month, put me in touch with social services in town, and taught my mom's caregivers what to expect in the coming years. My mom may have lost her fight with Alzheimer's, but there are thousands more in North Dakota who need help."

-Amber Moen, resident of Devils Lake

**“Alzheimer’s is tough and it’s great to have a lifeline like this.
I now feel more enabled and supported in caring for my father.”**

-Caregiver



North Dakota Dementia Care Services Program

The Alzheimer’s Association has served North Dakota residents through the Dementia Care Services Program (DCSP) since 2010 to improve disease management and increase family support to people living with dementia and their caregivers. Services include:

Care Consultation

Individuals with memory loss, family members, or concerned professionals meet with Alzheimer’s Association care consultants to assess needs, identify issues and concerns in order to increase knowledge and decrease caregiver stress. Individuals will receive care plans and referrals to community resources and follow up, as needed. Meetings can take place via the telephone or in a preferred location of the individual’s choice.

Physician Outreach

Outreach to medical staff in clinics, hospitals and public health agencies to encourage early detection, diagnosis and referrals for family education and support that may not be possible in the time constraints of a typical clinic visit.

Education - General Public & Professional Development

Workshops are offered on dementia-related topics, such as understanding memory loss, partnering with your doctor, and understanding communication. Classes are available for the general public, professionals, care partners, medical professionals, and law enforcement.

The Alzheimer’s Association has **educated 39,449 people** across the state, to increase **awareness** of community resources, to understand the disease process, and to improve the quality of care of people living with dementia **in North Dakota.**

Services Provided Outside of the North Dakota Care Services Program



24/7 Helpline (800.272.3900)

Reliable Information that serves people with memory loss, caregivers, healthcare professionals and the public by offering referrals to local community programs and services; dementia-related education; crisis assistance; and emotional support.

MediAlert® + Alzheimer's Association Safe Return®

A 24-hour nationwide emergency response service for individuals with Alzheimer's or another dementia who wander or have a medical emergency. We provide 24-hour assistance, no matter when or where the person is reported missing.

Support Groups

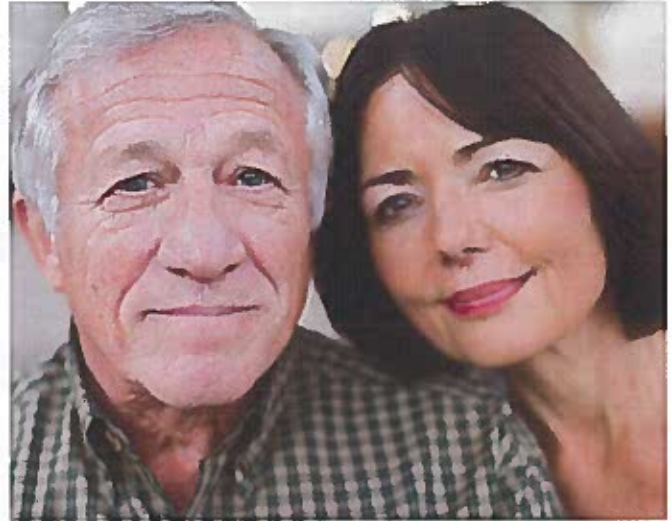
Support Groups are held in various locations throughout North Dakota and led by trained volunteer facilitators to provide support, assistance, and encouragement to individuals and their care partners impacted by dementia.



Improving disease management & increasing family support

Program Outcomes

Recent research has demonstrated that two types of programs have potential for reducing avoidable health care and premature nursing home placement, with one type of program being the caregiver supports in the DCSP, and the other focusing on the care delivery team. Studies of the effectiveness of caregiver support programs suggest that these programs have promise for reducing unnecessary emergency department visits and hospitalizations and reducing transitions to residential care for individuals with Alzheimer's disease and other dementias.



An evaluation from the Center for Rural Health at the University of North Dakota School of Medicine and Health Sciences found:



- Over a 42-month program period, the legislature appropriated an investment of \$2.2 million for the contract and has estimated results of long-term care cost saving of \$39.2 million, such as those incurred through hospital or emergency related services and delays in placing a person with dementia in long-term care facilities.
- Caregivers who were more engaged in DCSP activities had greater hospital and rural ambulance cost savings compared to caregivers who were less engaged.
- Caregivers who participated were more likely to complete important dementia care-related tasks like establishing a power of attorney and instituting health care directives.
- Caregivers who received services were twice as likely to either delay nursing home placement or decrease their likelihood of placement. The total cost avoided based on 46 people who indicated an increase in the amount of time to place a person with the disease in an institution was \$3,007,147.

alzheimer's  association®

Michigan Dementia Care and Support Program Pilot Program

Final Program Report to Stakeholders

October 31, 2017

Program Evaluation Staff

Ebony Reddock, PhD

Program Manager

Chad Jobin, LLMSW

Evaluation Associate

Bryan Frederick, MSW

Evaluation Fellow

So'Phelia Morrow, MSW candidate and MPH candidate

Evaluation Assistant

Ramona Perry, MSW/PhD candidate

Evaluation Assistant

Executive Summary

In October 2014, the Alzheimer's Association Greater Michigan and Great Lakes Chapters received state funds to implement a pilot care coordination program adapted from the North Dakota Dementia Care Service Program model. The program, entitled the Michigan Dementia Care and Support Program, launched in December 2014 in the counties of Macomb, Monroe, and St. Joseph.

At the conclusion of the MDCSP pilot, the Michigan Dementia Care and Support Program served 155 dyads comprised of individuals with mid-to-late stage Alzheimer's disease or dementia and their care partners. Program services are delivered by credentialed social workers, referred to as Care Counselors, and include in-home and phone-based consultation sessions, access to a 24/7 helpline, and referrals to support groups and other community-based services. These support services are meant to significantly delay the need for residential long-term care services for participating individuals with Alzheimer's disease or dementia and, as a result, save costs related to long term care borne by caregivers and the State of Michigan. The University Of Michigan School Of Social Work Curtis Center Program Evaluation Group was contracted to conduct an implementation and outcome evaluation of the program during its second year of operations.

Evaluation Results

Referrals to the Michigan Dementia Care and Support Program are made by Alzheimer's Association representatives and via the program's 24/7 helpline. As of September 30, 2017, 155 caregiver-person with dementia dyads have satisfied program criteria for participation and completed their initial Michigan Dementia Care and Support Program home visit. A majority (61%) of enrolled dyads reside in Macomb County. 22% of program dyads are from Monroe County and 17% reside in St. Joseph County. 66 (43%) were enrolled in 2015. Fifty-five dyads (36%) were enrolled in 2016. 34 dyads (22%) were enrolled in 2017.

Due to the rolling nature of program enrollment, 63 of the 155 dyads had completed *at least one Follow-Up Assessment* at the time of reporting. The following results represent change from Initial Assessment to Follow-Up Assessments:

Social Supports

- The majority of caregivers (59 out of 63) maintained good relationships with their PWDs from Initial to Follow-Up Assessment.
- The percentage of caregivers that perceived support from professionals increased from 62% in the Initial Assessment to 92% in the Follow-Up Assessment.

Knowledge of Dementia and Caregiving

- Seven caregivers indicated they had not taken a class on dementia at the time of the Initial Assessment but had taken a class by the time of the most recent assessment. 41 caregivers indicated on both the Initial and the most recent assessment that they had not taken a class.
- When asked about their knowledge on the topic of dementia, only 19 had indicated they had enough information at their Initial Assessment. 34 caregivers indicated on the first Follow-Up Assessment that they had enough information about the disease.

- At Initial Assessment, 13 caregivers reported having enough information on caregiving. At the time of the first Follow-Up Assessment, this number had risen to 39.
- At least half of caregivers felt confident dealing with five common issues: bathing, eating issues, recognition, sleep issues, and incontinence.
- From Initial to Follow-Up, larger increases in confidence were reported in wandering, sexually acting out, and eating issues.

Placement in Long-Term Care & Medical Service Utilization

- 87 of the 155 total dyads were discontinued from the program.
- 32% of dyads who left the program had PWDs who were able to remain at home until the caregiver had sufficient resources or the PWD was deceased.
- Increased care needs and behavioral issues were the most commonly noted reasons for placement in long-term care.
- Caregivers reported reductions in medical service utilization from baseline to first follow-up, and only minor increases in subsequent follow-up assessments.
- The majority of caregivers did not place loved ones in long term care after a year of enrollment in MDCSP. After 12 months of enrollment, there was 21% chance that a caregiver would place a loved one in long-term care.
- Comparing MDCSP placement to national figures suggests that the MDCSP averted 35 PWDs being placed in long-term care over the course of the pilot.
- Overall, the program is a cost-effective means of supporting caregivers. In averting 35 PWDs from being placed in long-term care, we found that there was an overall savings of \$2, 888, 655 to the State and a 434% return on investment.

Table of Contents

Program Evaluation Staff	2
Executive Summary.....	3
Table of Contents.....	5
Background	6
Methodology.....	9
Michigan Dementia Care and Support Program Service Population.....	10
Michigan Dementia Care and Support Program Participant Outcomes.....	13
Michigan Dementia Care and Support Program Clients and Program Discontinuation.....	18
Person with Dementia Medical Service Utilization Outcomes	20
Cost Savings Compared To Long Term Nursing Home Care	21
References	23

Background

Michigan Dementia Care and Support Program Overview

In October 2014, the Alzheimer's Association Greater Michigan and Great Lakes Chapters received state funds to implement a pilot care coordination program adapted from the North Dakota Dementia Care Service Program model. The program, called the Michigan Dementia Care and Support Program, launched in December 2014 in the counties of Macomb, Monroe, and St. Joseph. The MDCSP was designed to provide social work expertise, in-home care counseling, person-centered planning, and supplies and resources to families affected by dementia. Aside from providing support to families, the MDCSP was designed to help families care for persons with dementia (PWDs) and delay the placement of PWDs into long-term care. In 2016, the state median annual cost for long-term residential care in a semi-private room was \$91,250.

To be eligible for enrollment in Michigan Dementia Care and Support Program, participants must meet the following criteria: (1) the caregiver or person with dementia must reside in one of the three counties of operation; (2) the person with dementia must have a diagnosis of Alzheimer's Disease or related dementia; and (3) the caregiver must be facing significant challenges related to in-home care of a person in the mid-to-late stages of the disease.

Between January 2015 and September 2017, the Michigan Dementia Care and Support Program served 155 dyads comprised of individuals with mid-to-late stage Alzheimer's disease or dementia and their care partners. Program services are delivered by credentialed social workers, referred to as Care Counselors, and include in-home and phone-based consultation sessions, access to a 24/7 helpline, and referrals to support groups and other community-based services. These support services are meant to significantly delay the need for residential long-term care services for participating individuals with Alzheimer's disease or dementia and, as a result, save costs related to long-term care borne by caregivers and the state. The University Of Michigan School Of Social Work Curtis Center Program Evaluation Group was contracted to conduct an implementation and outcome evaluation of the program.

Michigan Dementia Care and Support Program: County Profiles

The Michigan Dementia Care and Support Program operated in three counties: Macomb County, Monroe County, and St. Joseph County (Table 1). Of the three counties of program operation, Macomb has the largest population at 867,730 residents-16% of whom are adults over the age of 65 years- and the highest mortality rate due to Alzheimer's disease (262.8 per 100,000)^{2,3}. Macomb also has the highest percentage of Black or African American residents compared to the other two counties, accounting for 11% of its population.

Monroe County, along with Macomb County, is designated as an urban county and covers the largest area of the three counties of operation (549.39 square miles)⁴. Among a population of 149,208 residents, 16% are adults over the age of 65 years.⁴ The mortality rate for Alzheimer’s disease in Monroe County was 38.2 per 100,000². In addition, between 2010 and 2014, Monroe had the highest median household income of all Michigan Dementia Care and Support Program counties at \$55,653.⁴

St. Joseph County had a 2016 population of 60,853 residents, 17% of whom were adults over the age of 65⁶. In St. Joseph County, the mortality rate for Alzheimer’s disease is 20.4 per 100,000^{2,3}. Among the counties participating in the Michigan Dementia Care and Support Program, St. Joseph had the highest number of Hispanic or Latino residents (7%).

Figure 1: MDCSP Participating Counties



Table 1: MDCSP County Profiles

	Macomb	Monroe	St. Joseph
<i>Total Population (2015)</i>	867,730	149,208	61,018
<i>Designation</i>	Urban	Urban	Rural
<i>Square Miles</i>	479.22	549.39	500.59
<i>Median Household Income (2015)</i>	\$54,582	\$55,653	\$44,449
<i>% of Female residents (2015)</i>	51%	51%	50%
<i>% of Male residents (2015)</i>	49%	49%	50%
<i>% of Asian residents (2015)</i>	4%	1%	1%
<i>% of Black or African American residents (2015)</i>	11%	3%	3%
<i>% of White residents (2015)</i>	82%	95%	94%
<i>% of Hispanic or Latino residents (2015)</i>	3%	4%	8%
<i>% of Older Adults (65+)</i>	16%	16%	17%
<i>Alzheimer’s disease Average Mortality Rate (per 100,000) (2011-2015)</i>	262.8	38.2	20.4
<i>Number of Michigan Dementia Care and Support Program Clients to Date</i>	79	30	22

Michigan Dementia Care and Support Program Final Report Purpose

The following report has been prepared by the Curtis Center Program Evaluation Group to provide stakeholders from the Alzheimer’s Association Michigan Chapters and the State of Michigan with data from the Michigan Dementia Care and Support Program’s three years of operation. The report focuses on data collected from the program’s Initial and Follow-Up Assessments. The data were analyzed to answer the following key evaluation questions:

1. Who was served, compared to the program’s target population?
2. Which care consultation services were provided to which client/care partner dyad?
3. To what degree have program participants attained the expected outcomes?

4. What are the circumstances that lead to placement in long-term care?
5. To what degree was the program cost-effective in delaying long-term, out of home care?

Methodology

Data Collection and Management

Prior to collecting data, the evaluation plan was submitted to the University of Michigan Institutional Review Board to ensure the protection of human subjects and approved with non-regulated status. To answer the key evaluation questions, quantitative and qualitative data were collected using the following tools from October 01, 2015 to September 30, 2017.

Michigan Dementia Care and Support Program's Initial Assessment: The Alzheimer's Association Initial Assessment form was revised for purposes of program evaluation to capture data pertinent to key evaluation questions. This form is administered to caregivers during the first in-home visit by program Care Counselors. It contains biopsychosocial information pertaining to enrolled caregivers and persons with dementia. This information includes:

Caregiver:

- Caregiving responsibilities
- Caregiving self-efficacy
- Family and social supports
- Financial information
- Medical conditions
- Mental health and substance abuse history
- Medical service utilization
- Plans for long-term care for person with dementia

Person with Dementia:

- Current living arrangements
- Dementia type and stage
- Exhibited behaviors related to Alzheimer's and/or dementia
- Family and social supports
- Level of assistance needed for activities of daily living
- Mental health and substance abuse history
- Medical conditions
- Medical service utilization

Michigan Dementia Care and Support Program Case Notes: This Alzheimer's Association form is used to collect information pertaining to Care Counselor interactions with program dyads. Care Counselors complete case notes after each formal Care Counselor interaction with program dyads. It contains designated sections for visit type and attendees (as applicable), visit narrative, and service and referral requests.

Michigan Dementia Care and Support Program Follow-Up Assessment: This Alzheimer's Association form was revised for the purposes of program evaluation. Care Counselors administer the Follow-Up Assessment at least three months after an enrolled dyad's Initial Assessment and every three months thereafter. The Follow-Up Assessment is a truncated version of the Initial Assessment, specifically focused on collecting data aligned with the key evaluation questions listed above.

Previous mid-year and year end reports utilized data from outreach activities, post-program surveys, satisfaction surveys, and data tables. This report focuses on the achievement of desired participant outcomes and utilizes assessment data only.

Data Collection Limitations

Outcome Data Sample Size

Although the program enrolled 155 dyads, 63 dyads had received at least one Follow-Up Assessment. Consequently, data included in this report pertaining to enrollee outcomes was analyzed using a relatively small sample size and accompanying results should be interpreted with caution.

Data on Long-term Care Placement

This evaluation employs a one-group evaluation design; no data were collected with a similar comparison group. Thus, results regarding the efficacy of the MDCSP are compared to results of similar studies and estimates of long-term placement nationally. Accompanying results should be interpreted in light of this.

Data Analysis

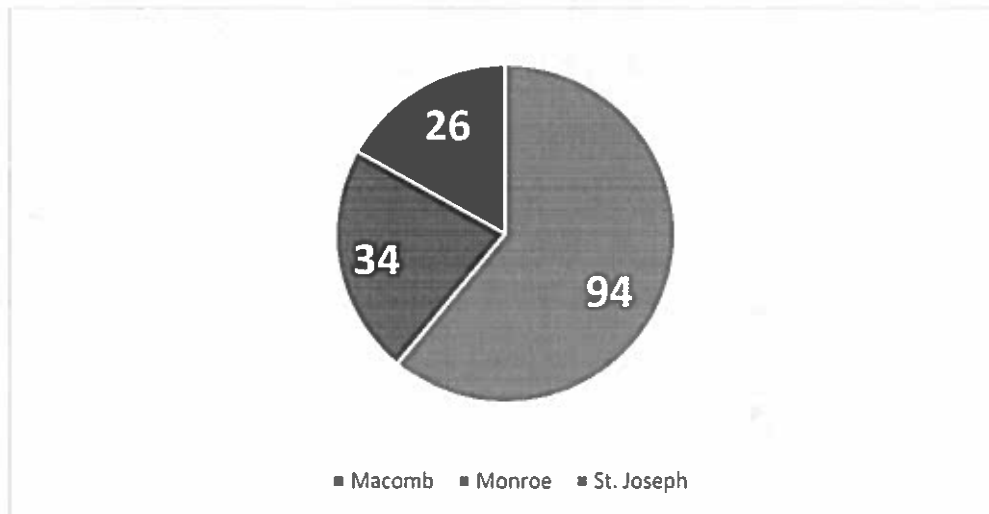
Microsoft Excel 2013 and IBM Statistical Package for the Social Sciences (SPSS; Version 24.0) was used to analyze all quantitative data. Data were analyzed to confirm statistical assumptions. Descriptive statistics, such as frequencies, were utilized to summarize program participation and participant responses to assessment questions asked at one time point. For data collected at two or more points in time, bivariate and multivariate statistical tests were conducted to identify statistically significant changes in participant responses between pre- and post-program, as well as statistically significant differences in participant outcomes. Valid percents were used for all averages and all percentages were rounded to the nearest whole number. To identify the extent of delay in long-term care placement, a Kaplan-Meier survival analysis was conducted. To identify cost-savings associated with the MDCSP, a cost-effectiveness analysis was conducted.

Michigan Dementia Care and Support Program Service Population

To acquire a better understanding of the Michigan Dementia Care and Support Program's population since the Program's inception, the evaluation team examined a variety of demographic data pertaining to program persons with dementia. The following demographic information represents 155 dyads for which demographic information was submitted.

155 caregiver-person with dementia (PWD) dyads satisfied program criteria and completed their Michigan Dementia Care and Support Program home visit and Initial Assessment.¹

Figure 2: Program Enrollment



Year of Enrollment: Out of 155 dyads, 66 (43%) were enrolled in 2015. Fifty-five dyads (36%) were enrolled in 2016. 34 dyads (22%) were enrolled in 2017.

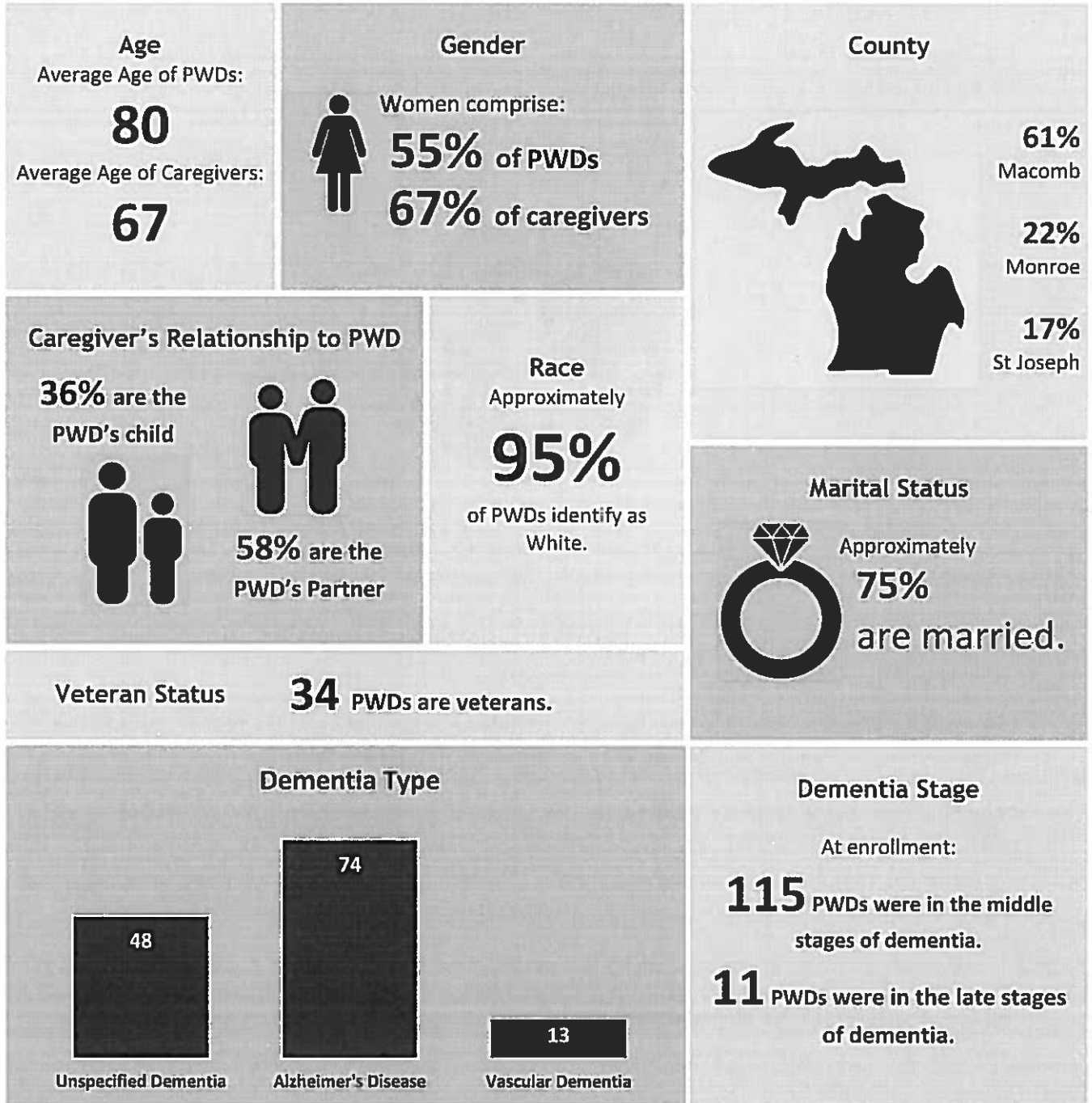
County of Residence: Ninety-four dyads (61%) resided in Macomb County. Thirty-four dyads (22%) resided in Monroe County, and 26 dyads (15%) resided in St. Joseph County.

Dementia Type: Eight dementia-related categories of illness were represented among enrolled persons with dementia: Alzheimer's disease (74, 48%), Unspecified Dementia (48, 31%), Vascular Dementia (13, 8%), Frontotemporal Dementia (5, 3%), Mixed Dementia (7, 3%), Mild Cognitive Impairment (2, 1%), Parkinson's disease (1, <1%), and Other (2, 2%). 5 persons (3%) did not have data on type.

Dementia Stage: One-hundred and fifteen (74%) enrolled persons with dementia were in the middle stage of dementia. 11 (7%) individuals were in the late stage of dementia. The stage of dementia was unknown for 21 (14%); eight early stage enrolled persons with dementia comprised 5%.

¹ One of the 155 dyads enrolled in the Michigan Dementia Care and Support Program has moved into Wayne County, where they are receiving comparable services from the Alzheimer's Association.

Figure 3: Program Demographics



Michigan Dementia Care and Support Program Participant Outcomes

Determining the extent to which Michigan Dementia Care and Support Program participants attained the expected outcomes was another facet of the evaluation. The specific outcome domains examined are as follows:

- Persons with dementia and caregivers access to social supports.
- Caregivers' understanding of the progression and impact of the disease.
- Caregivers' utilization of long-term care for their person with dementia.
- Person with dementia medical service utilization in the areas of 9-1-1 calls, ambulance use, emergency room visits, and in-patient hospitalizations.

The following sections present the Evaluation Team's findings in each of the abovementioned outcome domains.

While 155 dyads were enrolled in the MDCSP, 63 of these dyads had completed at least one Follow-Up Assessment, thereby allowing for the analysis of program-related outcomes.

Program Participation

The Michigan Dementia Care and Support Program is designed to provide supportive services to families affected by dementia. As of September 30, 2017, 155 dyads received an initial assessment. Out of those, 63 completed up to one follow-up assessment, 37 completed up to two follow-up assessments, 15 completed up to three follow-up assessments, and 8 completed up to 4 follow-up assessments.

On average, dyads were enrolled for 9 months. Time of enrollment ranges from 1 week to 32 months.

Caregiver and Person with Dementia Social Supports

The Michigan Dementia Care and Support Program strives to enhance access to social supports for enrolled dyads. Care Counselors work toward this goal by deploying strategies such as brainstorming with caregivers, walking them through their support networks, and helping them to understand that it is okay to ask for help.

Dyad access to social supports was tracked via three questions included on the program's Initial Assessment and Follow-Up Assessments. Caregivers were asked to assess whether they were on "good terms" with their family member living with dementia: "Is the caregiver on good terms with the person with dementia?" Sixty-three caregivers responded to this question. Sixty-one reported no change in their response from Initial to the first Follow-Up Assessment. The vast majority, 59 caregivers, maintained good terms with their loved one. Two caregivers indicated they were initially not on good terms with their loved one, but were on good terms at the time of the first follow-up assessment.

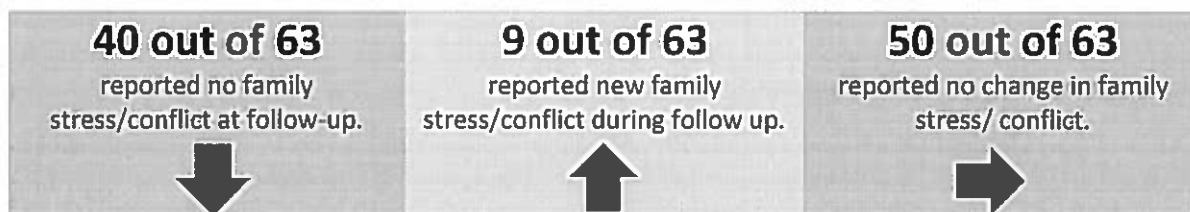
Figure 4: Care Dyad Relationship



Caregivers were also asked if they feel sufficiently supported by professionals during their Initial and Follow-Up Assessments (“Do you feel you have the support you need from professionals/community?”). In the sample of 39 dyads that responded to this question for both Initial and Follow-Up Assessments, a greater percentage responded affirmatively in the Follow-Up Assessment (92%) than in the Initial Assessment (62%), suggesting that some caregivers perceived more support from professionals after enrolling in MDCSP.

Caregivers were also asked if there were stresses or conflict between family members. Analysis suggested that most caregivers’ reports of family stress/conflict did not change. For example, comparing responses in the Initial and first Follow-Up Assessment, 36 caregivers reported no family stress or conflict both times, whereas 14 reported family stress or conflict both times. While nine caregivers reported emerging family stress or conflict in their Follow-Up Assessment, 4 reported that family stress or conflict was no longer present at the time of the first Follow-Up Assessment.

Figure 5: Care Dyad Family Stress/Conflict



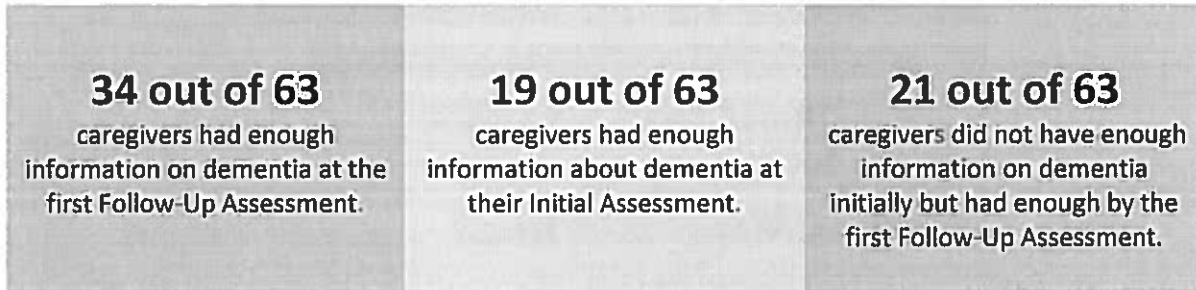
Caregiver Knowledge of Dementia and Caregiving

Another desired outcome of the Michigan Dementia Care and Support Program was improving enrolled caregivers’ “understanding of the progression and impact of the disease.” Caregivers were asked if they had previously taken an educational class on the topic of dementia. Out of 63 dyads completing two assessments, 41 caregivers indicated on both the Initial and the most recent assessment that they had not taken a class. Seven caregivers indicated they had not taken a class at the time of the Initial Assessment but had taken a class by the time of the most recent assessment.

When asked about their knowledge on the topic of dementia, 34 caregivers indicated on the first Follow-Up Assessment that they had enough information about the disease; only 19 had indicated they had enough information at their Initial Assessment. Twenty-one out of 63 caregivers (33%)

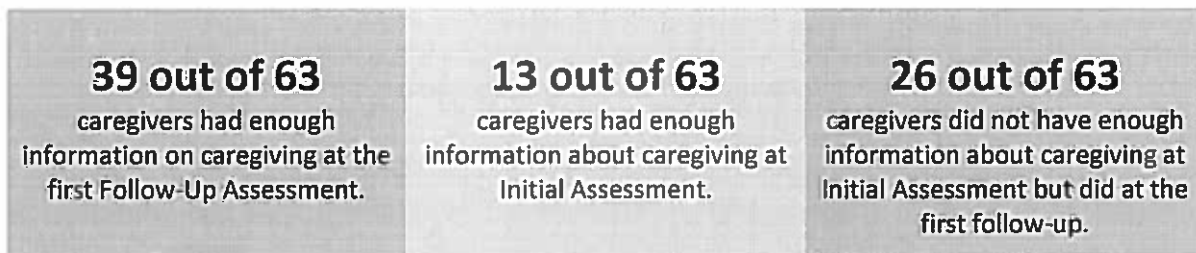
indicated they did not have enough information at the time of Initial Assessment, but did have enough about the disease at the time of the first follow-up.

Figure 6: Caregiver Understanding of Dementia



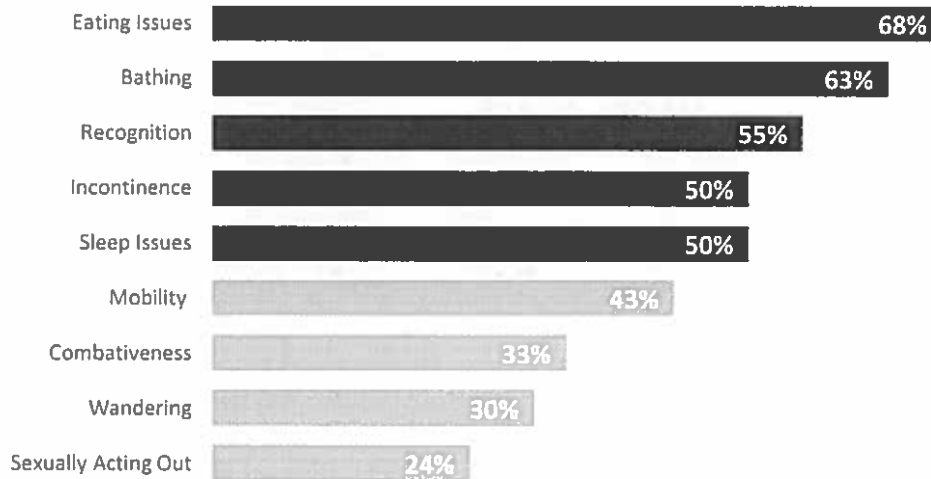
Caregivers were also asked to assess their knowledge of caregiving. Thirty-nine caregivers had enough information on caregiving at the time of the first Follow-Up Assessment; of those, 13 had enough information on caregiving at the time of the Initial Assessment. Twenty-six caregivers indicated they did not have enough information at the time of Initial Assessment, but did have enough information about caregiving at the time of follow-up.

Figure 7: Caregiver Understanding of Caregiving



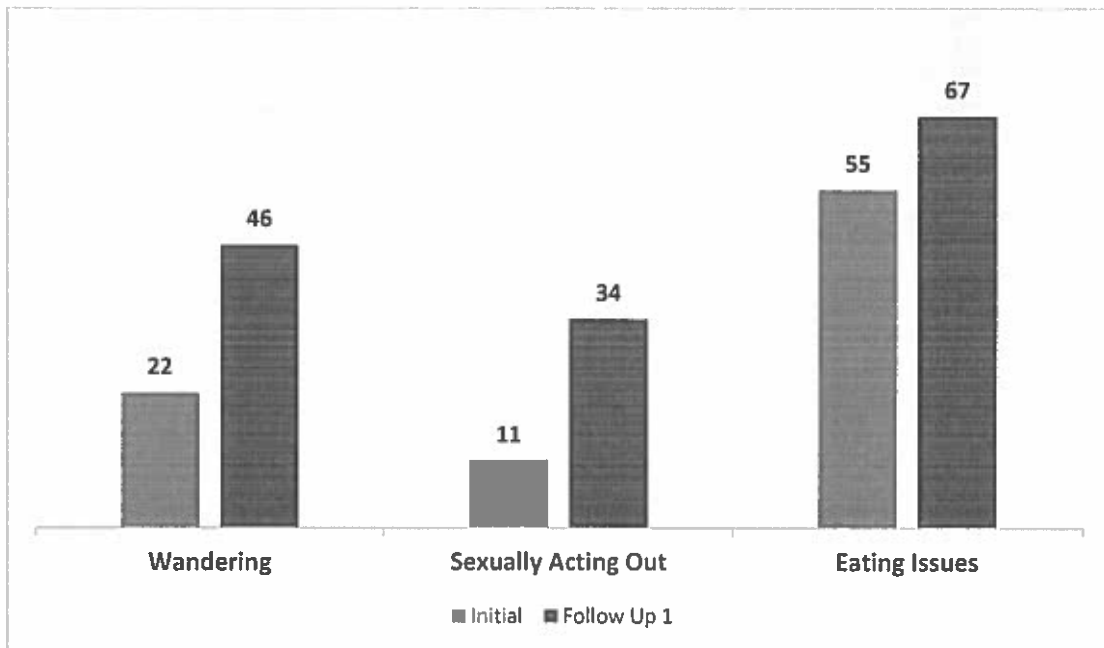
Along with knowledge of caregiving, the assessment also measured caregiver confidence in dealing with nine common issues.

Figure 8: Percentages of Caregivers Who Felt *Confident* or *Very Confident* in Their Caregiving Responsibilities at Initial Assessment



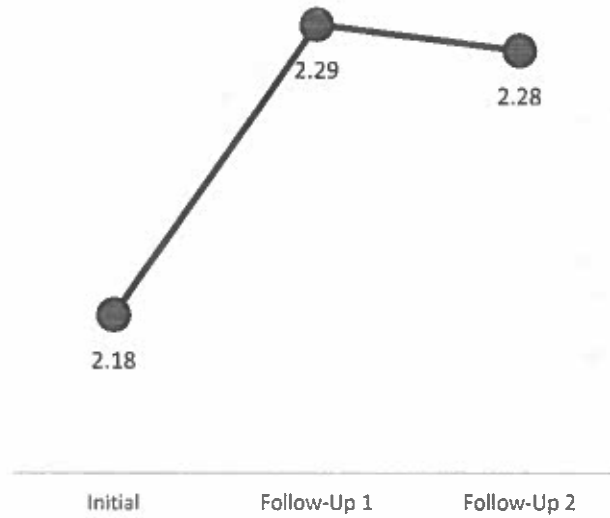
63 caregivers responded to confidence questions in both the Initial and first Follow-Up Assessments. Increases in confidence were observed in 7 of 9 responsibilities. The largest increases in confidence were reported in wandering (22% to 46%), sexually acting out (11% to 34%), and eating issues (55% to 67%).

Figure 9: Largest Increases in Confidence in Caregiving Responsibilities



On average, caregivers reported increasing confidence in caregiving responsibilities from Initial to second Follow-Up Assessment.

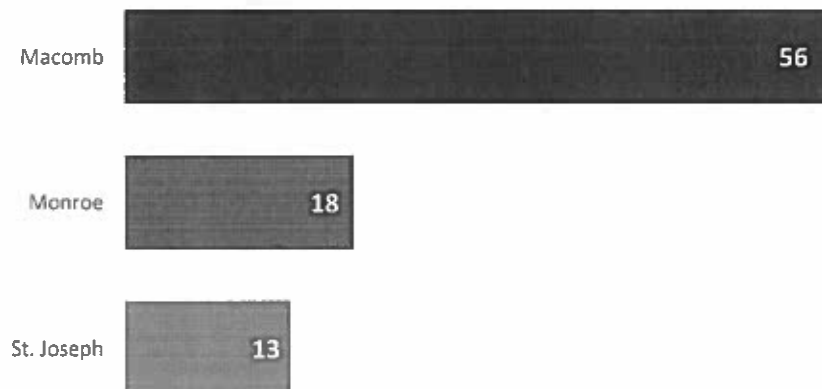
Figure 10: Average Level of *Confidence* in Caregiving Responsibilities



Michigan Dementia Care and Support Program Clients and Program Discontinuation

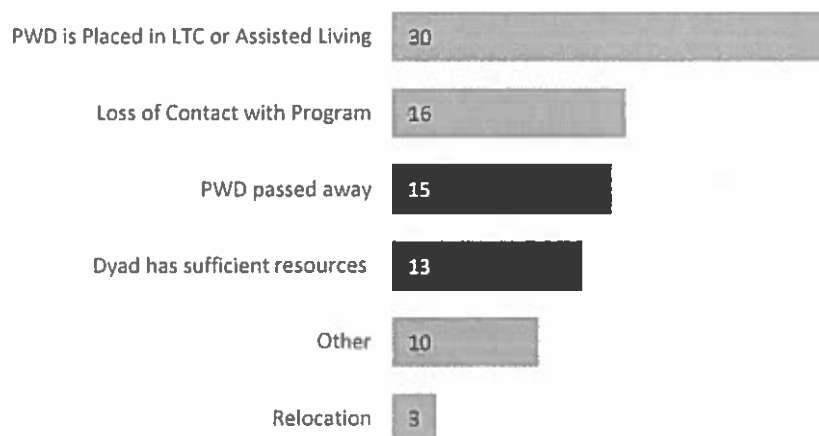
Of the 155 total dyads in the Michigan Dementia Care and Support Program, 87 discontinued the program. Upon enrollment in the MDCSP, 56 care dyads lived in Macomb, 18 dyads lived in Monroe and 13 dyads lived in St. Joseph.

Figure 11: Number of Disenrolled Dyads by County



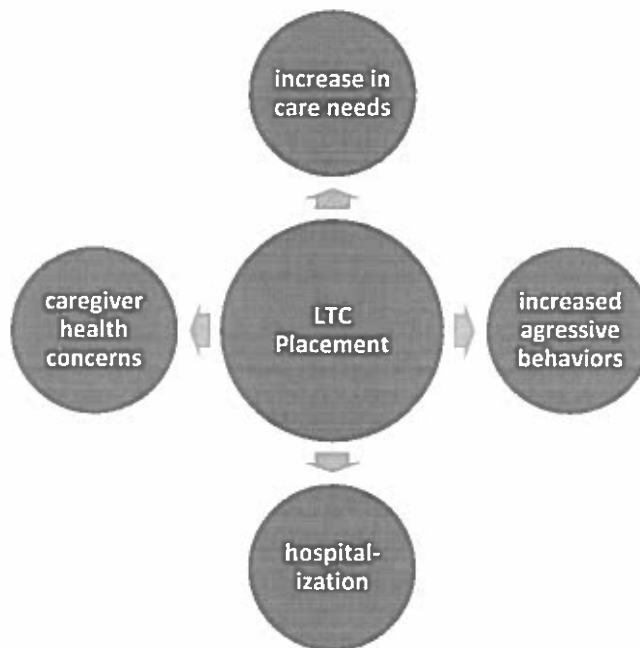
As seen in Figure 12, dyads had a variety of reasons for discontinuing use of the program. The most common reason (30) given for leaving the program was the person with dementia's placement in an assisted living facility or long-term care. However, out of the 87 disenrolled dyads, 32% (28 caregivers) reported that their PWDs were able to remain at home, leaving the MDCSP when the dyad had sufficient resources (13) or the PWD was deceased (15). Other reasons for leaving the program included: loss of contact with the program (16) and relocation (3).

Figure 12: Disenrolled Dyads by Reason



As noted in Figure 13, out of those who placed persons with dementia in long-term care, caregivers reported a variety of circumstances leading to placement. Caregivers often indicated that more than one circumstance influenced their decision to place their loved one. The most common reason for placement mentioned in the case notes was an increase in care needs such as “incontinence” and “declining health.” Other reasons for placement included: increased behaviors for instance, “uncontrollable behaviors” and “violent and aggressive behaviors”; and hospitalization/injury for example “hospitalization due to bacterial infection.” Caregiver health concerns were also mentioned as a reason for placement; however, this was described as secondary to the other reasons.

Figure 13: Reasons for Long Term Care Placement



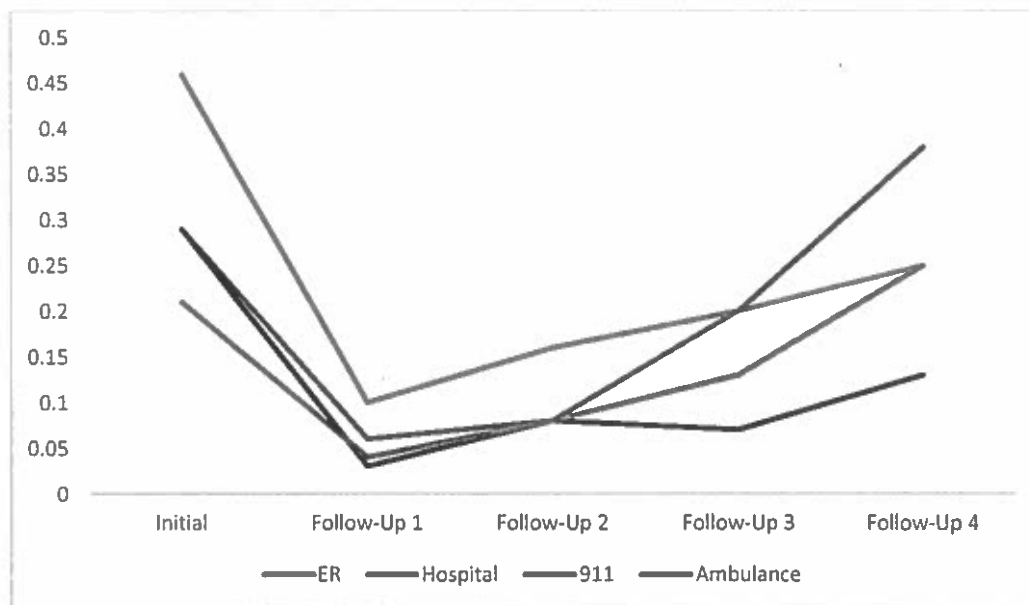
Person with Dementia Medical Service Utilization Outcomes

Reduction in medical service utilization illustrates one area in which the Michigan Dementia Care and Support Program contributes to cost savings for persons with dementia, caregivers and the state. In comparison to their utilization prior to entering the program, caregivers in the Michigan Dementia Care and Support Program reported using little to no services after participating.

Medical service utilization was tracked via four questions included on the Michigan Dementia Care and Support Program's Initial Assessment and Follow-Up Assessments. The first of the aforementioned questions asked: "In the last three months, how many times has the person with dementia gone to the emergency room?" Program dyads were also asked: "In the last three months, how many times has the person with dementia been hospitalized?" The Initial and Follow-Up Assessments also asked program dyads: "In the last three months, how many times has the person with dementia called 9-1-1?" Finally, program dyads were asked: "In the past three months, how many times has the person with dementia used an ambulance?"

On average, caregivers reported an initial decline in medical service utilization from Initial to the first Follow-Up Assessment. For example, the average number of times caregivers used ER services in one month at Initial Assessment was 0.46. By the first Follow-Up, 61 out of the 63 reported no use of ER services. Usage began to rise gradually by the time of the second and third Follow-Up Assessments which corresponds with PWDs' worsening conditions. All differences in usage were statistically significant at the 0.05 level.

Figure 14: Average Medical Service Utilization Across Follow-Ups



Long-Term Care

The Evaluation Team also examined the pattern of caregiver placement of persons with dementia in long-term care. Overall, most caregivers had not placed a loved one in long-term care after one year in the program. The shortest time to placement was 1 week after starting the program. The longest time to placement was approximately 22 months after starting the program.

Among all MDCSP caregivers, there was a 13% chance that, after six months in the program, any given caregiver would place a loved one in long term care versus leaving for other reasons or remaining in the program. After 12 months, there was a 21% chance that any given caregiver would place a loved one in long term care versus leaving for other reasons or remaining in the program. In other words, if 100 caregivers enroll in the program, by six months, 13 would have placed loved ones in long-term care and by one year, 21 would have placed loved ones in long-term care.

Cost Savings Compared To Long Term Nursing Home Care

The Evaluation Team also conducted tests to understand more about the cost savings of the MDCSP. The Evaluation Team conducted both a cost-benefit analysis and cost-effectiveness analysis.

Cost Benefit

The MDCSP costs \$209, 379 to operate for one year (MDCSP communication, 2016). The estimated cost of the pilot from January 2015 to September 2017 was \$540, 896. Since the onset of the program, 1431 service months were provided to caregivers by MDCSP staff. On average, dyads spent a total of 9.4 months enrolled in the program, costing an average of \$3553 per dyad. One potential additional cost is that of home- and community-based services (HCBS); the median cost is \$31, 590 a year in Michigan.⁷ Currently, the majority of PWDs receive very little in Medicaid or Medicare reimbursement for these costs; *therefore, these costs are not included in the cost-effectiveness analysis.* However, if the state were to bear both these costs, the cost for MDCSP and HCBS would be \$35, 143 per year. In contrast, the median cost of nursing home care in a private room costs \$98, 185 per year; the majority of patients in nursing home care stays are funded by governmental sources such as Medicaid and state matching programs.⁷

Cost Effectiveness

The Evaluation Team also conducted a cost-effectiveness analysis. Based on our analysis, the probability that an MDCSP participant placed a PWD in long-term care is 0.193 (e.g. 19.3% of participants have placed). The Alzheimer's Association found that only 58% of PWDs nationally lived in community settings. We used the figure of 0.42, or 42%, to estimate the percentage of persons with dementia that are in some form of long-term care.⁸ According to these figures, if the same 155 dyads had not been enrolled in the MDCSP, 65 PWDs would have placed in long term care, compared to the 30 placements reported by MDCSP participants. We estimated, based on this, that the MDCSP averted 35 people being placed in long term care.

The Evaluation Team calculated the cost savings of the MDCSP by comparing its cost per person to that of a private room in a nursing home. We chose program costs and nursing room costs in order to compare costs that would be typically be borne by the state. The Evaluation Team found that for every case of long-term placement averted, there would be a cost savings of \$82, 533. Given that we estimate the MDCSP averted 35 cases of PWDs placed into long term care over the course of the pilot, this amounts to an overall savings of \$2, 888, 655 and a return on investment of 434%.

References

1. Alzheimer's Association. (2016). *2016 Alzheimer's Disease Facts and Figures*. Retrieved from http://www.alz.org/documents_custom/2016-facts-and-figures.pdf
2. Michigan Department of Health and Human Services. 2017. *Alzheimer's Disease Deaths and Death Rates*. April 2017. <https://www.mdch.state.mi.us/pha/osr/CHI/CRI/frame.asp>.
3. Michigan Department of Community Health Data (2015 January 14). County and State Health Statistic Profiles, State of Michigan. Retrieved May 2016 http://www.michigan.gov/mdch/0,4612,7-132-2944_4669--00.html
4. United States Census Bureau (2016 May). State and County Quickfacts: Macomb County, M.I. Retrieved May 2017 <http://quickfacts.census.gov/qfd/states/26/26099.html>
5. United States Census Bureau (2016 May). State and County Quickfacts: Monroe County, M.I. Retrieved May 2017 <http://quickfacts.census.gov/qfd/states/26/26099.html>
6. United States Census Bureau (2016 May). State and County Quickfacts: St. Joseph County, M.I. Retrieved May 2017 <http://quickfacts.census.gov/qfd/states/26/26149.html>
7. AARP. (2017). Picking Up The Pace of Change: A state scorecard on long-term services and supports for older adults, people with physical disabilities, and family caregivers. <http://www.longtermscorecard.org/~media/Microsite/Files/2017/Web%20Version%20LongTerm%20Services%20and%20Supports%20State%20Scorecard%202017.pdf>
8. Alzheimer's Association (2016). 2016 Alzheimer's Disease Facts and Figures. https://www.alz.org/documents_custom/2016-facts-and-figures.pdf



NUMBER OF DEATHS FROM ALZHEIMER'S DISEASE (2017)

4,428

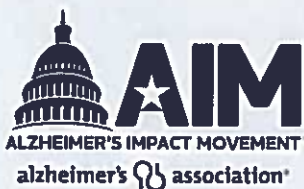
169% increase in Alzheimer's deaths since 2000

65+ NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S BY AGE*

** Totals may not add due to rounding*

Year	65-74	75-84	85+	TOTAL
2019	29,000	80,000	79,000	190,000
2025	34,000	100,000	85,000	220,000

Estimated percentage change



For more information, view the 2019 *Alzheimer's Disease Facts and Figures* report at alz.org/facts.

HOSPICE (2016)

8,626

of people in hospice with a primary diagnosis of dementia

16%

of people in hospice have a primary diagnosis of dementia

HOSPITALS (2015)

1,598

of emergency department visits per 1,000 people with dementia

23.4%

dementia patient hospital readmission rate

MEDICARE

\$27,244

per capita Medicare spending on people with dementia (in 2018 dollars)

MEDICAID

\$1.422 BILLION

Medicaid costs of caring for people with Alzheimer's (2019)

↑ 20.9%
change in costs from 2019 to 2025

CAREGIVING (2018)

517,000
Number of Caregivers

589,000,000
Total Hours of Unpaid Care

\$7,444,000,000
Total Value of Unpaid Care

\$376,000,000
Higher Health Costs of Caregivers

US STATISTICS

Over **5 million** Americans are living with Alzheimer's, and nearly **14 million** will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$290 billion** in 2018, increasing to **\$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three** seniors who dies each year has Alzheimer's or another dementia.