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# Doing **More** with **Less**: The Michigan Dementia Coalition

**A**lzheimer's disease and other forms of dementia have lagged behind other major public health threats in garnering the national attention and public resources necessary to contain the burden they impose on the nation. What can concerned organizations and individuals do when a major issue of aging is significantly shortchanged in the broad policy arena? The Michigan Dementia Coalition provides an example of the progress possible when limited resources are leveraged with collaboration, commitment, and thoughtful strategies. Michigan, like most states across the country, does not and has not allocated major amounts of monies to create state networks of Alzheimer's disease centers or other large allocations for dementia. The state, thus, serves as one example of how creative synergies and mutual commitments across organizations can heighten dementia-related activity and impact.

The Michigan Dementia Coalition evolved from a 1988

governor-appointed task force, from which recommendations and groundwork led to a 1990 state budget appropriation for a "dementia information network." With this funding, the Michigan Department of Public Health established a dementia program that has continued since 1990 to provide staff support for a statewide coalition of organizations and individuals committed to addressing Alzheimer's and dementia.

From 1990 to 1998, the fledgling coalition served primarily as an advisory body for dementia program grants to community agencies serving individuals with Alzheimer's and dementia and their caregivers. In 1998, the coalition developed a new purpose statement focusing on statewide dementia issues and priorities, developed structure and operating guidelines, and established a leadership team to guide ongoing efforts. Selected milestones that have marked the coalition's efforts since 1998 are shown on page 62.

Successive awards from the Administration on Aging (AoA) program of Alzheimer's Disease Demonstration Grants to States have helped underwrite coalition initiatives, and the coalition has served as the state's advisory body for these grants projects. Brief descriptions of the Michigan Dementia Coalition's experience addressing several priority goals help explain how the coalition effectively leverages limited resources to achieve significant success.

## **Caregiver Support**

Throughout the development of the Michigan State Dementia Plan, the Dementia Coalition recognized the role of family caregivers—the hidden healthcare workforce. Through testimony across the state, we listened to their concerns. What we heard, reports of high rates of stress, burden, and health risks for caregivers of people with dementia, was entirely consistent with what is well documented in the clinical and research literature. There-

fore, given the overwhelming need, the first goal of the 2003 agenda for the Michigan State Dementia Plan was to “increase support for family members who provide care for persons with dementia at home.”

An important structural component in working toward this goal was the deliberate establishment of a formal task force to bring together professionals in the aging network of the state (Office of Services to the Aging with professionals in the public health, mental health, and dementia networks [e.g., organizations like the Alzheimer’s Association]). Although all of these professionals worked with older adults, improving the integration among the programs was an explicit goal. The task force accomplished the following:

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***When public attention and resources are not sufficient to contain the burden dementia imposes on the nation, organizations and individuals must step in.***

development of a directory of dementia-friendly, adult daycare providers in the state; a respite care consumer factsheet that helps define types of respite care and steps to selecting respite care services; an award program that recognizes exemplary innovative dementia-focused respite

programs; and a set of recommendations to continue support of family caregivers. The nominated respite care programs serving persons with dementia (about twenty programs in both 2005 and 2007) demonstrated a variety of activities and services that promote excellence and innovation in respite care. Some incorporated supportive services such as counseling, care management, support groups, and caregiver education. A few added practical supports such as “Up & Go” programs, which provide staff to help participants get ready and transport them to and from the daycare center. Another offers overnight availability and flexible scheduling. All of the nominated programs include staff trainings on dementia, handling behaviors, effective

communication, and recreational programming. Along with meaningful activities for participants, several centers

had developed innovative activities such as relaxing multisensory concepts, spa programs, therapeutic gardens, and spiritual worship. The Respite Care Task Force evolved into the Caregiver Support Workgroup (CSW) of the Michigan Dementia Coalition in 2006. The purpose

of the CSW is to increase the effectiveness of dementia caregiver support throughout Michigan by facilitating communication between key service and program providers, and coordinating activities related to the identified dementia caregiver support priorities.

### **Caregiver Support Workgroup**

Workgroup accomplishments to date include the continued promotion of respite service programs with the Exemplary and Innovative Program Award that recognizes best practices in dementia care in adult day and, as of 2008, in-home respite programs. Presentations by these programs were made to professional groups at statewide conferences to promote replication and to encourage innovative practices. The workgroup plans to conduct the nomination program every three years.

The “Research-Based Recommendations for Effective Caregiver Interventions” (see the coalition website at [www.dementiacoalition.org](http://www.dementiacoalition.org)) was developed through research literature review and is evidence-based.

There are many areas of caregiver concerns that the group would like to address. However, there are a number of factors that require limiting the focus of the group, including the large geographic size of the state compared to the number of workgroup members,

## Milestones of the Michigan Dementia Coalition

- 2000** Identified physician education as a priority and convened a workgroup to develop a primary-care initiative.
- 2001** Sponsored a dementia conference for primary-care physicians and established the Primary-Care Dementia Network.
- 2002** Conducted a statewide assessment of the needs of individuals with dementia and caregivers.
- 2003** Identified five priority issues and developed a strategic plan to address them.
- 2003** Established a joint dementia coalition and office of services as part of the aging task force to improve dementia respite services throughout the state.
- 2004** Established a Michigan Dementia Coalition website.
- 2004** Established a workgroup to increase the dementia competency of direct-care workers.
- 2005** Obtained statewide survey data on the prevalence of memory loss, the prevalence of assessment, and the awareness of community resources for memory loss and dementia.
- 2006** Launched a public awareness campaign, WorriedAboutMemoryLoss.

limited available time of members, and a lack of financial resources. The workgroup's challenge is to utilize the resources it does have to promote the use of available services and information and to foster a variety of useful approaches for people with dementia and their caregivers.

### Primary-Care Initiative

Since the coalition's inception, physician education has been one of its highest priorities. Coalition members, particularly the community service agencies such as local chapters of the Alzheimer's Association, noted the prominence of caregiver dissatisfaction with the response of primary care

physicians to issues having to do with memory loss.

The challenges of effectuating change in primary-care practices are well known. Primary care physicians, typically overwhelmed with demands for their time and attention, are inundated with a constant barrage of important information. Getting their attention for Alzheimer's and other forms of dementia is particularly difficult because the prognosis is poor and most physicians feel powerless to improve the patient's health and quality of life.

Aware of these challenges, a coalition workgroup, led by the director of a university-based geriatric education center, forged ahead. Throughout 2001,

it developed a statewide conference for primary care physicians. The conference was designed to examine dementia care guidelines, several models of care, barriers to effective care, and strategies to overcome the barriers. The coalition's community organizations identified 100 primary care physicians leading dementia care in their communities and the coalition workgroup sent a special invitation to these 100 physicians to participate in the conference.

In addition to the geriatric education center director, the coalition workgroup consisted of individuals with a vested interest in physician education—a health educator and a neurologist from the Michigan

Alzheimer's Disease Research Center, a member of an Alzheimer's Association chapter, a specialist from the Michigan Department of Community Health, the director of a gerontology institute (also the Coalition chair), and the state-funded Dementia Program coordinator. This group included representatives of three of the state's big four universities.

Close to one-third of the invited physicians participated in the conference and formed the basis of a network of primary-care dementia leaders. Over the next several years, the coalition workgroup facilitated meetings and activities of this Primary-Care Dementia Network (PCDN) of physicians. The workgroup chair also chaired the physician network.

In addition to the time and expertise contributed by workgroup members, the Health Resources Service Administration and the Administration on Aging have contributed funds to the primary-care initiative. Grant projects and pooled resources have enabled the coalition's primary-care initiative to provide dementia workshops at physician conferences, to conduct various dementia seminars and conferences for physicians, conduct a community memory screening program, pilot test a dementia primary-care quality-improvement data system, develop five primary-care dementia educa-

tional modules, develop and conduct dementia academic detailing (which includes having a peer present specific information to a physician) across the state, and convene annual meetings of the PCDN.

The Michigan Dementia Coalition workgroup saw promise in equipping PCDN members with the tools for peer-to-peer outreach. In 2005, it developed and implemented a dementia-detailing model. Over a three-year period, physicians representing the coalition have conducted visits with more than 100 primary care physicians across the state. Evaluation indicates the visits were most effective in increasing physician and staff knowledge of the community resources available for patients with dementia and their caregivers. Many physicians and staff who received the dementia-detailing visits were already aware that the Alzheimer's Association chapters and local area agencies on aging provide services. What the visits achieved was to increase their knowledge of the specific programs and services available. Follow-up evaluation suggests that the visits led to an increase in referral of patients and caregivers to these agencies.

The PCDN, which maintains its membership base of around seventy-five primary care physicians, is now shifting its focus to 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 join together in outreach and education with primary-care providers in the eight communities.

### **Dementia-Related Competencies for Direct-Care Workers**

To address its priority of increasing the dementia-related competencies of direct-care health professionals, the coalition established three objectives: to increase awareness of dementia education and training available throughout the state by disseminating a dementia education and training directory; to identify dementia competencies needed by direct-care workers and disseminate the information; and to develop a dementia competencies self-assessment tool for direct-care workers.

The workgroup developed the *Michigan Dementia Education & Training Directory* guide and posted it online in 2005. Since then, it has been updated annually and is now searchable by county.

The first edition of another coalition publication, *Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers*, was completed in 2007, widely disseminated throughout Michigan and via the Internet.

Both can be downloaded from the coalition website ([www.dementiacoalition.org](http://www.dementiacoalition.org)). The coalition's dementia competencies self-assessment tool for direct-care workers, developed by a neuropsychologist over three years with support from the AoA Alzheimer's Disease Demonstration Grant to States, will be published later this year.

### Public Awareness

Community forums held around the state and a survey of households made clear that the coalition's original selection of public awareness about dementia as a priority was well founded.

Between November 2004 and September 2005, the Michigan Dementia Coalition was able to partner with the Diabetes and Other Chronic Disease Section at the Michigan Department of Community Health to include questions on cognitive impairment symptoms in a special telephone survey. The random-digit dialing 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 percent non-Hispanic whites, 13 percent African Americans, and 5 percent Latinos. Some 15 percent of respondents stated

that one or more members of their household had memory or thinking skills that were worse compared to one year previously. A reported 26 percent of the households with someone having memory or thinking declines reported having at least two members who had experienced such declines. Twenty-two percent of blacks reported a household memory or thinking decline, compared to 15 percent of Latinos and 14 percent of non-Hispanic whites.

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### ***The group used billboards, press releases, and e-mail to drive information-seekers to a website ([www.WorriedAboutMemoryLoss.com](http://www.WorriedAboutMemoryLoss.com)).***

Those with greater income reported a lower prevalence rate of memory or thinking declines. Nearly 40 percent of the households who said they had people with memory or thinking decline reported that the declines interfered with everyday activity, and yet only 30 percent 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 1 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.

The specific goal was to increase early intervention by promoting public awareness of the caregiver role and the early warning signs of dementia. The strategy outlined was to develop and implement a multiphase public education campaign based on best practices in social marketing. Many of the campaign decisions were made by consensus, throughout monthly meetings. Since the onset of caregiving is not a distinct event, many people can be in the position of providing substantial

assistance long before they begin to realize they are actually caregivers. Failure to recognize oneself as a caregiver is closely related to another awareness deficit in society: failure to recognize the early symptoms of diseases that cause dementia. These were the two awareness deficits the campaign sought to address.

Targeting the baby boom generation, the oldest of whom are at the age at-risk for memory loss, with members also making up the majority of caregivers, the planners selected the phrase "worried about memory loss" as the theme that would succinctly capture what people are feeling and avoid the stigma of words such as *Alzheimer's* and

dementia to capture people's attention.

The workgroup, in partnership with the agency of Jarmon Johnson Communications and Viacom Outdoor (now CBS Outdoor), devised a campaign that used billboards, press releases, and e-mail messages to drive information-seekers to a website (*www.WorriedAboutMemoryLoss.com*) that would provide information as well as links to key resources statewide.

The Dementia Coalition launched the WorriedAboutMemoryLoss campaign in January 2006 with simultaneous press conferences in four cities across the state. Throughout the month, the campaign advertised on billboards on high-traffic routes and, throughout the year, continued to issue press releases and informational blast e-mails. The campaign website, which logged more than 8,500 visitors in 2006, allowed individuals to pose specific questions directly to Dementia Coalition representatives, and a number were

subsequently assisted by the coalition's community agencies. This was one gratifying indicator that people were being reached by the campaign.

In a report issued at the end of 2006, the workgroup was able to share some other indicators of impact. By tracking website hits on a monthly basis, it was clear that that issuance of press releases could cause a spike in the number of hits. Similarly, the statewide, toll-free helpline maintained by the Alzheimer's Association was also able to track increased calls at times after a press release.

Throughout 2007 and 2008, the WorriedAboutMemoryLoss campaign has continued with some donated outdoor advertising, quarterly press releases, and maintenance of the campaign website. The campaign website now receives approximately 12,000 visitors per year. Over the past four years, the initial investment of the Dementia Coalition was matched by \$300,000 of products and services by

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## Fall 2009

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Eric Kingson and Jennifer Hicks, **Guest Editors**

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