

Michigan Dementia Plan Update

2009 through 2011



January 2009



STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH
LANSING

JENNIFER M. GRANHOLM
GOVERNOR

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January 21, 2009

Dear Fellow Michigan Citizens and Leaders:

I am delighted to share the 2008 Michigan Dementia Plan Update, which will assist the state in best meeting the needs of persons with dementia and their families and other caregivers. This plan builds upon the success of the 2003 Michigan Dementia Plan that was used to strategically address key needs of Michigan citizens. That plan and the culture of cooperation and collaboration by Michigan Dementia Coalition partners were key in attracting funding from the Health Resources and Services Administration, the Administration on Aging, the Centers for Disease Control and Prevention, and the private sector to increase our capacity to serve Michigan individuals and families coping with dementia.

This updated plan for 2009 through 2011 reflects the long-term commitment of Michigan to its citizens with Alzheimer's disease and other dementias. In 1987 Michigan recognized Alzheimer's disease and dementia as an emerging public health concern and stepped up to the challenge of addressing this issue. Since then, it has built and maintained a multi-disciplinary network of public, private, nonprofit, community, and academic partners to lead the state in addressing Alzheimer's and dementia issues.

This must continue to be a public health priority. Findings from Michigan's 2005 Behavioral Risk Factor Surveillance Survey suggest more than one-quarter of Michigan households have at least one person with memory or cognitive problems. We now estimate that Alzheimer's disease and other dementias affect 230,000 individuals in Michigan, and this number will rise in coming years. A person with Alzheimer's disease may require assistance and care for as long as 20 years, and the toll on caregivers is beyond calculation. Many of us will participate in caring for someone with dementia and will know first-hand how difficult and demanding this experience can be.

The Michigan Department of Community Health continues to support efforts to improve the quality of life of individuals in our state who are afflicted with Alzheimer's and related disorders, and the quality of life of those who support them. I urge Michigan citizens and leaders to join me in support for this strategic plan and the priorities outlined.

Together we can make a difference in the lives of our fellow citizens with dementia and the many families and others who care for them.

Sincerely,

A handwritten signature in cursive script that reads "Janet Olszewski".

Janet Olszewski
Director

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2009-2011 Priority Goals

- 1. Increase support for family members who provide care for persons with dementia at home.**
- 2. Promote best practices in dementia detection, assessment and care management in primary care.**
- 3. Advocate for dementia-friendly policies and promote the highest quality dementia care standards in Michigan long-term care systems reform efforts.**
- 4. Increase early intervention and support for persons with dementia and their caregivers by promoting public awareness of the caregiver role and the early warning signs of dementia.**

Introduction

The Michigan Dementia Coalition serves a vital role as the coordinating body for the group of professionals and organizations addressing dementia in Michigan. Comprised of consumer representatives, community groups, university partners, and government, the Coalition implements selected priority initiatives to reduce the burden of dementia in Michigan. The Michigan Dementia Coalition is guided by a Leadership Team (see Appendix A) and support staff from the Michigan Department of Community Health, Public Health Administration. The Coalition and its various workgroups have for the past five years pursued the priority goals identified in the **2003 Michigan Dementia Plan** (see www.dementiacoalition.org for a copy).

The Michigan Dementia Coalition developed the 2003 plan to guide its work through 2008. The 2003 plan identified priorities based on input from participants in community forums in Lansing, Marquette and Gaylord. Individuals with dementia, caregivers, and an array of professionals provided testimony for the 2003 plan. To update the plan to serve the Coalition for the next three years (2009 through 2011), the Coalition reviewed progress made toward the goals set in 2003 and carefully considered the current, most pressing needs, Coalition assets, and the potential of various strategies for continued progress.

Since 2003, while the prevalence of Alzheimer's has continued to increase in the state, the Michigan economy has struggled. Resources to address the burden of dementia have remained essentially the same. In this challenging environment, the 2003 Michigan Dementia Plan served the Coalition well, providing it with the clear focus needed to maximize use of scarce resources and create an effective collaboration. To pursue the priority goals, the Coalition:

- Convened a joint Dementia Coalition and Office of Services to the Aging Task Force to improve dementia respite services throughout the state,
- Established a Caregiver Support Workgroup to continue the caregiver support initiative,
- Established a Michigan Dementia Coalition website,¹
- Established a workgroup to increase the dementia competency of direct care workers,
- Obtained statewide survey data on the prevalence of memory loss, the prevalence of assessment, and the awareness of community memory loss and dementia resources, and
- Established a public awareness workgroup and launched a public awareness campaign, WorriedAboutMemoryLoss.

¹ Novartis Pharmaceuticals Corporation sponsored the website with an unrestricted grant in 2008 and has continued sponsorship for 2009.

The 2003 Plan identified five priorities. While these remain high priorities, the Coalition has determined that dementia competency of health care professionals will be incorporated with the other priority goals in this plan update. For 2009 through 2011, four workgroups will continue to lead the Coalition in pursuing four priority goals:

- 1. Increase support for family members who provide care for persons with dementia at home.**
- 2. Promote best practices in dementia detection, assessment and care management in primary care.**
- 3. Advocate for dementia-friendly policies and promote the highest quality dementia care standards in Michigan long-term care systems reform efforts.**
- 4. Increase early intervention and support for persons with dementia and their caregivers by promoting public awareness of the caregiver role and the early warning signs of dementia.**

This plan update identifies new objectives for each priority area. Objectives were carefully developed by workgroup members with input from colleagues and other Coalition participants to take advantage of existing resources and opportunities. In addition, possible Progress Indicators and Capacity Building Ideas have been identified for each priority area.

Progress Since 2003

The **2003 Michigan Dementia Plan** identified five priority goals for the Michigan Dementia Coalition to pursue in its efforts to reduce the burden of dementia in the state. The Coalition has made significant progress in each of the five priority areas. In addition, the Coalition developed a cognitive/memory component to be included in a statewide population-based survey (see Appendix B). Although not identified as a priority goal in the 2003 plan, the Cognitive/Memory Survey was an important tool for gathering information relevant to Coalition initiatives. The Coalition plan for 2009 through 2011 includes continuation of the Cognitive/Memory Survey in the Behavioral Risk Factor Surveillance System (BRFSS) survey conducted annually by the Michigan Department of Community Health.

Caregiver Support

The first goal of the 2003 Michigan Dementia Plan was to ***Increase support for family members who provide care for persons with dementia at home.*** Caregivers for persons with dementia are more likely to experience depression, burden, and anxiety than non-caregivers, as well as lower levels of physical health. Providing effective supports and services to family caregivers enhances care for the recipient and extends the capability of caregiving, thus delaying institutionalization.

As its first step toward this goal, in 2004 the Coalition convened a joint task force with the Office of Services to the Aging (OSA), including members of the aging services system. The task force looked at the number and geographic distribution of adult day care programs and then compiled and disseminated a statewide list of respite programs.

The task force also surveyed the state Area Agencies on Aging (AAAs) to determine the extent to which respite services were “dementia-friendly,” provided input in the revision of OSA respite service standards, and created and posted online a respite care fact sheet. To help identify innovative dementia respite services, the task force developed a statewide Best Practices Award for dementia day services (see Appendix C). The selected programs gave panel presentations at two statewide conferences.

The task force recommended continuing the best practices respite award, encouraging use of caregiver assessment tools, promoting dementia training to service providers, and increasing awareness of respite resources.

In 2006 the Coalition established a Caregiver Support Workgroup to continue work toward the caregiver support goal. In 2007, the workgroup replicated the 2004 Exemplary Respite Program nomination and award process, including both in-home

and adult day programs. It found that a growing number of organizations are adopting activities -- such as reminiscence and the arts -- that engage the person with dementia. Many facilities are providing dementia care training for their staff. The exemplary programs helped disseminate best practices through presentations at conferences and professional meetings. The workgroup plans to continue the nomination program with awards every three years.

The workgroup has continued updating annually the Adult Day Programs Directory with input from Coalition member agencies and networks.

To increase knowledge of effective caregiver interventions, a subcommittee of the workgroup prepared a synopsis of effective caregiver intervention literature. The Effective Caregiver Interventions summary has been disseminated and posted on the Coalition website.

Primary Care Initiative

The Coalition's second goal was to ***Promote a public health, disease management approach to dementia care in primary care practice that makes full use of best dementia care practices.*** Before 2003, a Coalition workgroup had launched a primary care initiative that led to the development of a network of nearly 35 primary care physicians with a special interest in dementia. Once the 2003 plan was developed, the network chair secured Health Resource Services Administration grant funds to support the initiative.

Together the Coalition and Primary Care Dementia Network (PCDN) sought to:

- Create educational modules that Primary Care Physicians could use and
- Create a method of face-to-face instruction and interaction with Primary Care Physicians.

Five educational modules were created and posted on the Coalition website, www.dementiacoalition.org (see Appendix D). These cover:

- Dementia in Primary Care
- Community Resources
- Clinical Diagnosis of Dementia
- Pharmacologic Treatment of Alzheimer's Disease
- Reimbursement for Dementia Care

For face-to-face instruction and interaction with physicians, the Coalition and PCDN adapted the academic detailing model. A physician from the PCDN, accompanied by a representative from an Alzheimer's Association chapter and a representative from the local Area Agency on Aging comprised the teaching group. These teams

visited practices for a brief visit and encouraged early detection, evaluation, and use of community resources for support of patients and their families.

Between 2005-2008, 15 physicians conducted 29 visits with 104 physician participants in 17 communities across the state. Post-visit interviews with attendees indicated these visits were effective in increasing physician and staff knowledge of the community resources available for patients with dementia and their caregivers. Immediate and three-month follow-up interviews indicated a high level of satisfaction with the detailing session, and increased use (though still lower than optimal) of community-based services.

The PCDN will concentrate on providing dementia expertise to a community-based inter-disciplinary geriatric education project in eight communities in the state. PCDN physicians and coalition member agencies will partner in outreach and education with primary care providers in these communities. In addition, the PCDN has become a core planning committee for an annual interdisciplinary continuing education conference on Alzheimer's disease and related disorders.

Health Professionals and Dementia

One of the five priorities in the 2003 Michigan Dementia Plan was to ***Increase the dementia competency of health care professionals***. When the CEO of a home health agency asked for input in designing dementia certification for home health aides, several Coalition members participated in a series of discussions. A general consensus emerged that:

- All direct care workers need dementia competency,
- Long-term care systems pose significant barriers (such as low pay, high staff turnover, and long-term care cultural issues),
- A certification program would be beyond the capacity or role of the Dementia Coalition or workgroup to maintain,
- Various high-quality dementia curricula and training programs exist but may not be well known, and
- Providing direct care workers with tools to increase their dementia competency could be the best strategy for increasing dementia competency of direct care workers.

The Coalition adopted the workgroup, which proceeded with three objectives: Increase awareness of dementia education and training available throughout the state by disseminating a state Dementia Education and Training Directory; identify dementia competencies needed by direct care workers and disseminate the information; and develop a dementia competencies self-assessment tool for direct care workers.

The workgroup developed the Michigan Dementia Education and Training Directory guide and posted it online (www.dementiacoalition.org) in 2005. Since then it has been updated annually and is now searchable by county.

The first edition of ***Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers*** (see Appendix E) was completed in 2007, widely disseminated throughout Michigan and via the Internet, and can be downloaded from the Coalition website. When the original guide was completed, a subgroup began working on a lower-literacy version. This “everyday language” version, completed in 2008, is also available from the website, and is now being widely disseminated in Michigan.

The Michigan Quality Community Care Council, a Dementia Coalition participating agency that registers direct care workers in Michigan’s Home Help Program, distributed guides to 1,855 direct care workers in 321 orientation sessions in 74 counties. Altogether, 5,000 printed copies of the guides have been distributed and the guide has been accessed online more than 30,000 times in 2008.

A neuro-psychologist developed the dementia competencies self-assessment tool for direct care workers over three years with support from the Michigan Alzheimer’s Disease Demonstration Grant to States (Administration on Aging grant). This included pilot testing with 159 direct care workers from 10 different long-term care provider agencies (including nursing home, assisted living, and home health care) across the state. Publication of the psychometric testing of the instrument and release of the tool are expected soon.

Residence Choices for Persons with Dementia

The 2003 Michigan Dementia Plan included a priority goal to ***Improve the choices for residence and care of persons with dementia***. From 2004 through the present, the Coalition has supported advocacy efforts to increase the number of long-term care Medicaid waiver slots in the state. The long-term care Medicaid waiver slots give Medicaid-eligible, nursing home-eligible individuals increased options for long-term care. The number of slots increased from 9,242 for 2004 to 9,758 for 2009.

Over the past five years, designated Michigan Dementia Coalition representatives served on the Michigan Long-Term Care Commission and its work groups. Coalition representatives spoke at Long-Term Care Commission hearings, increasing awareness and understanding of the unique long-term care needs of individuals with dementia. The Coalition supported long-term care systems reform grant applications of the Michigan Department of Community Health and participated on workgroups and advisory groups of various grant projects.

In 2008, the Coalition convened the Long-Term Care Dementia Workgroup. Sixteen Dementia Coalition representatives serve on the state's twelve long-term care entities (commission, workgroups, advisory councils, and task forces). Appendix F shows the current groups and Michigan Dementia Coalition representatives.

Public Awareness

The fifth priority of the 2003 Michigan Dementia Plan was to ***Increase early intervention by increasing public awareness of the caregiver role and the early warning signs of dementia.*** In 2004 the Coalition convened a workgroup to develop a public awareness campaign. The workgroup developed the concepts for a campaign, developed and issued a request for presentations from advertising agencies to evaluate their awareness campaign proposals, selected an agency, and worked with the agency to design a campaign.

This process included focus group testing of concepts, development of a database for media contacts, developing a database for eblasts, developing a campaign website, www.WorriedAboutMemoryLoss.com (see appendix G), securing additional campaign support, and billboard design.

The WorriedAboutMemoryLoss campaign was launched in January 2006 with simultaneous press conferences in Detroit, Grand Rapids, Lansing and Marquette. More than 100 people participated in the press conferences. During January, the website was advertised on 17 billboards in strategic high-traffic routes throughout the state (see Appendix H). Press releases were issued to 350 media outlets and eblasts were sent to 3,400 individuals and organizations. The campaign website had 8,640 visitors in 2006. The Dementia Coalition had personal contact with a number of individuals, the majority of whom were then assisted by the Coalition's community agencies.

Throughout 2007 and 2008 the WorriedAboutMemoryLoss campaign continued with some donated outdoor advertising, quarterly press releases, and maintenance of the campaign website. The campaign website receives about 12,000 visitors per year.

Caregiver Support

- Goal** Increase support for family members who provide care for persons with dementia at home.
- Workgroup** Chairs: Marci Cameron and Heddie Sumner
Members: Nora Barkey, Jen Burley, Dianne Carlson, Jim Carr, Dan Doezema, Jo Campbell, Lorraine Kremer, Lorie Massuch, Carrie Wexler Sherman, Sally Steiner, Lisa Vickers, Dona Wishart, Toni Young
- Objectives**
1. Identify and promote use of best community caregiver assessment tools and practices.
 2. Develop a profile of Michigan's home-based dementia caregivers to aid planning and advocacy efforts.
 3. Promote existing tools and resource materials including Effective Caregiver Interventions, in-home and community-based respite best practices, technology lexicon/assistive technology, and other selected resources.
 4. Facilitate and promote access to in-home and community-based dementia respite care in Michigan.
 5. Provide input in development and implementation of Alzheimer's Disease Demonstration Grant to States (ADDGS) home and community-based caregiver support services.

In response to needs expressed by caregivers and stakeholders in the 2002 statewide needs assessment, from 2003 to 2008 the Michigan Dementia Coalition identified and promoted best practices in respite care programs for people with dementia. A joint Dementia Coalition and Office of Services to the Aging Respite Task Force identified exemplary programs and disseminated best respite care practices information through the Coalition, aging network service providers, and websites. The Task Force also compiled a directory of respite service providers in Michigan.

With the Respite Task Force work completed in 2005, in 2006 the Coalition established a Caregiver Support Workgroup to continue initiatives that support family members who care for persons with dementia at home. The Caregiver

Support Workgroup updated the respite program directory and continued to identify and promote exemplary respite programs through awards and press releases. In 2007 the Caregiver Support Workgroup reviewed and summarized literature on effective caregiver interventions. The workgroup continues to disseminate and promote effective caregiver interventions.

The Alzheimer's Association reports that 70% of people with Alzheimer's or other dementias live at home and that 9.8 million family members, friends and neighbors provided unpaid care for a person with Alzheimer's disease or dementia in 2007.² This suggests that more than 324,000 Michigan residents are helping to care for someone with dementia. Caring for anyone with a chronic disease can be challenging and costly. Those who care for someone with dementia are even more likely to become depressed, suffer declining health, incur a financial burden, and even die sooner. However, effective support mitigates the negative effects of caring for persons with dementia and helps sustain the length of time that people with dementia can live in their own homes and communities.

Having identified the importance of providing caregiver support that is tailored to individual needs and circumstances, the Dementia Coalition's Caregiver Support Workgroup will turn its attention to helping program and service providers improve their caregiver assessment practices. The workgroup plans to identify the best caregiver assessment tools and practices and promote these among program and service providers. To help identify and monitor community caregiver needs, this workgroup will also develop a profile of community caregivers in Michigan. It will continue to promote tools and resources already developed or identified and continue to promote access to dementia respite care in Michigan.

Progress Indicators

Behavior Risk Factor Surveillance System (BRFSS) Caregiver Module in Michigan BRFSS in alternate years

Of caregivers registered in the OSA NAPIS data system, the percent caring for someone with cognitive impairment -- the April 2007 NAPIS report shows that 33% of caregivers were caring for an individual with a cognitive impairment; an increase could suggest an increased awareness of community resources, though other factors need to be taken into account

Capacity Building Ideas

Utilize Alzheimer's Disease Demonstration Grants to States (ADDGS) funding to develop programming to support caregivers.

² Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2007*. Chicago: Alzheimer's Association; 2007.

Look for grants to support stated objectives and consider other appropriate objectives to match available funding opportunities. Support organizations that are seeking grant opportunities that match the workgroup's stated objectives.

Primary Care Initiative

- Goal** Promote best practices in dementia detection, assessment and care management in primary care.
- Workgroup** Chairs: Alan Dengiz, MD and Mark Ensberg, MD
Steering Committee Members: Iris Boettcher, MD; Marvin Fields, MD; Bill Kerr, MD; Barbara Mercer, MD; Roman Politi, MD; and Christine Shina, MD – See Appendix I.
Primary Care Dementia Network – See Appendix J.
- Objectives**
1. Promote dementia case detection and assessment.
 2. Promote use of Primary Care Dementia Network (PCDN) education modules.
 3. Explore with Alzheimer's Association Chapters, the Office of Long-Term Care Supports and Services, and the Primary Care Dementia Network how best to maintain and disseminate information on dementia assessment providers in Michigan.
 4. Support dementia component of the Geriatric Education Center of Michigan (GECM) inter-disciplinary community geriatric team outreach and education project in eight communities: Marquette, Traverse City, Grand Rapids, Lansing, Saginaw, Flint, Detroit, and Kalamazoo.
 5. Help plan the dementia conference day of the annual Issues on Aging Conference.
 6. Continue to provide quarterly newsletters with Network updates, dementia news, and information about dementia resource materials.

Increasing knowledge of best practices and enhancing care management practices in primary care emerged as one of the highest priorities in the 2002 statewide needs assessment. The experiences of caregivers and patients with dementia, as well as the published literature, continue to illustrate the need for improving dementia identification and care management in primary care. Primary care physicians are the first line of defense for most people concerned about memory loss or early signs of cognitive impairment.

In 2005 the Michigan Department of Community Health completed a special statewide survey that included a question asking people where they would recommend someone go with complaints about memory or thinking problems. More than 60% indicated they would recommend going to “the doctor.” The next most frequent response (11%) was “the Internet.” Primary care physicians are key in early detection and dementia care, including referral to available support services.

Over the past five years the Michigan Dementia Coalition coordinated a network for primary care physicians with a special interest in dementia. The Michigan Primary Care Dementia Network (PCDN) now consists of more than 80 primary care physicians. In 2005, a Health Resources Services Administration grant to the Geriatric Education Center of Michigan (GECM) led to the development of dementia academic detailing, designed as a peer-to-peer outreach tool. An Administration on Aging grant through the Michigan Department of Community Health helped sustain dementia detailing 2006-08. PCDN physicians, along with Alzheimer’s Association representatives and Area Agency on Aging representatives completed 29 dementia detailing visits to providers across the state.

Along with dementia detailing, the GECM and PCDN developed five educational modules (see Appendix D) for primary care physicians and identified and distributed numerous other resource materials to primary care practices. The educational modules are available on the Coalition website at www.dementiacoalition.org and have been promoted in academic detailing and quarterly PCDN newsletters.

In 2006 the PCDN established a Steering Committee with physicians serving as regional representatives of the PCDN membership (see Appendix I). The PCDN co-chairs and Steering Committee members contributed substantially to the success of dementia academic detailing throughout the state.

In 2008, a new three-year grant to the GECM included a cognitive component as one of four core components. This grant project offers the PCDN the opportunity to extend dementia expertise into eight Michigan communities by serving as consultants to inter-disciplinary geriatric education teams. In addition, the Dementia Coalition and PCDN will promote the use of best dementia screening and assessment tools, continue to promote the education modules, explore how best to provide dementia assessment provider information and participate in planning the dementia component of the annual Issues on Aging Conference.

Progress Indicators

Proportion of Michigan residents with memory or thinking problems who have been assessed by a physician (per Behavioral Risk Factor Surveillance System special module in Michigan BRFSS in alternate years with Caregiver Module)

Of caregivers registered in the OSA data system (NAPIS), the percent caring for someone with cognitive impairment -- the

April 2007 report shows that 33% of caregivers were caring for an individual with a cognitive impairment; an increase in this percentage could suggest an increased awareness of community resources, though other factors need to be taken into account

Comparison of project county helpline contacts to non-project county helpline contacts -- that is, the percentage of the Alzheimer's population in Geriatric Education Center of Michigan project counties that contact the Alzheimer's Association before and after the project compared to the percentage of the Alzheimer's population that contact the Alzheimer's Association before and after project in non-project counties

**Capacity
Building Ideas**

Continue to partner with the Geriatric Education Center of Michigan and other Coalition partners on grant projects in line with primary care initiative objectives.

Long-Term Care

Goal Advocate for dementia-friendly policies and promote the highest quality dementia care standards in Michigan long-term care systems reform efforts.

Workgroup Chair: Susan Steinke
Members: Jen Burley, Bob Buryta, Marci Cameron, Doug Chalgian, Roxanne Chang, Michael Daeschlein, Sara Duris, Susan Erspamer, Andy Farmer, Micki Horst, Elizabeth Longley, Michelle Munson-McCorry, Portia Morehead, Sally Steiner, Dave Stickles, Jackie Tichnell, Damita Zweiback

- Objectives**
1. Identify and develop information focusing on key points to be made in advocacy for people with dementia as they pertain to the various long-term care workgroups and initiatives in Michigan.
 2. Develop recommendations for community service agencies regarding provision of long-term care dementia information and assistance to avoid gaps, minimize unnecessary duplication, and ensure consumer needs are met.

In its 2003 statewide needs assessment, the Dementia Coalition heard from many caregivers and others about the need for improvements in the long-term care delivery system. Concerns included the widespread lack of dementia competency of providers and workers, the lack of community-based options for persons with dementia, and insufficient quality control and accountability requirements for various types of residential care.

According to the Alzheimer's Association, 70% of all nursing home residents have some degree of cognitive impairment and 47% have a diagnosis of Alzheimer's or another dementia in their medical record.³ The dementia population in long-term care is particularly vulnerable to system flaws and weaknesses since their ability to speak or advocate for themselves ranges from, at best, compromised to, at worst, no longer possible.

The dementia competencies self-assessment tool and dementia competencies guide for direct care workers developed by the Coalition are valuable tools that the

³ Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2007*. Chicago: Alzheimer's Association; 2007.

state's long-term care system can use to promote dementia competency among direct care providers.

The Dementia Coalition participates in the state's Long-Term Care Commission and workgroups and has been a staunch advocate for increasing community-based care options for persons with dementia. This year the Dementia Coalition formally convened its own Long-Term Care Dementia Workgroup to facilitate dementia representation in the state's long-term care systems reform process. Appendix F shows the current groups participating in Michigan's long-term care systems reform.

To equip workgroup members and other Coalition members to advocate on behalf of people with dementia, the workgroup will identify and disseminate key points to increase awareness of the unique needs of people with dementia across the continuum of long-term care settings.

As Michigan implements a "single point of entry" delivery system, there is a need to look at the role of agencies such as the Alzheimer's Association chapters in providing dementia-specific long-term care information and referral services. This workgroup will attempt to identify the areas where clarification is needed and develop recommendations to increase the overall efficiency and effectiveness of long-term care information and referral for people with dementia.

Progress Indicators

Number of Michigan Dementia Coalition representatives serving on long-term care systems reforms workgroups, committees, grant projects, etc.

Number of times presentations (including testimony) are made in support of goal

If data become available, monitor the proportion of persons with a dementia diagnosis granted Medicaid waiver slots and the proportion served by SPEs, home health, Home Help, assisted living facilities, nursing homes, etc.

Public Awareness

- Goal** Increase early intervention and support for persons with dementia and their caregivers by promoting public awareness of the caregiver role and the early warning signs of dementia.
- Workgroup** Chair: Sara Duris
Members: Roxanne Chang, Micki Horst, Joy Spahn, Dave Stickles
- Objectives**
1. Work with Geriatric Education Center of Michigan (GECM) community geriatric teams to identify, develop (if needed), and disseminate materials that help increase public awareness.
 2. Promote dissemination of information through eblasts:
 - Update eblast database.
 - Promote Michigan Dementia Coalition participant dissemination of eblasts.
 3. Prepare public awareness talking points and slides for dropping in PowerPoint presentations and promote their use among Michigan Dementia Coalition participants.
 4. Promote broad dissemination of WorriedAboutMemoryLoss (WAML) cards.
 5. Enhance WAML website with additions and more frequent updates.
 6. Expand educational outreach (for example, to Local Health Departments, medical professional associations,⁴ and Medicaid managed care organizations).

As with other priorities of the Michigan Dementia Plan, the need for increased public awareness was identified in the 2003 statewide needs assessment. Early recognition and assessment of dementia symptoms are important for various reasons. Among the most important:

- Providing the opportunity to identify any underlying cause that is reversible,

⁴ Michigan Academy of Family Physicians, Michigan Osteopathic Association, Michigan State Medical Society.

- Allowing people in the early stage to participate in planning for their future, and
- Allowing families more time for legal, financial and care planning.

Another important public awareness need is for people to know where to turn for help. To those working in this field, it seems apparent that those with concerns about a loved one's memory should contact the Alzheimer's Association. Yet, many people do not make the connection between memory problems and Alzheimer's disease. Additionally, the onset of symptoms is often so insidious that those close to the person with early signs are slow to recognize the changes. This lack of recognition is coupled with a widespread tendency for denial of a much-stigmatized disorder.

To pursue the 2003 plan objectives, the Michigan Dementia Coalition was allotted \$64,000 for a public awareness campaign. In 2004 the Coalition developed the www.WorriedAboutMemoryLoss.com (WAML) campaign and launched it in January 2005. The campaign consisted of outdoor advertising (billboards), monthly press releases, and a dedicated website. The campaign targeted the Boomer demographic, many of whom are providing support to elderly parents or other relatives, and are also now themselves approaching an age when their risk is higher. Although the Coalition could not sustain the level of funding through subsequent years, it has continued quarterly press releases and maintained the dedicated website.⁵

Over the next three years, the workgroup will work with the Geriatric Education Center of Michigan (GECM) community teams to identify, develop (if needed), and disseminate materials that help increase public awareness. It will try to increase its website's visibility by adding GECM teams to its WAML database, promoting dissemination of eblasts through Coalition and other networks, and focusing on more frequent website updates and additions. It will also solicit Coalition member participation in promoting the WAML website by developing talking points for Coalition members to add to other presentations and making WAML promotional cards available.

Progress Indicators

Number of Michigan Dementia Coalition participants forwarding eblasts and number of recipients

Number of website visits

Number of Michigan Dementia Coalition participants using public awareness talking points

⁵ Forest Pharmaceuticals Corporation sponsored the WAML website in 2008.

**Capacity
Building Ideas**

Number of presentations incorporating public awareness talking points

Request continued support from pharmaceutical company.
Explore funding for public education messages for community groups like Faith in Action to use.

Ask major health plans to participate in campaign.

Ask major health plans, Employee Health Plans, and drug companies to add WAML link to their websites.

Appendix A

**Michigan Dementia Coalition
Leadership Team**

Peter A. Lichtenberg, PhD, ABPP
Chair
Director, Institute of Gerontology, Wayne State University

Sara Duris
Public Policy Coordinator
Michigan Council of the Alzheimer's Association

Judith Heidebrink, MD
Clinical Assistant Professor of Neurology
University of Michigan Medical Center

Micki Horst, MA
Dementia Program Coordinator
Michigan Public Health Institute

Rochelle Hurst, BSN, MA
Acting Director
Division of Chronic Disease & Injury Control
Michigan Department of Community Health

Preston Martin
Vice President
Alzheimer's Association – Greater Michigan Chapter

Suzann Ogland-Hand, PhD
Director
Center for Senior Care
Pine Rest Christian Mental Health Services

Appendix B

Cognitive/Memory Survey

In 2004 and 2005 the Michigan Dementia Coalition developed questions to be asked in a statewide survey conducted by the Michigan Department of Community Health with the same methodology used in the national Behavioral Risk Factor Surveillance Survey. The survey was administered to 2,656 people with over-sampling of African Americans, Latinos, and individuals over age 45 to better determine household prevalence of memory disorders.

Survey respondents reflected the U.S. Census with 79% Non-Hispanic Whites, 13% African Americans, and 5% Latinos. Fifteen percent of respondents stated that one or more members of their household had memory or thinking skills that were worse compared to the previous year. Twenty six percent of households with someone having memory or thinking declines reported having at least two members who had experienced such declines. Blacks reported a household memory or thinking decline prevalence of 22% compared to 15% of Latinos and 14% of Non-Hispanic Whites.

Those with greater income reported a lower prevalence rate of memory or thinking declines. Nearly 40% of the memory or thinking decline households reported that the declines interfered with daily activity and yet only 30% of the group had been evaluated by a health professional. General physical health was highly related to higher rates of memory and thinking declines. Only one percent of respondents knew about the Alzheimer's Association. These data allowed the Michigan Dementia Coalition to report on current household prevalence of memory changes and underscore the need for public awareness.

Appendix C

Innovative & Exemplary Respite Care Program Awards

In 2005 and 2007 the Michigan Dementia Coalition recognized adult day respite programs that provide exemplary or innovative services to meet the diverse and changing needs of individuals with dementia and their caregivers.

2005 Award Programs

- ***Alzheimer's Association – Rebecca and Gary Sakwa ADC*** for introducing the Snoezelen (relaxing multi-sensory equipment) concept. The program provides three support groups: men's, women's, and early-stage. Respite is available during group meetings. The two adult day centers supported by the Greater Michigan Chapter offer family caregivers access to the full array of Chapter services including care management, counseling, education, and the 24-hour, 7-days/week telephone helpline. The southwest Detroit location targets African Americans and Hispanics who have low to moderate income and live in the city.
- ***Otsego House Adult Day Center*** for its "Up & Go" Program that addresses the challenges in getting people with dementia to a day care program. Staff members drive to people's homes, help them get ready, and then transport them to the program. They also transport them back home and provide in-home respite until the caregiver gets home, helping to serve working caregivers. The program hires vocational health students to supplement professional staff.
- ***Seasons Adult Day Center*** for extensive training for all Family Care staff throughout the organization to ensure consistent philosophy of care, competency dealing with behaviors, and activities designed as a treatment model. The program provides dementia training for all newly hired staff and includes ongoing training in weekly staff meetings. The program has a registered nurse onsite, a beauty salon onsite, and a secure courtyard.
- ***Turner Geriatric Center Silver Club ADS Center*** for addressing personal needs by offering "spa services" such as hair care, relaxing massage, hand and foot soaks, showering and shaving assistance, and nail care. Services are also offered to caregivers one day a month to help relieve the stress of caregiving.

2007 Gold Level Award Programs

- ***Alzheimer's Association-Greater Michigan Chapter's In-Home Respite Program*** for their person-centered programming, specialized support groups, and caregiver assessment and access to services.

- ***Silver Club Programs of the University of Michigan Geriatrics Center*** for their adaptation to different stages of disorders, reminiscence therapy, cognitive games, and community collaboration.
- ***Rebecca and Gary Sakwa Adult Day Program of the Alzheimer's Association-Greater Michigan Chapter*** offers late stage dementia programming, therapies such as Snoezelen, music, dance, and art, and also multilingual and intergenerational programming.

2007 Silver Level Award Programs

- ***Alliance Senior Day Services of the Center for Disability Services at Western Michigan University*** for their practicum for graduate students, counseling and strategies to assist families, assessment and research studies.
- ***Covenant Senior Day Program's*** transportation and flexible scheduling.
- ***Dorothy & Peter Brown Jewish Community Adult Day Care Program's*** engagement of participants in community activities and extensive community educational offerings.
- ***Evergreen Commons Adult Day Health & Respite Program's*** Prayer Circle support of spiritual life for persons with dementia, particularly those in middle to advanced stages.

Appendix D

Primary Care Dementia Network Dementia Education Modules

Access modules at the Michigan Dementia Coalition website:
www.dementiacoalition.org

Dementia in Primary Care

Discusses the epidemiology and under-diagnosis of dementia. Addresses barriers to diagnosis as well as the benefits of early diagnosis in the treatment, management and care of dementia patients and their families and caregivers. Describes the signs that should trigger an investigation of possible dementia.

Clinical Diagnosis of Dementia

Discusses the important components of the history and physical exam, and contains information about relevant diagnostic studies and methods of evaluating cognitive function. Also distinguishes disorders such as depression, delirium and mild cognitive impairment in addressing the differential diagnosis of dementia.

Pharmacologic Treatment of Alzheimer's Disease

Discusses pharmacologic management of Alzheimer's disease and other forms of dementia. Addresses safety issues, caregiver support, and guidelines for recommended referrals for especially challenging issues.

Community Resources

Describes the benefits of referring patients and family caregivers to community social services; identifies the specific needs of patients and families at the time of diagnosis; and provides an annotated list of key community resources for dementia education and support. Also makes suggestions for practice redesign to ensure effective linkage with community social services, and includes a community resource handout for patients and families.

Reimbursement for Dementia Care

Deals with billing for dementia care in the office, domiciliary care and nursing home environments. Provides guidance on the effective use of primary and secondary codes, and the use of evaluation and management codes at appropriately high levels.

Rev. 01/08

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Appendix E

Development of *Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers*

First edition, 2006

Second edition with minor modifications, 2007

Everyday Language Edition, 2008

Credit for the development of the guide goes foremost to Michelle Munson-McCorry. As a home health care agency administrator concerned that her staff be dementia-competent, she initiated the process that led to developing the guide. Michelle helped define competencies and provided leadership throughout the process. Harvey Zuckerberg, Executive Director of the Michigan Home Health Association, and Micki Horst, Coordinator of the Michigan Dementia Coalition, brought together individuals with expertise and interest to participate in the initiative. Micki and Lorie Massuch provided staff support and project management assistance throughout the project.

Primary contributors to the development of the competencies were: Kim Curyto, PhD; Chris Hennessey, MA; Micki Horst, MA; Kathryn Ann Kozlinski, LPN, MEd; Lorie Massuch, BA; Michelle-Munson McCorry, RN, CDPI; and Lauren Swanson, MA. Organizations with significant representation were: Complete Compassionate Care, Greater Michigan Chapter of the Alzheimer's Association, Macomb County Department of Senior Services, Mental Health and Aging Project, Michigan Department of Community Health, Michigan Great Lakes Chapter of the Alzheimer's Association, Michigan Public Health Institute, Michigan Office of Services to the Aging, the Paraprofessional Healthcare Institute, and Pine Rest Christian Mental Health Services.

Special thanks to Portia Ross-Morehead and Robin Thompson, direct care workers, whose insightful comments contributed to the process. Numerous other individuals made important contributions at various stages throughout the process: Dale Adler, MA; Jean Barnas, MA; Jennifer Burley, BA; Marci Cameron, MA; Debby Conarty; Chris Curtin, RN; Cean Eppelheimer; Paula Hoegemeyer, RN; Marcia Mittelman, MA; Rachel Richards, BA; Maureen Sheahan; Chris Simons, CTRS; Sara Szokowski; Shelly Weaverdyck, PhD; Kim Walsh, MS; Adult Day Programs of the Alzheimer's Association, Greater Michigan Chapter; Complete Compassionate Care home health workers; Macomb County Adult Day Service Program Staff, and Seasons Adult Day Services.

A subgroup of the Dementia Competencies Workgroup developed the Everyday Language version of the Guide. Concepts and competencies remained the same as in the original version. Subgroup members were: Marci Cameron, Kathryn Ann Kozlinski, Lorie Massuch, and Maureen Sheahan.

Various other organizations supported the project including the Michigan Department of Community Health, Michigan Public Health Institute, and the Michigan Office of Services to the Aging.

Development of the guide was supported, in part, by the Alzheimer's Disease Demonstration Grants to States from the Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201 (CFDA #93-051) to the Michigan Department of Community Health. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Point of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

Appendix F

**Michigan Dementia Coalition Long-Term Care
Reform Representatives**

Michigan Long-Term Care Commission – Bob Buryta and Andy Farmer

Workforce Development Workgroup – Jen Burley, Marci Cameron, and
Michelle Munson-McCorry

Prevention & Caregiver Support Workgroup – Nora Barkey, Marci Cameron,
Sara Duris, and Damita Zweiback

Public Education & Consumer Participation Workgroup – Terry Eldred

Finance Workgroup – Doug Chalgian

Person Centered Planning Workgroup – Roxanne Chang

Quality Management System Workgroup – Elizabeth Longley, Susan Steinke
and Dave Stickles

MDCH Office of Long-Term Care Supports & Services Consumer Task Force –
Nora Barkey, Roxanne Chang, Portia Morehead, and Susan Steinke

State Profiles Grant Project – Sara Duris and Jackie Tichnell

Nursing Home Diversion Grant Project – Marci Cameron, Elizabeth Longley, and
Sally Steiner

Michigan Direct Care Work Force Initiative – Marci Cameron, Michelle Munson-
McCorry and Sally Steiner

Long-Term Care Partnership Insurance Project – Bob Buryta

Appendix G
Awareness Campaign Website:
www.WorriedAboutMemoryLoss.com



Worried for >>>

Who To Call >>

Articles/Information:

- Michigan physician and geriatrician Alan Dengiz, MD, is featured in a [PBS program on Alzheimer's disease](#). Dr. Dengiz is Co-Chair of [Michigan's Primary Care Dementia Network](#) (PDF).
- [Caregiver Stress Check](#) Caregiving can be stressful. Get the help you need.
- [Traditions prompt many Hispanics to hide Alzheimer's disease](#).
- [Mental Health and Aging Project](#).
- [Five simple brain exercise tips](#).

FAQ

Are memory loss and dementia the same thing?

Although many of us are aware of some mild changes in memory as we age, those with more serious memory loss often do not recognize their symptoms. Repeated questions, forgetting whole events, and getting lost in familiar places are just a few of the common signs of memory loss that are not associated with normal aging.

[More FAQs here.](#)

The Michigan Dementia Coalition

This website is a product of [The Michigan Dementia Coalition](#).

Our Partners

Parents

If you are concerned about a parent's memory loss or similar changes, you are not alone. Memory loss is an increasing concern of older people and can signal a genuine medical problem.

Spouse

"Something just doesn't seem right!" you say to yourself. "I forget things too sometimes, but it's like he just can't remember anything!" Or maybe you've noticed other changes that are making you uneasy...

Self

After age 40 most of us notice that we have moments of forgetfulness. If we know others with a disease or condition that causes memory impairment, we may be extra sensitive or concerned about these memory lapses.



PEOPLE NOTICE CHANGES IN LOVED ONES DURING THE HOLIDAYS

The holidays may be the only time all year that some families get together. It's not unusual for family members to notice changes in loved ones that were not visible the year before or during phone calls.

Changes can range from clear differences in physical health and appearance to more subtle alterations in mood and cognitive abilities. Sometimes these changes are immediately apparent to a visiting relative or friend. Other times it is a nagging feeling that things are not quite right, causing lingering anxiety for the visitor long after they have returned to their own home.

Increasing longevity has brought with it both benefits and new challenges. The decline of a parent's health or intellectual capacity often requires adult children to become involved in decisions about a parent's life. These decisions are not easy and there are no simple solutions. Each older person and family system is unique. The right answer for one family may be inappropriate for another faced with a similar situation and decision.

[Contact us for partnership information](#) | [Media Center: Ad Slicks, Television Spots, Radio Spots and News Releases](#)

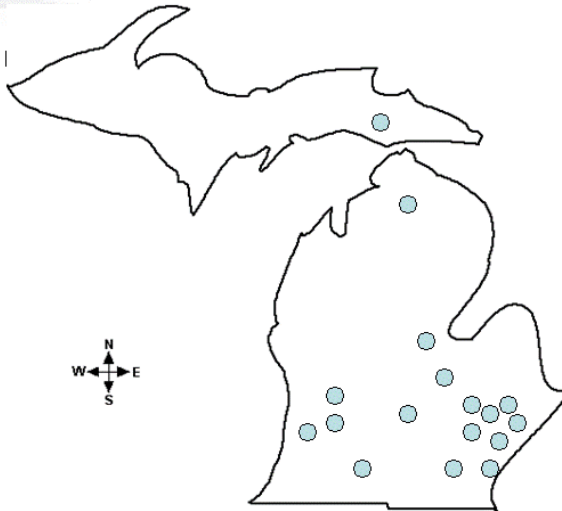
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Marketing/Communications/Web Design: [JJCommunicate](#) | [Jeff Tow Creative](#)

Appendix H

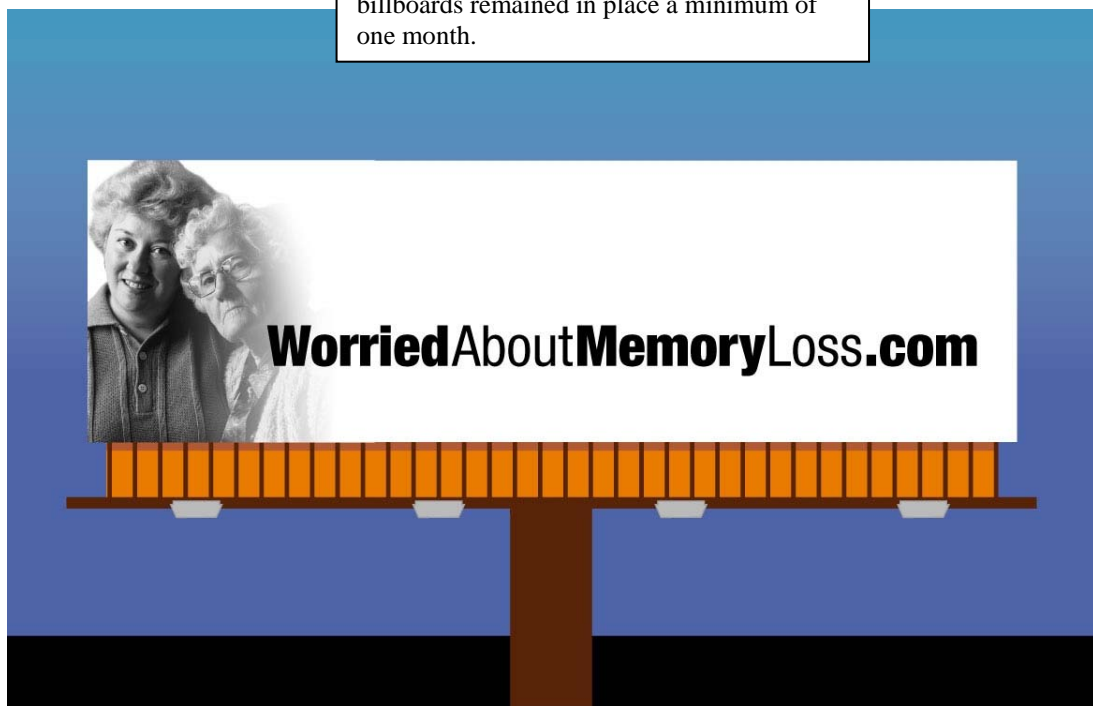
Awareness Campaign Billboards

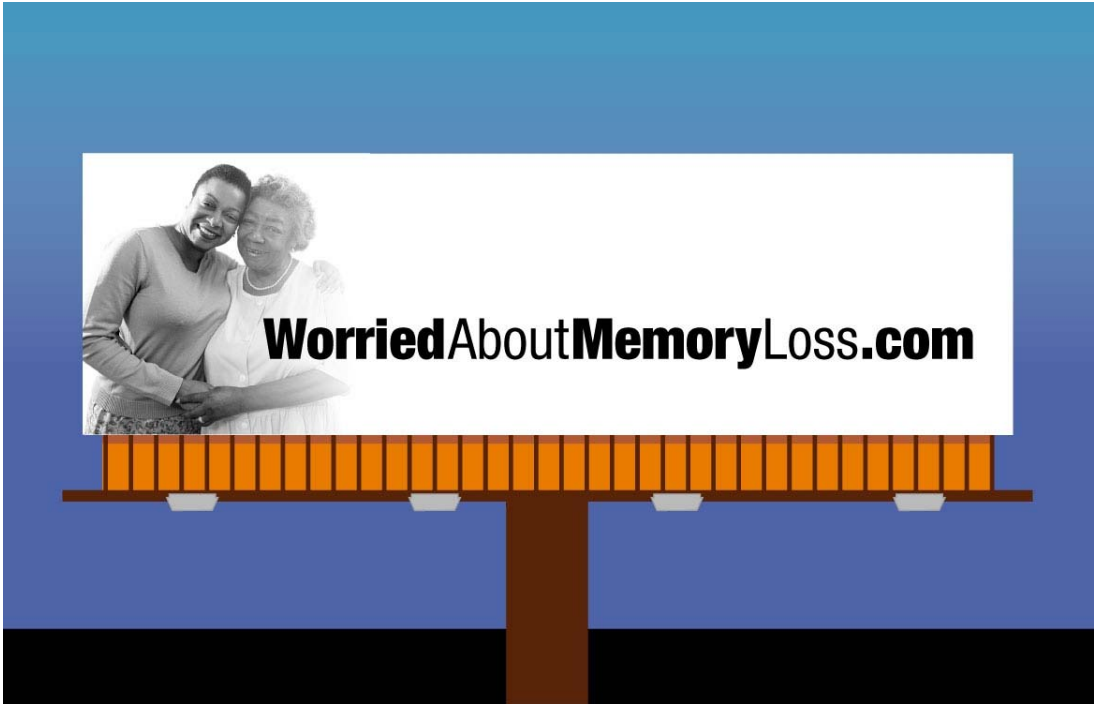


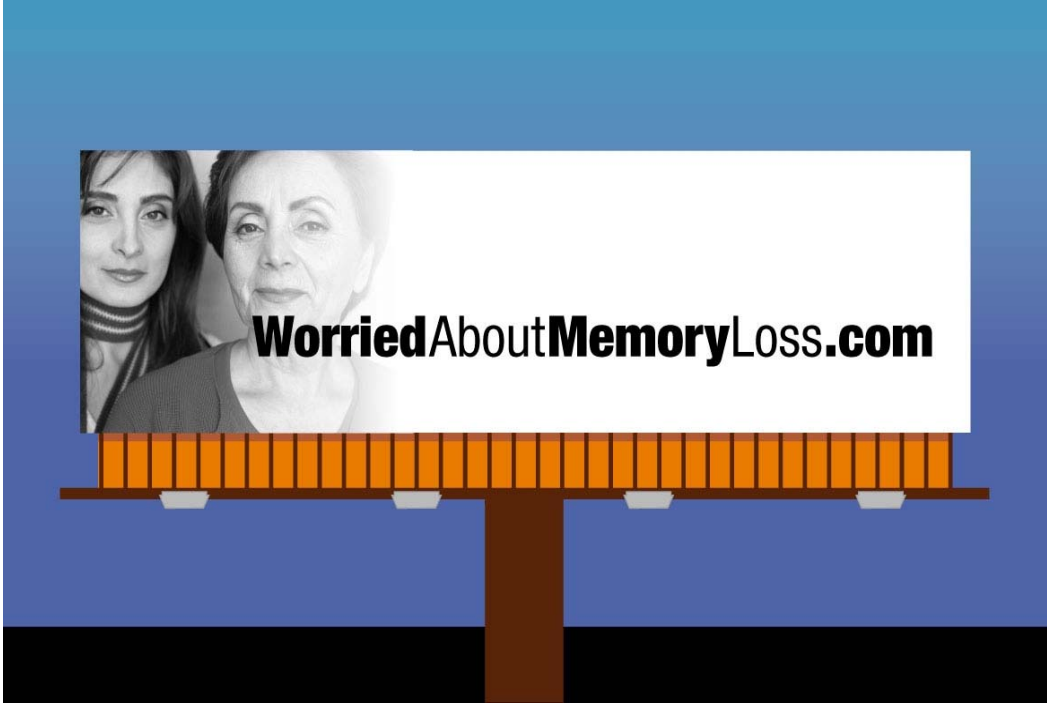
Billboard Locations
January 2006 - December 2006



Billboards were strategically located along high-traffic corridors throughout the state. Daily impressions was 820,500 and billboards remained in place a minimum of one month.





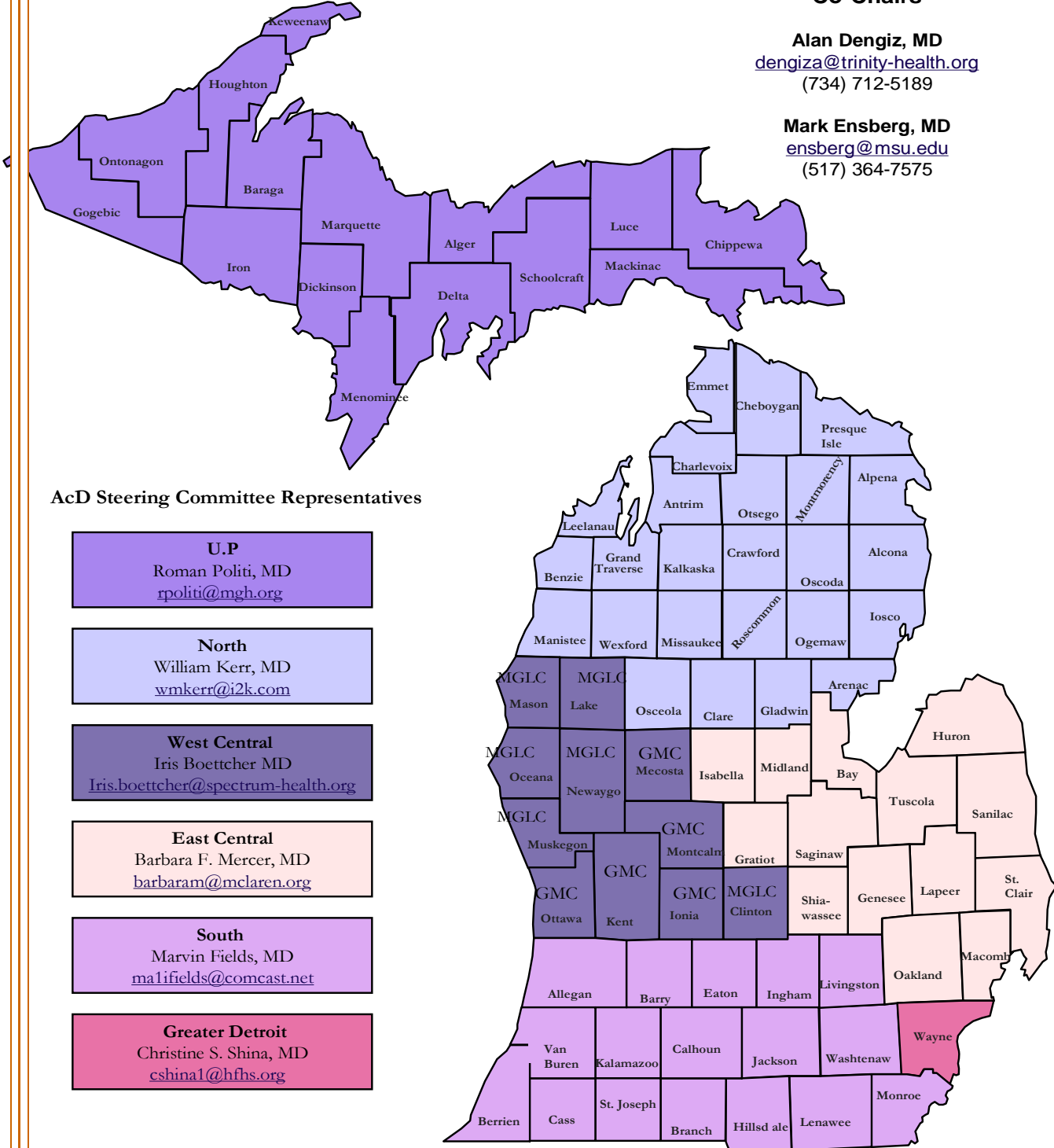


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Appendix J
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