

# Preparing Minnesota for Alzheimer's: The Budgetary, Social and Personal Impacts

*Minnesota will be the first state in the nation prepared for Alzheimer's*





# **Preparing Minnesota for Alzheimer's: the Budgetary, Social and Personal Impacts**

**Report to the Minnesota Legislature**

**by**

**The Minnesota Board on Aging**

**on behalf of**

**The Alzheimer's Disease Working Group**

**January 15, 2011**

The cost of preparing this report was \$30,000 in private funds provided by the Alzheimer's Association Minnesota—North Dakota to pay for the work group's expert teams and the writing of the report

For additional information on this report and the other materials prepared as part of this effort, visit the Alzheimer's Disease Working Group's website at:

<http://alzworkinggroup.pbworks.com/w/page/4134483/FrontPage> or

[www.mnaging.org](http://www.mnaging.org)

This information is available in alternative formats to individuals with disabilities by calling 651-431-2500 or 800-333-2433. TTY users can call through Minnesota Relay at (800) 627-3529. For Speech-to-Speech, call (877) 627-3848. For additional assistance with legal rights and protections for equal access to human services programs, contact your agency's ADA coordinator.



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## To The Minnesota Legislature:

It has been a unique honor and a privilege to serve on the Alzheimer's Disease Working Group. Ninety-two individuals from all walks of life and from every corner of Minnesota labored over fifteen months to examine the needs of Minnesotans with dementia, the special needs of their caregivers, the present practices of the Minnesota medical community, and the community resources available to patients and caregivers. Six expert teams conducted numerous meetings to develop recommendations for improving our state's capacity to address the current needs of nearly 100,000 Minnesotans with Alzheimer's and to prepare the state for an ever larger proportion of our citizens who will be afflicted by this disease.

We are proud of our work as it represents the thinking of some of the nation's best researchers, clinicians, professional care providers, as well as the inputs of those suffering from the disease and the concerns of their caregivers.

I am one of those caregivers. For the past sixteen years I have dedicated my life to providing for the physical and emotional needs of my wife, who was diagnosed with Alzheimer's disease in 1994. Abandoning all professional and social associations, I devoted the next six years of my life to providing intensive, twenty-four hour-a-day care as my wife slipped ever further into the grip of this devastating disease. Since 2001 my spouse has lived within the confines of a nursing home, slowly shedding all the external manifestations of her uniqueness as a human being. Unable to read or speak, to recognize her family and friends, and incapable of standing or walking, she is condemned to spend the rest of her life in a wheel chair or in bed. This disease has already stolen twenty years of her life – and our journey is not over. Our story is not unique. It is repeated in the 100,000 Minnesota families who are caring for an Alzheimer's patient.

There is no known prevention or cure for this disease. While researchers are exploring a myriad of approaches to preventing or halting the progress of the disease, it is probable that a remedy is at least a decade away. As Alzheimer's disease is predominantly a disease of the elderly, our rapidly aging population foretells that tens of thousands of Minnesotans will be joining the ranks of the 100,000 Minnesotans now afflicted.

Without the prospect of an early cure, our report concentrates on managing the disease and its consequences for patients, their caregivers, and the community at large. We call for increased awareness of the disease by the medical profession and the community at large. We stress the importance of early detection. We highlight the importance of integrative care. We note the significant cost savings for the state when caregivers are supported in their efforts to keep the patient at home.

We believe that four parties are primarily responsible for implementing our 23 recommendations: the Minnesota medical community; the Minnesota Department of Human Services; Minnesota Department of Health; and the Alzheimer's Association Minnesota—North Dakota. Each has an important part to play. If we work together, we can have a powerful impact on the lives of thousands of Alzheimer's patients and their caregivers, while significantly reducing the costs of this disease to our state. It is a goal worthy of our continuing effort.

Sincerely,

Charles M. Denny, Jr.  
Chair, Alzheimer's Disease Working Group



## Members of the Alzheimer's Disease Working Group

*(Members of expert teams are listed in Appendix B)*

1.	Terry Barclay, PhD	Neuropsychologist, Center for Dementia and Alzheimer's Care and the Alzheimer's Research Center, HealthPartners
2.	Mary Birchard	President and CEO, Alzheimer's Association Minnesota—North Dakota
3.	Jayne Clairmont	CEO, English Rose Suites and Board Member, Minnesota Board on Aging
4.	Patricia Cullen, CAE	President and CEO, Care Providers of Minnesota
5.	Jayne Hager Dee	Regional Director, Karen Shirer Extension Center for Family Development, University of Minnesota Extension and Board Member, Minnesota Board on Aging
6.	Michael Demmer	President and CEO, Prairie Senior Cottages LLC and Aging Services of Minnesota
7.	Charles M. Denny, Jr.	(Chair of working group) Caregiver, and Retired CEO, ADC Telecommunications
8.	Michael Donohue	Person with Alzheimer's disease, Community Member
9.	Kathleen Harrington	Chair, Minnesota Board on Aging
10.	Robert Held	Division Director, Nursing Facilities Rates and Policy, Minnesota Department of Human Services
11.	Deb Holtz	State Ombudsman for Long-Term Care, Minnesota Board on Aging
12.	Neil Johnson	Executive Director, Minnesota HomeCare Association
13.	William Keigan	Person with Alzheimer's disease, Community Member
14.	Mary Manning	Division Director, Health Promotion and Chronic Disease, Minnesota Department of Health
15.	Anne Murray, MD, MSc	Associate Professor of Medicine and Geriatrics, Chronic Disease Research Group, Hennepin County Medical Center
16.	Ronald Petersen, PhD, MD	Director, Alzheimer's Disease Research Center and Cora Kanow Professor of Alzheimer's Disease Research, Mayo Clinic College of Medicine
17.	Catherine Sampson	Director, Arrowhead Area Agency on Aging
18.	George Schoephoerster, MD	Geriatrician, Geriatric Services of Minnesota
19.	Carol Shapiro	Caregiver, Community Member
20.	John Thomas, MD	Medical Director, Hospice of the Red River Valley

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## Purpose of Report

As Minnesota experiences an historic increase in its older population over the next 40 years, the number of individuals with Alzheimer's disease and other dementias is expected to grow dramatically. In order to more fully understand this issue, the 2009 Minnesota Legislature called on the Minnesota Board on Aging to convene an Alzheimer's Disease Working Group to study the status of Alzheimer's in Minnesota and make recommendations to the Legislature for needed policy and program changes that would prepare the state to address future increases in Minnesotans with the disease.

In 2004, the national Alzheimer's Association had begun an initiative to encourage state Legislatures to create state plans to address this impending health crisis. In 2009, the Alzheimer's Association Minnesota—North Dakota began seeking House and Senate members who felt strongly that such legislation was needed in Minnesota. Representative Steve Gottwalt and Senator Patricia Torres-Ray saw the need for these state level planning efforts and were concerned about Minnesota's level of preparedness. They agreed to become chief authors. The Association initiated a successful advocacy effort to secure additional co-authors and provide testimony at relevant committee hearings. The chief authors also encouraged their fellow legislators to support their bill to study the issues and prepare Minnesota to deal with Alzheimer's.

Once enacted, the Minnesota Board on Aging and the Alzheimer's Association partnered to meet the requirements of Minnesota's legislation. The Association played several key roles: it helped the Board identify experts to serve on the working group, brought its expertise to the table, staffed and served on the expert teams, and committed its organization to work for the full implementation of the recommendations made by the working group. The Alzheimer's Association also graciously provided private funding to support the work group's expert teams and the writing of the report, since no new state funds were appropriated for this purpose.

## Alzheimer's Disease Working Group

The legislation required the newly created Alzheimer's Disease Working Group to examine the needs of individuals with Alzheimer's disease, the services available to meet these needs and the capacity of the state and providers to meet current and future challenges. The working group was also to make recommendations on needed policies and responses. The legislation required that the group include representatives with a collectively broad spectrum of knowledge, expertise and experience in Alzheimer's disease.

The charge to the working group and full excerpt from the enabling legislation is included in Appendix A of this report. The complete citation is Laws of MN, 2009, Chapter 159, Sec. 110.

The working group held its first meeting on August 27, 2009. Charles M. Denny, Jr., a family caregiver and retired business leader in the state, was elected as the group's chair. A list of the working group members is included on page 2, and expert team members added later in the process are listed in Appendix B of this report.

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The working group decided to break into five teams to complete its charge. Each “expert team” was to focus on the issues within a particular topic and identify key issues and priority needs, and then develop recommendations to present to the working group. The working group invited a number of additional experts in Alzheimer’s disease to join the expert teams and help complete the assigned work.

The expert teams created were:

1. Early identification and support
2. Health and health care
3. Achieving quality in services
4. Dementia capable communities
5. Research
6. Financial issues (added later)

The Board on Aging and Alzheimer’s Association staff assisted in pulling together information and available research and preparing background briefs for each of these teams. An online accessible web portal was created to allow working group members to submit relevant research articles and to communicate Alzheimer’s-related information to each other and the general public. The process was intended to invite public participation and comment. Notices of all meetings of the working group were posted in the State Register.

These efforts resulted in a number of documents that summarize national and state demographic and prevalence data on Alzheimer’s, describe critical issues and provide examples of what other states have proposed in their Alzheimer’s plans. These background documents can be accessed at <http://alzworkinggroup.pbworks.com>

A steering committee, composed of leaders from the Board on Aging, the Alzheimer’s Association, the meeting facilitator and the chair of the Alzheimer’s Disease Working Group, was created to provide oversight and direction to the process. Over several months, the teams worked to draft their reports. They presented their findings and priorities to the larger working group at various points in the process – in January, May and June. In November, the working group met to adopt the final report. These large working group meetings were led by the meeting facilitator who was responsible for helping the chair and the group members arrive at a set of priorities and recommendations.

Toward the conclusion of the process, a sixth team was formed to focus on financial issues surrounding the recommendations. Specifically, the Financial Issues team reviewed the costs that Alzheimer’s disease imposes and the cost savings that might result from investments in early identification and treatment, caregiver support programs and other initiatives being discussed by the working group’s five other expert teams.

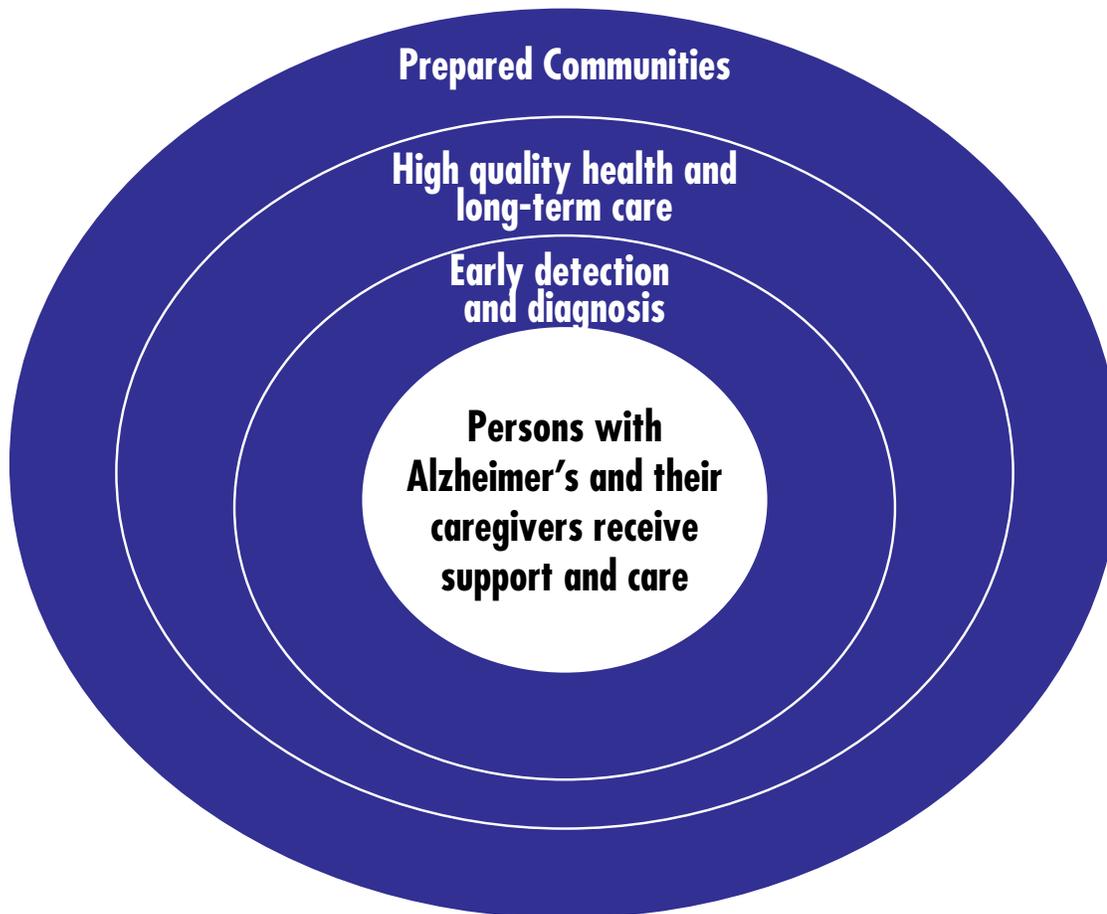
Altogether, the process involved over 90 individuals with expertise in every facet of Alzheimer’s disease. Each individual volunteered many hours over the span of a year to ensure that the final report and recommendations reflected the most critical actions that Minnesota must take to prepare for the dramatic growth in the prevalence of Alzheimer’s disease.

The diagram below summarizes the working group’s perspective on the ultimate outcome of its efforts: to ensure that persons with Alzheimer’s and their caregivers receive person-centered care. In order for this to occur, medical care, long-term care and communities are critical ingredients that must be transformed so they collaborate much more closely to provide seamless support for affected persons and their caregivers.

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## Figure 1. Alzheimer's Disease Working Group

### Vision of Person-Centered Care



### Use of this report

This report represents the priorities and recommendations of the Alzheimer's Disease Working Group. It does not presume to address all aspects of an issue as broad and complex as Alzheimer's. The group's intent was to identify the greatest needs from the perspective of the person and family who are trying to deal with this disease and its effects, which are devastating and life changing.

### Transformative change

Throughout its deliberations, the working group found broad consensus among its members on the key problems in the current care and support for persons with Alzheimer's, and agreement on the types of transformative changes required to improve the situation and change the system permanently for the future.

Central to the working group's vision is the transformation of how we provide and manage medical care for persons with Alzheimer's and the urgent need to train all medical providers serving older persons in the detection, diagnosis and management of Alzheimer's and other dementias. Transformation also needs to occur in how we support persons with Alzheimer's and their caregivers. In order to take on and sustain this daunting task, family caregivers need more ongoing comprehensive assistance with care options, simpler access to good information about services, and the reassurance that those who are providing care to their family member with Alzheimer's are competent to provide the care and meet accepted standards of practice.

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Communities also need to be transformed and prepare to support the growing number of their citizens touched in some way by Alzheimer's. They need help to educate and inform their populations, and put key elements in place to support and protect those with Alzheimer's and their caregivers.

The working group's recommendations assume that these changes will be made within the existing systems of care and services, to make them truly prepared for Alzheimer's. The group does not envision the creation of a separate continuum of care for those with dementia. Rather, the changes suggested would improve care management for all persons with chronic health conditions.

*In order to take on and sustain this daunting task, family caregivers need more ongoing comprehensive assistance with care options, simpler access to good information about services, and the reassurance that those who are providing care to their family member with Alzheimer's are competent to provide the care and meet accepted standards of practice.*

It should also be noted that the legislative action steps included in the Recommendations section relate only to those recommendations requiring state action. Action steps for all other recommendations will be developed and monitored by the Minnesota Prepares for Alzheimer's 2020 (MPA 2020), an ongoing group proposed to be established to ensure the implementation of the recommendations in this report.

Note: Whenever the terms "Alzheimer's" or "Alzheimer's disease" are used in this report, they should be understood as "Alzheimer's disease and other dementias" unless otherwise indicated.

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# Trends and Service Needs of the Alzheimer's Population

In 2011, the large baby boom generation—born between 1946 and 1964—begins turning age 65, and for the next 40 years, the aging of Minnesota's population will dominate the demographic landscape. Such a permanent shift in the age of a society has never happened before, and there are few guideposts for how to prepare for this dramatic change.

Along with the aging of Minnesota's population, another shift will also occur. The number of individuals with Alzheimer's disease is expected to grow dramatically. This is due primarily to the fact that the risk of getting Alzheimer's disease is closely associated with older age. It is particularly prevalent among the "oldest-old," those 85 years of age or older, which is the fastest growing age group in Minnesota and the nation as a whole.

The large increase in the older population and the associated rise in Alzheimer's have enormous implications for our society. Each of us hopes for a long and healthy life, and in fact, many of us will get our wish since Minnesota has the second highest life expectancy (behind Hawaii) of any state. Minnesota's life expectancy at birth now stands at 80.5.<sup>1</sup>

Even though this disease occurs one person at a time, the human toll it exacts from the affected individuals, their families and society is profound and will be staggering when growing numbers of families in every Minnesota community are struggling to bear the caregiving and financial burdens presented by Alzheimer's.

## Dementia and Alzheimer's Disease

Dementia is a general term that describes a set of symptoms caused by a number of different brain disorders. These symptoms involve cognitive decline that is severe enough to disrupt daily life and cause impairment in one or more of the following domains:

- Memory, or the ability to learn and recall new information.
- Language, or the ability to write or speak, or to understand written or spoken words.
- Visual and spatial function, or the ability to understand shapes and objects, to correctly judge spatial relationships and to identify and use symbols, maps, etc.
- Executive function, or the ability to plan, reason, solve problems and focus on a task.

Different types of dementia have been associated with distinct symptom patterns and distinguishing microscopic brain abnormalities. See Appendix C for information on the most common types of dementia.

*"Our government is ignoring what is likely to become the single greatest threat to the health of Americans: Alzheimer's disease, an illness that is 100 percent incurable and 100 percent fatal. It attacks rich and poor, white collar and blue, and women and men, without regard to party. A degenerative disease, it steadily robs its victims of memory, judgment and dignity, leaves them unable to care for themselves and destroys their brain and their identity—often depleting their caregivers and families both emotionally and financially."*

*--Op-Ed by  
Sandra Day O'Connor  
and others*

*--NYT, October 27,  
2010*

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## Symptoms of Alzheimer's disease

Alzheimer's can affect individuals in different ways, but the most common symptom is a gradual decline in the ability to remember new information. This happens because the damage done to brain cells usually begins in the regions of the brain involved in forming new memories. As the damage increases, individuals begin to experience additional difficulties.

Common early symptoms of Alzheimer's include repeating questions and comments, relying more on notes and calendars, misplacing things, struggling with names and getting lost driving. Behavioral changes also are common and may include irritability, apathy, aggression, agitation and depression. Later symptoms include impaired judgment, disorientation, more behavioral changes, and eventually, difficulty speaking, walking and even swallowing.<sup>2</sup>

According to the Alzheimer's Association, the ten warning signs of Alzheimer's disease include:

**Table 1. Ten Warning Signs of Alzheimer's Disease**

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, work or leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing ability to retrace steps
8. Increase in poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

## Risk factors for Alzheimer's disease

Because Alzheimer's disease is a chronic disease, most experts believe that it develops as a result of a variety of risk factors, much like other chronic diseases.

### Age

The greatest risk factor for Alzheimer's is advancing age. However, it is important to point out that Alzheimer's is not a part of normal or healthy aging. Most persons with Alzheimer's are over 65, and the proportion of people with Alzheimer's doubles every five years after the age of 65. For persons over age 85, one out of every two persons has Alzheimer's or some other form of dementia.<sup>3</sup> That said, people can develop the disease in their 30s, 40s and 50s, and when this occurs, it is referred to as "young onset" or "early onset" Alzheimer's. Even though young onset Alzheimer's is relatively uncommon compared to late onset, it still affects nearly 200,000 people in the United States.

### Genetics and family history

Alzheimer's disease is the object of intense genetic analysis. Researchers have observed that having a parent or sibling with Alzheimer's does increase one's risk of developing the disease. In addition, many mutations, or variant forms, on one of four genes are associated with the disease and have been identified. Three of these genes are linked to the young onset Alzheimer's. If someone has one of these gene mutations, he or she absolutely will, at some point,

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develop the disease. The chance of inheriting this type of Familial Alzheimer's Disease from an affected parent is 50:50. The frequency of this type of Alzheimer's, however, is very rare, possibly accounting for less than one percent of all cases.

The fourth gene "ApoE4" is linked to a greater susceptibility for developing late onset Alzheimer's (over the age of 65). ApoE4 is a variant form of a gene that encodes the production of a protein called apolipoprotein E, which may play a role in repairing connections between brain cells. People with one copy of ApoE4 have a greater risk of getting Alzheimer's than people with other forms of the gene, and people with two copies of ApoE4 have an even greater risk. Still, having this gene does not guarantee that someone will develop Alzheimer's, and most people with Alzheimer's do not have this particular gene.

### **Mild Cognitive Impairment (MCI)**

Mild cognitive impairment (MCI) is thought to be a transitional state between normal aging and early dementia. Individuals with MCI usually experience impairment in memory or cognitive abilities that are severe enough to be noticeable to the persons affected and to those who know them well. MCI is detectable on tests of mental function, but not serious enough to significantly interfere with typical activities of daily living. Experts say that as many as 10 to 20 percent of persons 65+ have MCI, and those with MCI are at increased risk of developing Alzheimer's or another dementia, although not all will. A recent study from Olmsted County in Minnesota documents the frequency of MCI in the general population and serves as a benchmark for how common this pre-dementia condition is in Minnesota. In this study, individuals with MCI progressed to dementia at a rate of 9 – 15 percent per year.<sup>4</sup>

### **Presence of other chronic conditions**

Researchers are also looking at the presence of other chronic conditions that damage the body's vascular system, such as heart disease, high blood pressure, stroke and diabetes, which tend to increase the risk of getting Alzheimer's. Since the brain is considered the largest vascular organ in the body, anything that disturbs the vascular system generally might also affect the brain and increase the risk of Alzheimer's and other dementias.

### **Treatments and risk reduction strategies**

There are no available treatments to stop or reverse the progression of Alzheimer's disease. There are no Alzheimer's "survivors." In addition, many of the promising drugs now in clinical trials have failed to slow or delay the onset of symptoms. Thus, the current treatments available for Alzheimer's disease aim at reducing the cognitive and behavioral symptoms of the disease. The US Food and Drug Administration has approved two types of medications to treat cognitive symptoms of Alzheimer's. These drugs affect the activity of two different chemicals involved in carrying messages between the brain's nerve cells. One type is cholinesterase inhibitors that prevent the breakdown of acetylcholine, a chemical messenger important for learning and memory. The other drug is memantine that works by regulating the activity of glutamate, a different chemical messenger involved in learning and memory.

Researchers are working hard to understand how general health status, lifestyle, social engagement and cognitive stimulation may affect the onset and progression of Alzheimer's disease. Many studies suggest strong links between brain health and regular exercise and a diet that includes plenty of fruits, vegetables, grains and is low in fat and sugar.

## Prevalence of Alzheimer's Disease

There are a variety of approaches that have been used to estimate the prevalence of Alzheimer's disease within the population. Prevalence is the total number of persons with the disease that includes both new cases and old cases. The prevalence estimates presented here are based upon the work of the national Alzheimer's Association as described in its recent report 2010 Facts and Figures as well as the earlier work of Dr. Liesi Hebert et al.<sup>5</sup>

It is estimated that about 5.3 million persons in the United States have Alzheimer's disease. Most of these (5.1 million) are persons over age 65, and about 200,000 are persons under age 65.<sup>6</sup> This means that 1 out of every 8 persons 65+ (or 13 percent) has Alzheimer's disease. As the large baby boom generation ages, the numbers of cases will soar because the increase in the oldest age groups will be so dramatic.

### Dramatic growth in older population increases prevalence

According to recent population projections, Minnesota's population over age 65 will more than double between 2000 and 2030, rising from 594,000 to 1.3 million in 2030. By 2050, when all the large baby boom generation will be over age 85, Minnesota will have 324,000 persons over age 85, and an estimated 10,000 individuals over the age of 100.<sup>7</sup>

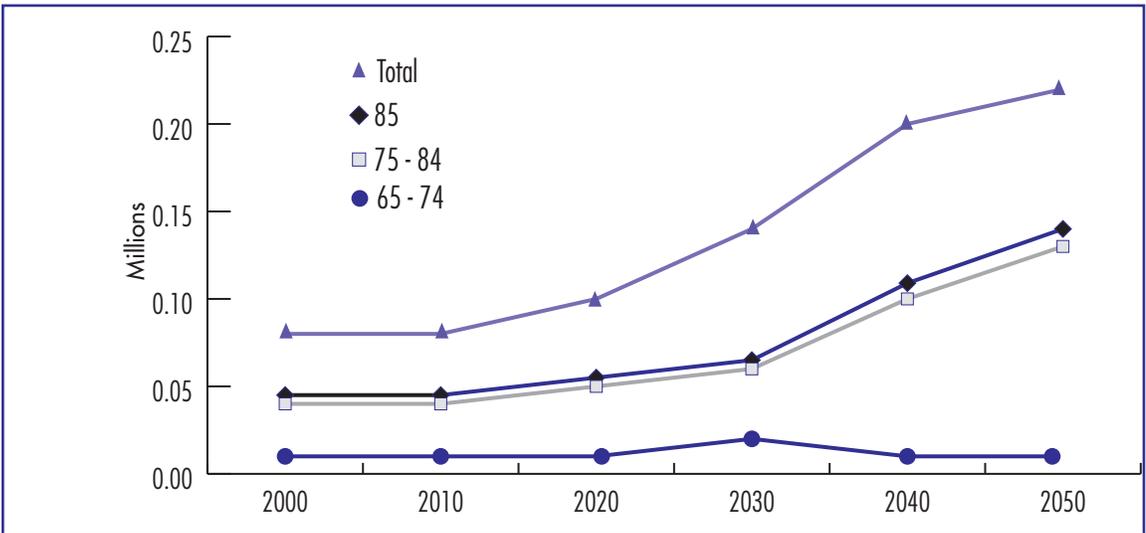
**Table 2. Projected Number of Minnesotans with Alzheimer's Disease by Age Group, from 2000 to 2050**

Year	65 – 74	75 – 84	85+	Total
2000	4,500	43,000	40,000	88,000
2010	5,000	40,000	45,000	90,000
2020	5,022	45,000	52,000	102,000
2030	9,000	68,000	65,000	142,000
2040	6,700	90,000	101,000	197,700
2050	6,510	77,000	136,000	219,500

*Source: Rates projected by Hebert, et al, 2003 used to estimate Minnesota numbers*

As the rapid growth of the oldest age groups in Minnesota and the United States continues, the age distribution of Alzheimer's disease will change. As Table 2 and Figure 2 indicate, the number of Minnesotans with the disease will increase by nearly 20 percent by 2020, and then double by 2040. The numbers of Minnesotans over age 85 with Alzheimer's will more than triple between 2000 and 2050, rising from 40,000 to 136,000 by 2050. By 2050, Minnesota is expected to have nearly 220,000 persons with Alzheimer's.<sup>8</sup>

**Figure 2.**  
**Projected Number of Older Persons in Minnesota with**  
**Alzheimer’s Disease by Age Group, from 2000 to 2050**



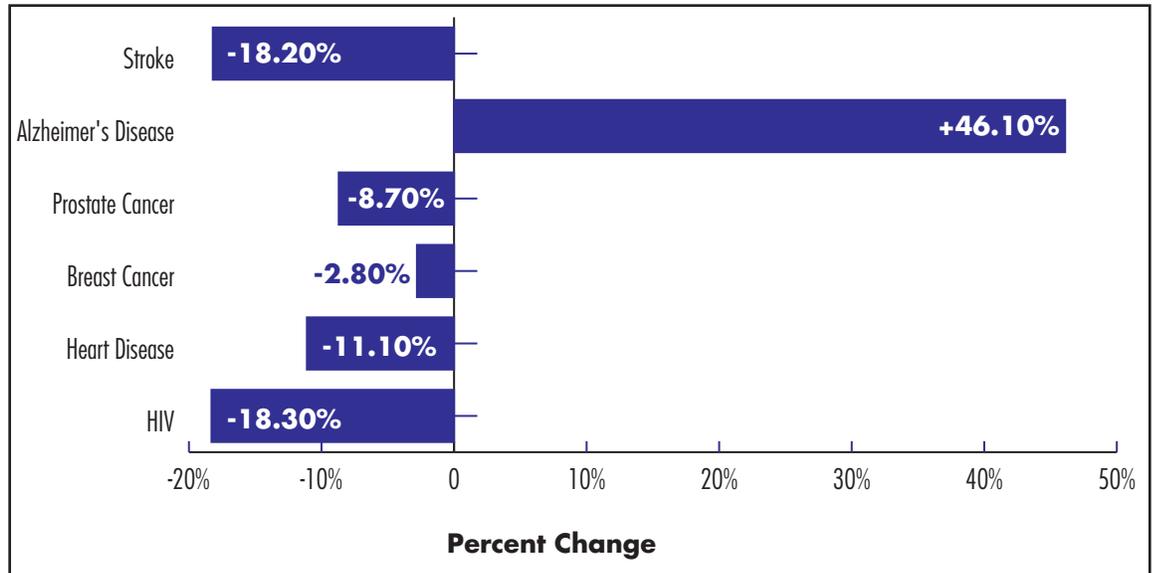
*Source: Rates projected by Hebert et al, 2003 used to estimate Minnesota numbers*

### Alzheimer’s as cause of death

Alzheimer’s disease is the fifth leading cause of death among persons over age 65 and sixth leading cause of death for all ages in the United States.<sup>9</sup> Alzheimer’s as a cause of death has continued to rise significantly over the past few years, while other major causes of death—stroke, cancer and heart disease—have declined. Figure 3 illustrates the growing disparity between these causes of death. Experts believe that the major efforts made to treat other diseases have resulted in a decline in death rates from those diseases, while deaths from Alzheimer’s have continued to increase.<sup>10</sup> Fewer people are dying from the traditional killers like heart disease but are living long enough to develop Alzheimer’s and die from that. It also reflects the current lack of any effective preventive or treatment strategy.

According to the national Alzheimer’s Association estimates, Minnesota’s number of deaths due to Alzheimer’s and age-adjusted rates (per 100,000) are very close to the national average at 1,299 deaths in 2006 for a rate of 22.2 per 100,000, compared to the US total of 22.6 per 100,000.<sup>11</sup>

**Figure 3. Percentage Changes in Selected Causes of Death between 2000 and 2006 in U.S.**



Source: National Center for Health Statistics: Final Data for 2000 and Heron et al, 2008

## Family Caregivers

Alzheimer's disease has been called a family disease. "It captures and involves the whole family, physically, spiritually, emotionally and financially. The whole family needs assistance."<sup>12</sup> An estimated 10 million individuals in the U.S. provide unpaid care to persons with Alzheimer's and other dementias. Most of these individuals are female relatives of the person with Alzheimer's, although a growing proportion includes men and other informal sources such as neighbors and friends.

It is estimated that nearly 200,000 Minnesotans are caring for persons with Alzheimer's or other dementias. They provide 223 million hours of unpaid care each year, which represents a value of \$2.6 billion in unpaid care, with each hour valued at \$11.50 per hour.<sup>13</sup> It should be noted that an estimated one-third of those with Alzheimer's disease and other dementias who still live in the community are living alone, and therefore do not have caregivers closely available to provide needed day-to-day assistance and help with self-management.<sup>14</sup> Because of the expected growth in the numbers of older people living alone, providing assistance to this population will become a critical issue in the future.

## Benefits and burdens of caregiving

Family caregivers providing care for an older relative with Alzheimer's or other dementias experience some benefits associated with their role, such as fulfilling their familial obligation as a spouse, adult child or grandchild. But for many, the burdens of caregiving far outweigh the benefits. Time deficits, emotional strain, health risks, mental health problems, enormous financial burdens and foregone opportunities are all common burdens associated with caregiving. Unique to caring for a loved one with Alzheimer's is the overall sadness and emptiness of watching the constant decline of the loved one as they progress through the disease, as the disease robs them of all vestiges of their former selves.

## Caregivers of persons with memory concerns

The Behavioral Risk Factor Surveillance System (BRFSS) is a federally administered, state-based health survey that collects information on health risk behaviors and health practices. The current BRFSS questionnaire does not include direct questions on Alzheimer’s or other dementias. However, some states, including Minnesota, have chosen to conduct an optional BRFSS caregiver module which includes questions related to caregiver concerns about memory and thinking of the person they care for, the “care receiver.”

The 2008 Minnesota BRFSS data indicates that many of the issues of caregivers for those with and without memory concerns are the same. However, there were some notable areas of difference in the data. These are summarized below in Table 3.<sup>15</sup>

*“Since 2001 my spouse has lived within the confines of a nursing home, slowly shedding all the external manifestations of her uniqueness as a human being. Unable to read or speak, to recognize her family and friends, and incapable of standing or walking, she is condemned to spend the rest of her life in a wheelchair or in bed. This disease has already stolen twenty years of her life – and our journey is not over. Our story is not unique.”*

*--Charles M. Denny, Jr.*

**Table 3.**  
**Issues Faced by Caregivers of those with and without Memory Concerns**

Issues Faced by Caregiver	With Memory Concerns		Without Memory Concerns concerns	
	N	%	N	%
Duration of care provided by caregiver				
3 – 5 years	66	23.3	76	16.6
6 years or more	66	21.8	69	15.7
Difficulties faced by caregivers				
Creates stress	133	23.0	111	15.0
Not enough time for self and family	110	19.0	109	14.0
Caregiver self-reported activity limitations				
due to health problems	95	31.8	99	21.8
Assistance required by care receiver				
Feeling anxious or depressed	61	11.0	52	7.0
Help with learning/remembering/confusion	65	22.0	111	15.0

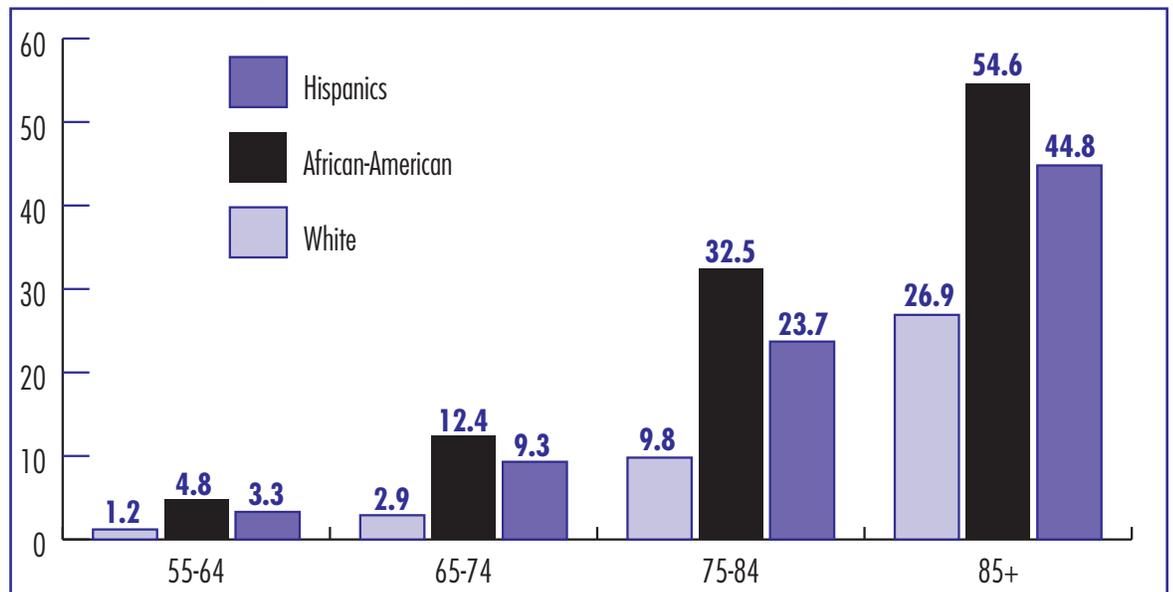
Because of the significant contribution of family caregivers to the care of their older relatives, any reduction in the caregiving role has enormous public policy implications. Data from the Survey of Older Minnesotans indicate some decline over the past 20 years in the proportion of assistance provided by family and informal sources, declining from 97 percent in 2001 to 92 percent in 2005.<sup>16</sup> A recent study of long-term care financing by the Department of Human Services estimated that Minnesota spends an additional \$30 million annually for each 1 percent decline in informal sources of care for the elderly. Once the family can no longer provide care, most elderly quickly exhaust their resources and become eligible for public programs that pay for long-term care.<sup>17</sup>

## Alzheimer’s disease, race and ethnicity

While Minnesota-specific prevalence data on Alzheimer’s among ethnic, immigrant and tribal communities is not available, experts believe that Minnesota’s experience is consistent with national trends. These trends indicate that African-Americans and Hispanics have higher rates of Alzheimer’s disease and other dementias at all ages than do whites. (No data appears to be available on Asian or American Indian populations.)

National data indicates that African-Americans tend to be two times more likely than non-Hispanic whites to have Alzheimer’s disease or other dementias. Hispanics are one and one-half times more likely than non-Hispanic whites to have Alzheimer’s or other dementias. Both of these groups have higher rates of chronic conditions such as high blood pressure and diabetes, and thus the higher Alzheimer’s rates may be related to these factors. Figure 4 below compares the prevalence of Alzheimer’s and other dementias by race and ethnicity.<sup>18</sup>

**Figure 4. Proportion of Americans Age 55 and Older with Cognitive Impairment by Race and Ethnicity**



Source: *Special Report: Race, Ethnicity and Alzheimer’s Disease*, created from *Health and Retirement Study*, 2006 and included in the 2010 edition of *Alzheimer’s Disease Facts and Figures*.

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## Cost of Alzheimer's disease

There is no single source of information on the direct and indirect costs of Alzheimer's and other dementias in Minnesota that includes expenditures by Medicare, Medicaid, public and private payers and out-of-pocket expenditures by families. However, using the national projection prepared for the Alzheimer's Association by The Lewin Group, it is estimated that the total annual cost of care for Alzheimer's disease and other dementias in Minnesota in 2050 will be \$20 billion. The following estimates are illustrative of the real costs of Alzheimer's for families, businesses and payers.

**Costs to the family:** The primary costs to families of seniors with Alzheimer's are the costs of various long-term care programs and services, such as in-home supportive services, adult day care, or residential programs such as adult foster care, assisted living or nursing facilities. These costs can be huge. In 2010, the average cost of assisted living per month in Minnesota was \$2,960, and the cost for a memory care unit would be even higher. The average monthly cost of care in Minnesota nursing facilities is \$4,076 per month or \$49,000 per year. Once again, care in dementia units can be significantly higher. In-home support and respite services can range from unpaid help from family and friends to many thousands of dollars per month for licensed staff.

The average cost of home health care in Minnesota is \$28.00 per hour. In cases of young onset Alzheimer's, loss of employment income and health insurance can add dramatically to family cost. Because of the high cost of care, most families quickly exhaust their personal resources and must turn to public programs for assistance. Further work is needed to identify in more detail the devastating financial impact of Alzheimer's on individual and family resources and what options there might be to address this burden.<sup>19</sup>

**Costs to businesses:** According to national surveys, nearly 60 percent of those caring for an adult over the age of 50 are working. The majority of those caregivers work full-time. Working caregivers report that their caregiving responsibilities affect their work:

- 57 percent report arriving to work late, leaving early or taking time off.
- 17 percent have taken a leave of absence.
- 10 percent switched from full-time to part-time hours.
- 9 percent left the workplace as a result of their caregiving responsibilities.

The average cost to U.S. employers of full-time employees who are caregivers totals \$33.6 billion per year in lost productivity. This averages \$2,110 per employee.<sup>20</sup>

**Costs to various payers:** The following are national data but there is no reason to believe that Minnesota's overall results would vary significantly. Tables 4 and 5 below summarize the health costs by source and by health service for persons in Medicare with and without Alzheimer's or other dementias. The costs for those with Alzheimer's or other dementias are considerably higher.

**Table 4. Average Per Person Payments by Source for Health and Long-Term Care Services, Medicare Beneficiaries Aged 65 and Older, with and without Alzheimer’s Disease or Other Dementias, 2004**

Average Per Person Payment	Beneficiaries with no Alzheimer’s or other dementias	Beneficiaries with Alzheimer’s or other dementias
Total Payments*	\$10,603	\$33,007
Medicare	5,272	15,145
Medicaid	718	6,605
Private insurance	1,466	1,847
Other sources	211	519
HMO	704	410
Out-of-pocket	1,916	2,464
Uncompensated care	201	261

*\*Payments by source do not equal payments exactly due to the effect of population weighting  
Created from data from Bynum, Medicare Current Beneficiary Survey  
Source: Alzheimer’s Disease 2010 Facts and Figures*

**Table 5. Average Per Person Payments for Healthcare Services, Medicare Beneficiaries Aged 65 and Older, with and without Alzheimer’s or Other Dementias, 2004**

Healthcare services	Average per person payment for those with no Alzheimer’s or other dementias	Average per person payment for those with Alzheimer’s or other dementias
Hospital	\$2,748	\$7,663
Medical provider*	3,097	4,355
Skilled nursing facility	333	3,030
Home health care	282	1,256
Prescription medications	1,728	2,509

*\*"Medical provider" includes physician, other medical provider, laboratory services, medical equipment and supplies.  
Created from data from Bynum, Medicare Current Beneficiary Survey.  
Source: Alzheimer’s Disease 2010 Facts and Figures*

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# Role of the State and Alzheimer’s Association in Service Provision

The legislation called for the working group to examine the array of needs of individuals diagnosed with Alzheimer’s, followed by a description of the services available to meet these needs, and the capacity of the state and current providers to meet these and future needs. This analysis concluded that much of the state’s response to Alzheimer’s disease up to now has focused on the long-term care system, but that gaps in long-term care services for persons with Alzheimer’s and their caregivers are growing. While long-term care is a critical (and very costly) component of Alzheimer’s care, the working group believes that the state must adopt a much more comprehensive set of strategies to respond to Alzheimer’s as future needs skyrocket. This includes a major transformation of medical care for Alzheimer’s and tighter coordination between medical care, long-term care and community components. (The complete analysis of the needs, trends and the state’s capacity to meet these needs is included in Appendix D.)

This section provides a general description of the current role of the state and the Alzheimer’s Association Minnesota—North Dakota in providing services to those with Alzheimer’s.

## State role in services for persons with Alzheimer’s and their caregivers

The state plays a major role in the administration and provision of long-term care services for all older persons including those with Alzheimer’s and their caregivers. Many of these roles are shared with other entities including counties, providers, health plans, tribal organizations and Area Agencies on Aging. The roles of the state are listed below by agency, including special mention of any Alzheimer’s or dementia-specific service or program.

### Minnesota Department of Human Services (DHS)

- Administers and funds specific home and community-based services through five Medical Assistance (MA) waivers (and the non-MA Alternative Care program for older persons) that serve older persons and persons with disabilities who are eligible for MA and at risk of institutional placement but who prefer to live in their home or another community setting. Services are also provided to caregivers of those eligible for these programs.
- Funds and provides oversight of nursing facilities and other residential settings for persons in need of institutional care.
- Contracts with health plans to provide all MA-covered health and medical services including chronic care management to older persons who receive their care through MA.
- Licenses specific services, facilities and some categories of direct care workers in long-term care, e.g., adult day care, foster care, Personal Care Attendants (PCAs).
- Administers and provides oversight of both the Vulnerable Adults Act (VAA) and county adult protective services to follow-up on VAA reports of potential adult abuse, exploitation or neglect.
- Administers the Community Services/Service Development (CSSD) grant program, which provides seed money to a broad range of providers and organizations, to support new or expanded service models.

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## Minnesota Department of Health (MDH)

- Responsible for licensure, registration and certification of hospitals, health care homes, clinics, home care agencies, housing with services establishments, assisted living facilities, nursing facilities, including approval of memory care and dementia units.
- Provides quality assurance and quality information for consumers related to the agencies and facilities that MDH licenses and regulates.
- Provides quality assurance through the regular surveying of all licensed agencies and facilities and completing regular assessments of nursing facility residents.
- Operates the Office of Health Facility Complaints where consumers can lodge complaints against licensed providers.
- Hosts the state nursing home report card on the MDH website.
- Monitors compliance with existing dementia-specific training requirements for long-term care staff in home care agencies, housing with services, assisted living and nursing facilities.

## Minnesota Board on Aging (MBA)

- Governor-appointed 25-member board that serves as the federally designated “state unit on aging” under the federal Older Americans Act (OAA) targeted at all persons 60 and over regardless of income who need supportive services to remain independent.
- Designates seven Area Agencies on Aging under the OAA to carry out federally mandated functions to provide information and assistance to older adults and their families, and administer federal Title III OAA and related grants for provision of nutrition, chore, transportation, caregiver support and caregiver counseling services in their planning and service area. Area Agencies also provide program development and coordination to help local communities and providers develop new services to fill gaps.
- Provides information and assistance for older individuals and families as they look for options and services to meet their needs, through the Senior LinkAge Line® and the website [www.MinnesotaHelp.info](http://www.MinnesotaHelp.info)™.
- Administers several grant programs related to health promotion, chronic care management, falls prevention, Medicare Part D and health insurance counseling.
- Operates Office of Ombudsman for Long-Term Care, a mandated service under the OAA, to act as a mediator for consumers and their families who are having problems with a facility or agency that is providing long-term care, and offer specific information about long-term care services and programs to consumers and their families.

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- Administers federally funded projects on Alzheimer's care, piloting several evidence-based models for persons with Alzheimer's and their caregivers in specific communities throughout the state. These projects are: 1) testing new approaches for services to people in the earliest stages of dementia (the Memory Care Initiative); 2) translating a model developed by New York University to provide enhanced support to caregivers so they are able to continue caregiving longer and delay nursing home placement (Minnesota Family Memory Care); 3) testing a new caregiver assessment tool that scores the caregiver's emotional levels and needs, and offers customized strategies to provide support (Tailored Care™); and 4) implementing a program to boost the type of education and intervention given to caregivers in the existing caregiver support network around the state (Powerful Tools for Caregivers). These innovative projects are also testing options for supporting caregivers in ethnic, immigrant and tribal communities. Eventually, the hope is that these projects can be implemented statewide.

## Role of the Alzheimer's Association Minnesota—North Dakota

The Alzheimer's Association is the largest non-profit voluntary health organization dedicated to scientific research, advocacy, and providing care and support to people with Alzheimer's disease and related disorders and their families. Specific services provided include:

- **Information Helpline:** professional staff is available to answer questions about Alzheimer's disease and related disorders 24 hours a day, seven days a week, in 140 languages.
- **Care Consultation:** offers individualized assistance, problem solving and identification of resources for persons with memory loss and their families.
- **Education:** professional and community education is provided on a variety of dementia-related topics across the state.
- **MedicAlert + Safe Return:** a nationwide identification, support and enrollment program that provides assistance when someone with Alzheimer's or a related dementia wanders and becomes lost. Assistance is available 24 hours a day, 365 days a year.
- **Support Groups:** available at a variety of times of the day and week for spouses, adult children, family caregivers and people with dementia.
- **Advocacy:** A state and nationwide effort improves dementia care and services; access to community-based care; quality care in residential settings; and expands funding for research and public programs serving people with dementia.

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## Needed Policies and Recommendations

Based upon its year-long analysis of the needs and problems of persons with Alzheimer's, the Alzheimer's Disease Working Group concluded that the systems with the greatest influence over the care and outcomes of persons must be transformed in order to change the way we support persons with Alzheimer's' and their caregivers.

This transformation focuses on much earlier identification of Alzheimer's and other dementias and a team approach to the provision of medical and long-term care once dementia is diagnosed. The transformation also includes an immediate focus on beefing up the training that physicians, nurses and allied health professionals receive on dementia and its management, improving the quality of long-term care provided to those with Alzheimer's and activating communities to increase their level of support for persons with Alzheimer's and their caregivers. These changes will improve the quality of care and quality of life for persons with Alzheimer's and their caregivers, and also have the potential for major cost savings over time.

*The Alzheimer's Disease Working Group believes Minnesota needs a much stronger and comprehensive statement on Alzheimer's disease, which articulates the state's commitment to policies and actions that support its citizens affected by the disease and prepares the state for the enormous increases in Alzheimer's that lie ahead.*

### State policy on Alzheimer's

The state currently has only limited "policy language" on Alzheimer's disease in legislation, relating to required training on dementia for agencies and facilities that advertise services to this population. The working group believes Minnesota needs a much stronger and comprehensive statement on Alzheimer's disease, which articulates the state's commitment to policies and actions that support its citizens affected by the disease and prepares the state for the enormous increases in Alzheimer's that lie ahead. If enacted, the legislative actions included in each section of recommendations would demonstrate the state's commitment to prepare for Alzheimer's.

### Health reform supports Alzheimer's

Since 2006, Minnesota has been heavily engaged in the development and implementation of state level health care reform. Minnesota's health care reform legislation, which passed in 2008, focused on a number of system changes in the health system, including a strengthened clinical care model centered in the concept of "health care homes" with expanded chronic care capabilities.

Both the department of human services and the department of health have recognized the importance of chronic care reform for a long time. However, the Board on Aging has been the unit of state government most engaged with Alzheimer's as a chronic condition needing special focus due to the high need for health and long-term care services by persons with Alzheimer's and their caregivers. Over the past 10 years, the Board on Aging and DHS have invested \$10 million in both federal Alzheimer's grants and state grant funds to improve Alzheimer's care. These dollars have focused on rebalancing long-term care from nursing homes into community settings, integrating long-term care with medical care systems and embedding evidence-based approaches to family caregiver support in programs around the state.

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Within its programs and grants, the Board on Aging has approached Alzheimer's care in a comprehensive way with attention to four elements. These elements include:

- Detection of signs and symptoms of cognitive decline (leading to earlier identification).
- Quality diagnostic workup and a possible diagnosis (either within primary care or through specialized diagnostic clinics when necessary).
- Coordinated care planning for both medical and supportive service needs.
- Education and support of family caregivers.

These elements are compatible with the fundamentals of quality chronic care and sensitive to the fact that, over time, an individual with Alzheimer's cannot be expected to be responsible for self-management of their medical and supportive service needs.

### **Working group recommendations consistent with MBA work on Alzheimer's**

The Board on Aging strongly supports the recommendations of the Alzheimer's Disease Working Group. They are consistent with its policies on chronic care and Alzheimer's care, and provide a comprehensive view of what is required to make needed transformative changes for better care of those with Alzheimer's and other chronic conditions. The Board believes that the report provides a strong foundation for the state to address a health care issue of significant magnitude to all Minnesotans.

### **Focus groups review recommendations**

Focus group meetings were held with members of several diverse communities as well as persons with early stage Alzheimer's, and the working group recommendations were presented to them for their review. The members generally supported the recommendations made by the working group. There appear to be several common themes in the comments across the focus groups, including:

- The need for more education and information for the general community (not just older persons) to reduce the stigma surrounding Alzheimer's, ensuring that this is done in ways that are culturally appropriate.
- More emphasis on survival skills and "non-drug" interventions that persons can use to cope with the symptoms of Alzheimer's disease.
- An array of services and programs is critical to supporting persons with Alzheimer's disease, so that each person and family can find the services that best support their unique situation. (The detailed comments from these focus groups are included in Appendix E.)

### **Recommendations**

The next section presents the needs and issues identified by each of the expert teams, and the recommendations and legislative action steps adopted by the working group.

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# 1. Identify Alzheimer's Early

## Lack of diagnosis of early stage Alzheimer's

Few Minnesotans receive a diagnosis of mild cognitive impairment (MCI), early stage Alzheimer's disease or other dementias, largely due to the lack of medical providers who routinely assess cognitive function and deliver early and accurate diagnoses. Because a diagnosis of cognitive impairment is so rare, few Minnesotans with MCI or early dementia receive interventions of any kind.

There are several reasons for the lack of a diagnosis. Many people and their families do not want a firm diagnosis, because they believe that nothing can be done anyway. There may be concerns about losing a driver's license, losing insurance coverage or just not wanting to "open a can of worms." Individuals are not aware of the importance of early identification and support. They do not understand the "gift of time" that an early diagnosis can give them, to start possible treatments, spend time with family and plan for the future.

*Individuals are not aware of the importance of early identification and support. They do not understand the "gift of time" that an early diagnosis can give them, to start possible treatments, spend time with family and plan for the future.*

## Providers unaware of benefits of early identification

Medical providers are equally unaware of the importance of early identification. They too think about the effects of an Alzheimer's diagnosis for which they can prescribe few if any treatments. However, one of the biggest barriers for medical providers has been the lack of adequate reimbursement for a diagnostic workup and ongoing management of dementia.

Fortunately, a major reimbursement barrier has been removed through a recent change in Medicare. The federal Patient Protection and Affordable Care Act (PPACA) enacted in 2010 included an annual wellness visit as a new benefit within Medicare, beginning in January 2011. This visit is available at no cost to the Medicare beneficiary. Assessment of cognitive status is a required part of this wellness visit. Providers will complete this assessment because they can now receive reimbursement for the services provided in this visit. Even for those not on Medicare, there is some potential for screening to be included in the benefits that all health insurance plans are required to cover. The benefits of earlier diagnosis from the medical provider perspective include improved management of the disease, ability to treat and manage co-existing conditions and the opportunity to help the patients and their families plan ahead.

A published University of Wisconsin study projected dramatic savings to the state and federal government and affected families by early identification of dementia through physician and clinic-based screening combined with drug and non-drug interventions. The net fiscal benefits of the combined intervention to the State of Wisconsin were large enough to generate savings of approximately \$10,000 per diagnosed patient, even if Wisconsin paid all program costs not covered by Medicare.<sup>21</sup> A project currently underway at the Minneapolis Veterans Administration Medical Center has established the operational feasibility and acceptability to patients of cognitive screening. Over time, the project will document financial and caregiver resilience outcomes stemming from earlier identification of those with cognitive impairment.<sup>22</sup> Similarly, the Mayo Clinic is operating an ongoing population study that will illuminate outcomes and costs over time for Olmsted County citizens with mild cognitive impairment or Alzheimer's.<sup>23</sup>

**Figure 5.**

**Net benefits of diagnosis and treatment of a 70-year old married woman with Alzheimer’s disease**

Mini-Mental State Exam (MMSE) = 28 at time of diagnosis, which is early stage Alzheimer’s	Present Value of Net Social Benefits*	Present Value of Wisconsin Fiscal Savings	Present Value of Federal Fiscal Savings
Interventions:			
Drug (given to those with normal decline)	\$172,000	\$15,000	\$28,000
Drug (given to those with slow decline)	98,000	6,000	13,000
Caregiver intervention (for normal decline)	10,000	4,000	21,000
Drug AND caregiver intervention	125,000	16,000	34,000

\*defined as money that family, employer and government save due to early intervention  
 Source: David L. Weimer and Mark A. Sager, 2009.

*The net fiscal benefits of the combined intervention to Wisconsin were large enough to generate savings of approximately \$10,000 per diagnosed patient, even if Wisconsin paid all program costs.*

**Recommendations**

1. Recognize cognitive screening as a “vital sign,” and assess the cognitive health of all Medicare patients at the annual wellness visit included as a new Medicare benefit beginning in January 2011.
2. Communicate with medical providers, individuals and families about the importance and benefits of early identification of persons with Alzheimer’s, through websites, awareness campaigns and collaboration with medical organizations.
3. Ensure that patients with early stage Alzheimer’s are given good information about available interventions as soon as possible after diagnosis, in order to improve disease knowledge and management, promote overall physical and cognitive health and enhance quality of life.

**Legislative Actions to Implement Recommendations**

1. The commissioner of health shall request that Minnesota Community Measurement include rates and results of cognitive screening as a measurement for physician and clinic services for Minnesotans 65 years of age and older.
2. The commissioner of human services shall require cognitive screening data to be collected and reported to the department for all Minnesota health care program contracts serving Minnesotans 65 years of age and older and then shall make the resulting information available to the public in appropriate formats.
3. The commissioner of health, working in cooperation with the Alzheimer’s Association Minnesota—North Dakota and other appropriate groups, including but not limited to medical provider groups, care coordinators, family members and social workers, shall contract with a vendor to develop a Dementia Clearinghouse website for: a) professionals and researchers working with persons with Alzheimer’s and other dementias, and b) individuals with mild cognitive impairment or dementia and their families. (Full version of this legislative action is included in the research section.)

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## 2. Use “Health Care Home” for Alzheimer’s Care

### Best practice for Alzheimer’s care is now emerging

Alzheimer’s is a disease that affects both health and cognition, and the medical care system has a major impact on the care and the outcomes for patients with Alzheimer’s. However, until recently, Minnesota’s health care community did not agree on what care model best integrated effective approaches to identification, care planning and coordination of services for Alzheimer’s disease. As a result, many physicians and other medical providers were unsure of effective practices or unaware of evidence-based practice models and therefore not aggressively focused on care of Alzheimer’s disease in their patients.

There is growing evidence that effective management of chronic disease, including Alzheimer’s, requires a commitment to a team approach for care of the patient. While some health plans and medical practitioners in Minnesota are now using a team model of care, many are not. As a result, many persons with Alzheimer’s do not get maximum benefit from the medical care they receive.

The new model called “health care home” is quickly becoming the clear preferred option for care of patients with chronic conditions, including Alzheimer’s. It places a coordinating team at the center of the model—surrounding the person and the caregiver—that includes all health, long-term care, other family and community partners, and requires close coordination and communication among them all.

The health care home model is also more effective at managing serious and disabling chronic conditions than current delivery models. For example, two of the most disabling conditions – Alzheimer’s disease and falls – are often not managed well, and result in high levels of health care utilization and nursing home placement. Under the health care home model, the providers would use the team members to more successfully manage the patient’s care, resulting in lower medical and long-term care costs and lower hospital admission and readmission rates. Research has shown that this model reduces disparities in health care outcomes among elders in ethnic, immigrant and tribal communities.

### Lack of funding stream for effective care models

Lack of reimbursement is a major reason that many physicians and clinics have not adopted the team approach in their practice. There are additional costs involved in a team approach to care management, and these have not been reimbursed by Medicare in the past.

However, new funding streams may help remove this barrier. A new Medicare demonstration of the health care home model set to begin in Minnesota in 2011 will pay providers a monthly, risk-adjusted, care coordination fee, which will provide some of the resources needed to support this model. In addition, as described earlier, beginning January 2011, Medicare will pay for assessment of cognitive issues as a mandated part of the new annual wellness benefit for Medicare beneficiaries.

*There is growing evidence that effective management of chronic disease, including Alzheimer’s, requires a commitment to a team approach for care of the patient.*

## Lack of attention to patient needs across the whole care and life spectrum

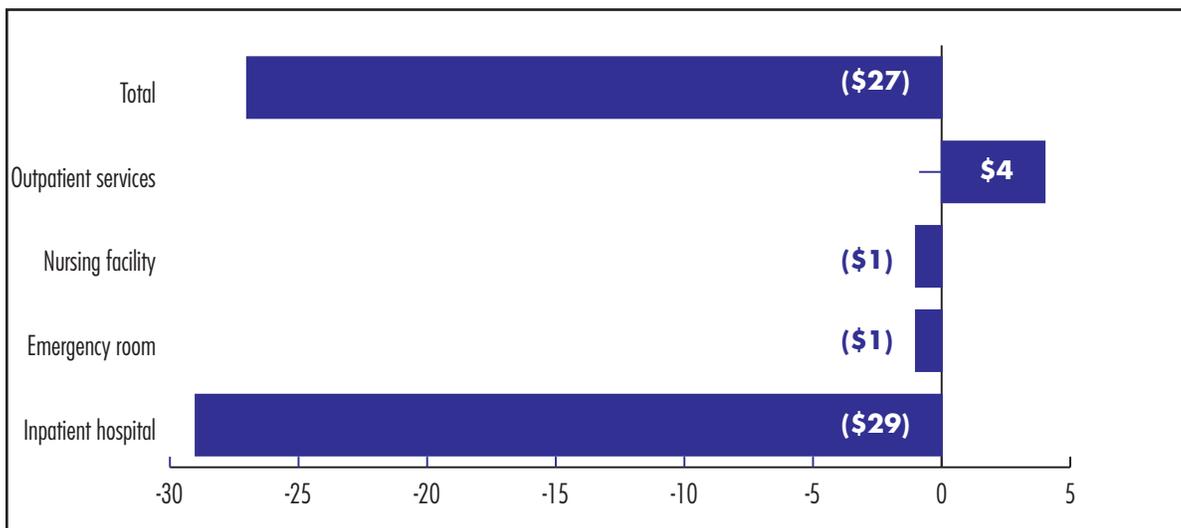
In the care of their patients with Alzheimer's and other dementias, physicians and other medical providers are often very focused on the current stage of Alzheimer's and what to do to address current issues. Thus, it is easy to neglect the need to help the patient and family think ahead and complete advance planning for future stages of the disease. The affected persons and families need permission to talk about end-of-life or palliative care, and they need materials, legal documents and basic information to help them through this often difficult decision-making process.

### Recommendations

1. Once identified, cognitive impairment should become an organizing principle for all other preventive and medical care of the patient, in coordination with their caregivers, supported by a health care home team, with special attention to points of care transitions.
2. Provide assistance to patients and families in making critical decisions across the whole spectrum of care, including palliative, hospice and end-of-life care, in a culturally appropriate manner.
3. Include a service within the health care home model that connects the patient and the family to professional care management immediately upon diagnosis and supports the family during the entire course of the disease, especially for those with MCI or early dementia, in a culturally appropriate manner.
4. Create a "disease educator" position for Alzheimer's disease similar to those for other chronic diseases, to work with persons diagnosed with the disease and provide practical disease information and care coordination for those persons and their caregivers.

### Figure 6. Estimated impact on monthly cost of serving patients in a medical home vs. current care model

**Total savings = \$27/person/month**



Source: Minnesota's Proposal for Medical Home Demo, June 2010

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## Legislative Actions to Implement Recommendations

1. The Minnesota Board on Aging shall offer information for individuals and family members about all stages of Alzheimer's (with special attention to early stage), and about disease knowledge and management, promoting overall physical and cognitive health and enhancing quality of life, through its consumer assistance service or through links to these types of information. This information shall also be posted on the recommended Dementia Clearinghouse website.
2. The commissioner of health in consultation with the commissioner of human services and the Minnesota Board on Aging shall jointly gather information and materials for individuals with Alzheimer's or other dementias and their families regarding health care directives and planning for end-of-life care and support. This information shall also include materials on Honoring Choices, a new initiative sponsored by the Twin Cities Medical Society and several partners, to engage patients in discussions with their health care providers, family members and other loved ones about their desires and values related to future health care treatments and end-of-life decisions. All these materials shall be posted on the recommended Dementia Clearinghouse website.

*The affected persons and families need permission to talk about end-of-life or palliative care for their member with Alzheimer's, and they need materials, legal documents and basic information to help them through this often difficult decision-making process.*

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## 3. Achieve Quality and Competence in Dementia Care

### Few quality standards for dementia care in medical care

There are few if any generally recognized and accepted quality standards, performance measures or ongoing quality improvement standards for the care that physicians, nurses and other health professionals provide to persons with Alzheimer's and their families.

### No specific quality standards for dementia care in long-term care

The majority of the formal care providers that serve persons with Alzheimer's or other dementias are long-term care providers. Examples include home care agencies, adult day care programs, assisted living and nursing facilities. Depending upon the organization and the service they provide, the organization and/or staffs are licensed, registered or certified. However, none of these credentials include specific standards for dementia care. There is a Minnesota statutory requirement for staff that work in agencies or facilities that serve those with dementia to have basic dementia care training, but there is no requirement that the workers demonstrate that they are competent in these skills. In most of these settings, workers are trained to provide care necessary to implement the individual care plan authorized for that person, and the documentation of that activity is used as an indicator of "quality of care."

The national Alzheimer's Association recently published standards for dementia care in a variety of settings, which provide a comprehensive set of standards for patient care, staffing and training, and environmental requirements for quality care of those with Alzheimer's and other dementias. Many consider these to be the "the gold standard" for use by caregivers and providers as they evaluate and seek to improve the dementia care they provide. However, these standards have not been widely disseminated or modified for use in training a wide range of caregivers and providers. These standards can be found at [http://www.alz.org/professionals\\_and\\_researchers\\_dementia\\_care\\_practice\\_recommendations.asp](http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp)

### Families don't get enough help of the right kind

Family caregivers wear many hats, and one of them is locating services in the community that can help them in their job of caring for a family member with Alzheimer's. When they are asked, caregivers say that they need much more assistance navigating all the available options for supportive services in the home, making transitions between health and supportive service providers and choosing a facility when care at home is no longer feasible.

There is no single comprehensive information source for laypersons that explains the natural history and course of Alzheimer's disease, alerts families to the resources needed and available to meet common needs, and advises them on how to determine the quality of care provided by a specific program or organization. When the expert team on achieving quality realized this was a need, they developed a Matrix for use by families as they seek options in the community. An example of the questions included in the matrix is shown in Table 6. It is intended to help families obtain consistent information on quality and availability so they can make better decisions when choosing service providers. The full matrix is included on the Alzheimer's Disease Working Group website at <http://alzworkinggroup.pbworks.com>

*When the expert team on achieving quality realized this was a need, they developed a Matrix for use by families as they seek options in the community. It is intended to help families obtain consistent information on quality and availability so they can make better decisions when choosing service providers.*

## Table 6. Quality Evaluation Matrix for Families Questions to Ask about Services

Are resources available (in your community)?
Are resources well-known, accessible and widely used?
Are growth plans adequate for expected need?
Are best practices available?
Are quality measures available?
Is education (of those providing service) adequate?
<i>(Sample of Matrix developed by members of Achieving Quality Expert Team for use by families of persons with Alzheimer's as they choose providers and resources)</i>

### Recommendations

1. Provide easy access to information about options and services across all stages of the disease, in order to smooth transitions between services and settings, including transfer of clinical records at the time of these transitions.
2. Adopt the dementia care practice recommendations developed by the Alzheimer's Association as the "gold standard" for dementia care in Minnesota, and take steps to make families, paid caregivers and all providers more aware of them and encourage them to utilize the standards.
3. Create a flexible curriculum for caregiver education based on these standards and on existing best practices that can be applied in multiple settings and formats to both paid and unpaid caregivers.
  - a. Create a public recognition program that is compatible with the report card for home and community-based services being developed by the state, to enable consumer choice of provider based on quality.
  - b. Include a system of certification and incentive-based options or rewards for dementia competency, including dementia care that is culturally competent. Ensure that care management services are also dementia-competent by defining quality standards and including these providers in this system of certification.

### Legislative Actions to Implement Recommendations

1. The commissioners of health and human services shall revise the nursing home report card to measure and report quality indicators and quality of life for persons with Alzheimer's disease and other dementias.
2. The commissioner of human services shall include a measure for dementia care competence within the home and community-based services report card currently under development.
3. The commissioner of health shall include the new dementia care standards for nursing homes required in the federal Patient Protection and Affordable Care Act (PPACA) in the existing Minnesota regulatory standards and requirements for nursing homes.
4. The commissioner of health shall be given the authority to apply the dementia training requirements currently in place for licensed services that advertise care for those with dementia, to all licensed services serving more than three individuals with Alzheimer's disease or other dementias.

## 4. Prepare Our Communities and the Public

### Communities need guidance in how to prepare for Alzheimer's

Many of Minnesota's communities are interested in the concept of Communities for a Lifetime, which emphasizes features that make communities good places to grow up and grow old and support their residents of all ages and abilities. The types of activities included in preparing communities for Alzheimer's are very similar to the ones involved in creating communities for a lifetime, e.g., creating supportive physical infrastructures like housing and transportation options, strengthening social and volunteer opportunities to connect with other residents, and expanding service infrastructures to increase the number and type of services and amenities available to residents of the community.

Minnesota does not have a common definition of the features of a community prepared for Alzheimer's, so that it can be communicated to and adapted by communities statewide. Our state cannot achieve its vision of a state prepared for Alzheimer's without communities working to establish the features contained in a common definition, e.g., training of public safety officials about dementia, creation of respite services for caregivers. Most communities do not have the tools and methods to assess their readiness for Alzheimer's. In addition, most communities do not have a clear understanding of what specific actions they can take to become a "community as caregiver" for persons with Alzheimer's in their community, and how to do it in a way that respects the individual's privacy and dignity.

### Need for community supports for caregivers is critical

Caregivers often look to informal sources in the community such as trusted friends and neighbors for help and support. Every Minnesota community includes caregivers of persons with Alzheimer's and other dementias, and surveys show that they prefer locally sponsored sources of key services and supports, such as respite, protective services or transportation. As the population ages and more elderly need caregivers, including the growing number of persons with Alzheimer's who live alone, there will be fewer family members available, which makes the concept of the "community as caregiver" an essential concept and practical necessity.

*As the population ages and more elderly need caregivers, including the growing number of persons with Alzheimer's who live alone, there will be fewer family members available, which makes the concept of the "community as caregiver" an essential concept and practical necessity.*

**Table 7. Minnesota Family Caregiver Ratios\***

Year	Total 85+	Females 45-64	Ratio*
2000	85,600	537,100	15.94
2005	103,000	646,700	15.93
2010	108,910	732,700	14.86
2015	119,200	761,600	15.65
2020	125,300	753,100	16.65
2025	139,300	725,600	19.20
2030	168,900	718,900	23.50
2035	221,800	733,70	30.24

\*Ratio equals the number of people age 85+ to 100 females age 45-64  
Source: Transform 2010. What Will Keep Family Caregivers Caring?  
Policy Brief for Boomers Mean Business forum, March 2009.

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## **General public needs education about Alzheimer's**

There is a great need for increased public awareness of Alzheimer's disease at the community level. Many myths and inaccurate information exist about Alzheimer's disease and its impact on persons who have the disease. The general public is often unaware of the true needs of persons with Alzheimer's and, as a result, may be resistant to making their community more supportive for those with Alzheimer's and their caregivers.

### **Recommendations**

1. Create and disseminate a list of key elements a community should have to support those with Alzheimer's and their caregivers, and urge Minnesota communities to adapt this list for their use.
2. Create "action kits" for communities that help them assess their progress toward development of these key elements.
3. Develop, enhance and improve the variety and supply of informal and formal supports for caregivers of persons with Alzheimer's, including supports appropriate for elders and their caregivers in ethnic, immigrant and tribal communities.
4. Create and implement a multi-year public awareness campaign (targeted at the general public and communities) to increase knowledge about Alzheimer's and reduce the stigma now associated with the disease.

### **Legislative Actions to Implement Recommendations**

1. The Minnesota Board on Aging shall ensure that the elements of a community prepared for Alzheimer's are included in its ongoing training and technical assistance for communities for a lifetime, and included on its communities for a lifetime website. Best practice models for ethnic, immigrant and tribal communities shall also be provided on this website.

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## 5. Train Medical Providers in Dementia Care

### Inadequate dementia training of medical providers who serve older persons

The curriculum used to train physicians, nurses and other allied health professionals in Minnesota does not adequately address Alzheimer’s disease and other dementias. Right now, for example, the University of Minnesota medical school provides two hours of training on dementia as part of the four-year curriculum to train all future physicians. Even those specializing in neurology receive only general information on the entire field of mental disorders, including Alzheimer’s disease and other dementias likely to affect the older population.

The curricula for other health professionals—nurses, pharmacists, therapists—lack adequate coverage of these topics as well. Given the fact that medical providers in 2030 will be caring for more older patients because of the aging population, these providers need a better understanding of the diseases that will affect growing numbers of their patients.

### Recommendations

1. Mandate the inclusion of information on Alzheimer’s and other dementias in the training curriculum and continuing education requirements of physicians, nurses and allied health professionals who serve older persons. These courses should include early detection and diagnosis of cognitive impairment, dementia care interventions and management of the disease.
2. Develop protocols and best practice standards for care of persons with Alzheimer’s, and use these in the training of physicians, nurses and allied health professionals.
3. Dementia care management competencies must be developed and taught in medical schools, academic health centers and allied health professional education and also to the full range of helping professionals, family care partners and community agency partners.

*Right now, for example, the University of Minnesota medical school provides two hours of training on dementia as part of the four-year curriculum to train all future physicians.*

### Legislative Actions to Implement Recommendations

1. The regents of the University of Minnesota are requested to develop a plan, with specific timelines, for responding to the needs of an aging population in Minnesota using the following mechanisms:
  - a. Expanding dementia care education in the core curriculum of the medical school.
  - b. Reinstating an academic geriatric education program at the medical school.
  - c. Reinstating the geriatric fellowship program within the medical school, and/or developing a new site at the University for the geriatric fellowship program currently at Hennepin County Medical Center.
  - d. Creating educational experiences for primary care specialties related to longitudinal management of dementia patients by interdisciplinary teams, including transitions in care settings.
  - e. Making similar changes in nursing education in the School of Nursing and the education within other schools that train allied health professionals.
2. The director of the office of higher education shall evaluate and report on the curriculum changes needed to incorporate dementia care competence in all related health care education programs.
3. The commissioner of health shall add dementia care competence as a requirement for receipt and forgiveness of rural health loans and grants made available to individuals being trained as physicians, nurses or other allied health professionals to serve rural areas.

## 6. Pursue Cost-Saving Policies

### Need to publicize the true and total cost of Alzheimer's

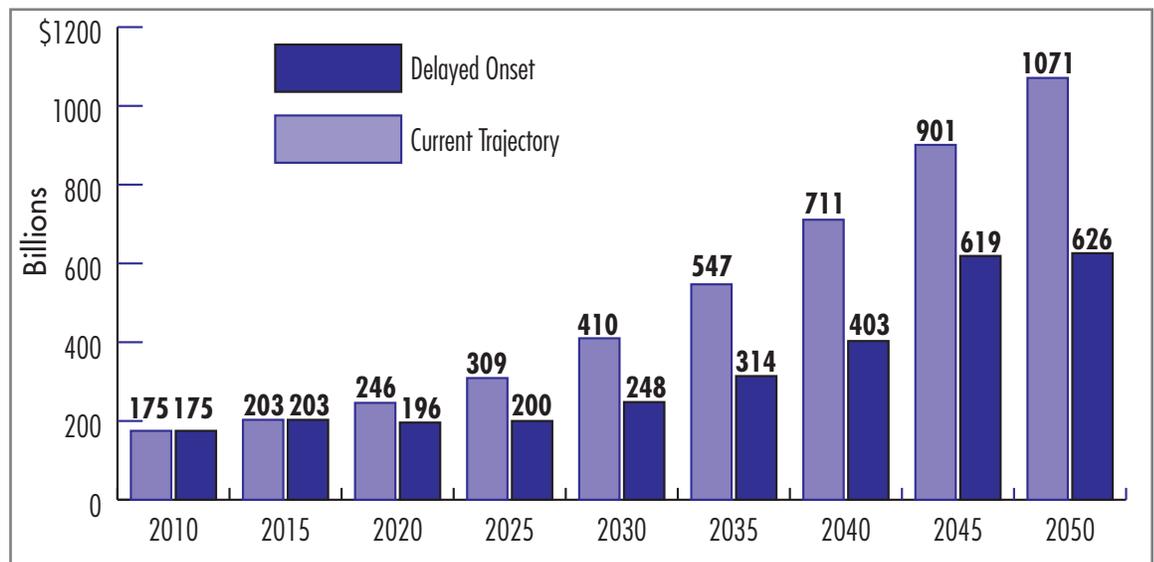
The public and policymakers generally are not aware of the real and total costs of Alzheimer's disease. The growth in the numbers of individuals with Alzheimer's will take a huge financial toll, reaching an annual cost of over \$1.0 trillion in the U.S. and an estimated \$20 billion in Minnesota by 2050.<sup>24</sup> Given these dire projections, these groups need to be educated about the enormity of the cost of Alzheimer's and the financial burden it represents.

### Need to intensify our search for strategies that save money

If we don't work to identify Alzheimer's disease early, we miss potential for cost savings. If we don't work to intervene smartly with caregivers to enhance the support they receive, we miss other important opportunities for cost savings. There is a growing body of research that documents the cost effectiveness of particular care strategies for persons with Alzheimer's, but these findings are not always utilized to inform how care is provided.

The recent report from The Lewin Group, under contract with the national Alzheimer's Association, illustrates the financial savings of a five-year delay in the onset of Alzheimer's. This study found that slowing the progression of the disease by five years would save \$200 billion a year in the U.S.<sup>25</sup> (See Figure 7.)

**Figure 7. Impact of a 5-year delay in onset on costs, Americans age 65+ with Alzheimer's disease and other dementias, 2010 - 2050**



Source: *Changing the Trajectory of Alzheimer's Disease*, June 2010

### Recommendations

1. Replicate and expand evidence-based models that have been successful at improving care and saving money in the treatment of persons with Alzheimer's and their caregivers, e.g., early detection, strong caregiver support models, better management of medical care.
  - a. Minnesota should investigate the econometric model developed at the University of Wisconsin that shows screening and identifying individuals with Alzheimer's in early stages results in overall cost savings to the state of \$10,000 per diagnosed patient.<sup>26</sup>

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- b. The state should support expansion of programs that use the New York University caregiver counseling model proven to increase the duration of family caregiving and delay nursing home placement by 18 months on average.<sup>27</sup>
  2. The state should advocate for several changes that would promote cognitive screening for Alzheimer's and make it more universally available and reimbursed through health insurance.
    - a. Minnesota stakeholders should applaud the Centers for Medicare and Medicaid Services (CMS) inclusion of cognitive assessment as a required element of the new annual wellness benefit to be covered by Medicare beginning in 2011.
    - b. Minnesota stakeholders should urge the U.S. Preventive Services Task Force that decides which preventive services must be covered without cost-sharing for younger populations, to specifically deliberate on inclusion of cognitive screening.
    - c. Cognitive screening and Alzheimer's care should be included as a required activity to obtain Health Care Home payments for the appropriate patient caseloads under Medicare, Medicaid or private coverage.
  3. Include measurement of Alzheimer's care outcomes in the recently awarded Medicare demonstration of the health care home set to begin in Minnesota in 2011.

## **Legislative Actions to Implement Recommendations**

1. The commissioner of human services, in conjunction with the commissioner of health and the Minnesota Board on Aging and other appropriate state offices, shall jointly estimate differences in the outcomes and costs of caring for those with Alzheimer's disease and other dementias (using current practice as a baseline), compared to the outcomes and costs resulting from: 1) earlier identification of Alzheimer's and other dementias, 2) improved support of family caregivers, and 3) improved collaboration between medical care management and community-based supports.
2. The commissioner of health, in consultation with the commissioner of human services, within the department's responsibility for implementation of the health care home, shall collect baseline data and then compare the annual cost and quality of health care for individuals diagnosed with Alzheimer's served through health care homes, to the cost and quality for comparable individuals served in non-health care home clinics.
3. The commissioners of health and human services shall develop and include a health care home requirement for dementia care competence for certified providers receiving care coordination payments for serving individuals over 65 years of age.
4. The commissioners of health and human services shall, when appropriate, include a dementia care component in Minnesota's application for health reform grants under the federal Patient Protection and Affordable Care Act (PPACA), and shall apply, as appropriate, for available care transition grants to establish demonstration(s) of best practices for transitions of persons with Alzheimer's disease and other dementias.

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## 7. Intensify Research and Surveillance

### Need for more volunteers to participate in Alzheimer's research

In order to support Minnesota research of Alzheimer's, more volunteers are needed who are interested in participating in research, so that our state's researchers have more information on Minnesotans with Alzheimer's and can apply their findings to promoting best treatment and care practices within Minnesota as well as more broadly.

### Need for more accurate prevalence data for Minnesota

Due to the small numbers of Alzheimer's diagnoses compared to other chronic conditions, data on prevalence of the disease has been limited. In areas where studies are yielding good data on the prevalence of dementia, researchers are able to provide estimates of the presence of cognitive impairment and even the "conversion" rate from mild cognitive impairment (MCI) to Alzheimer's within the population. This effort needs to expand and include more individuals from diverse populations around the state.

### Need to expand and sustain research

Minnesota has a strong tradition of excellent research that has contributed greatly to the advancement of our understanding of Alzheimer's and other dementias. The federal government is the main funder of promising research in our state, and continued funding is essential so that research on prevention, treatment and finding a cure for Alzheimer's can continue and intensify.

### Recommendations

1. Create and fund a web-based dementia clearinghouse and resource center to serve persons concerned about Alzheimer's and other dementias. The clearinghouse would provide information about research findings, disease management and information on how individuals can enroll in ongoing research studies.
2. Use information from cognitive screenings completed in Minnesota as part of the new annual wellness visit covered by Medicare as a means of developing better statewide prevalence data on cognitive impairment in Minnesota, by reporting the data to Minnesota Community Measurement for further research, validation and development of estimates.
3. Increase the number of individuals in Minnesota who participate in community research studies on Alzheimer's, especially those from diverse communities.
4. Continue aggressive research for prevention, treatments and a cure for Alzheimer's.

*"If we could simply postpone the onset of Alzheimer's disease by five years, a large share of nursing home beds in the United States would empty. And if we could eliminate it, as Jonas Salk wiped out polio with his vaccine, we would greatly expand the potential of all Americans to live long, healthy and productive lives — and save trillions of dollars doing it."*

*--NYT,*

*October 27, 2010*

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## Legislative Actions to Implement Recommendations

1. The commissioner of health, working in cooperation with the Alzheimer's Association Minnesota—North Dakota and other appropriate groups, including but not limited to medical provider groups, care coordinators, family members and social workers, shall contract with a vendor to develop a Dementia Clearinghouse website for: a) professionals and researchers working with persons with Alzheimer's disease and other dementias, and b) individuals with mild cognitive impairment or dementia and their families.
  - a. For the professionals and researchers, the website shall include comprehensive information on Alzheimer's and the care of those affected, including information about early identification, assessment and diagnostic tools for use in screening and diagnosis, best practice models, recent research findings, and approaches that are culturally appropriate and suitable for care of those with Alzheimer's in primary care settings across Minnesota.
  - b. For individuals with the disease and their families, the website shall provide educational resources regarding risk factors and potential prevention of and treatments for the disease, and opportunities to participate in dementia research.
2. The director of the office of minority and multicultural health of the Minnesota Department of Health shall report on the barriers and incentives for expanded participation of persons from ethnic, immigrant and tribal communities in research on Alzheimer's disease and other dementias.

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## Conclusion and Next Steps

The increase in Alzheimer's disease in Minnesota will bring enormous cost and burden to individuals with the disease, their families and caregivers, employers, communities and the state. The huge financial burden will be borne by all these groups, and without any change, the burden will be heaviest on public funding, as the numbers of individuals with Alzheimer's increase, and their family caregivers are stretched beyond their capacity and exhaust their resources.

There is no available treatment to stop or reverse the progression of Alzheimer's disease and there are no Alzheimer's "survivors." We must intensify our collaborative efforts to find treatments and a cure for this disease. However, there is hope for a better future through implementation of strategies that foster early identification and improved management of the disease, improvement in the standards of care for dementia, provision of strong support for caregivers and preparation of our communities. If these transformations are incorporated into our medical, long-term care and community systems through a statewide approach, we can reduce overall costs and provide better care and management that will improve the quality of life for affected individuals and their families.

*If these transformations are incorporated into our medical, long-term care and community systems through a statewide approach, we can reduce overall costs, and provide better care and management that will improve the quality of life for affected individuals and their families.*

### Potential impact of recommendations

The transformation envisioned by the working group will not only improve care, but will deliver a return on investment and cost savings in several areas.

1. It will provide incentives for medical providers to do cognitive assessment at Medicare annual wellness visits, which will result in early identification, and will allow the person, caregiver and the rest of the team to put a plan in place, which will prevent costly mistakes or hurried decisions.
  - Studies underway at the Minneapolis Veterans Administration clinics indicate that patients will accept cognitive screening, and that promising results are achieved when dementia is identified and care planning and management is begun immediately.<sup>28</sup>
  - The Weimer-Sager study recently completed in Wisconsin estimated a savings to the state of \$10,000 per person identified through early identification and screening.<sup>29</sup>
2. It will educate and train all allied health professionals within their primary curriculum and continuing education about Alzheimer's' disease and best practices for treating the disease, which will increase the knowledge, skills and abilities of all those professionals and increase their ability to provide good patient care when Alzheimer's is identified.
  - Rigorous ongoing studies in Olmsted County, Minnesota, will allow us to understand our state's own prevalence of mild cognitive impairment (MCI) and rates of conversion to MCI from normal functioning, and from MCI to dementia, and the related health and long-term care costs associated with all stages of the disease.<sup>30</sup>
  - The state's own proposal to Medicare for the recently awarded demonstration of the health care home estimates a \$27 per person per month savings over all the older patients treated, primarily due to better management of chronic conditions including Alzheimer's and other dementias.<sup>31</sup>

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3. It will make evidence-based strategies for providing support to caregivers universally available throughout the state, which will mean caregivers will care longer, which will result in dramatic savings in long-term care costs because caregivers won't place their family members in nursing homes as quickly.
    - The right kind of support of spousal caregivers has been shown in a randomized, controlled trial to delay nursing facility placement by 18 months compared to the usual support model provided in an Alzheimer's Disease Research Center.<sup>32</sup> This intervention is currently being translated into rural and urban program sites in Minnesota, which are demonstrating positive outcomes that are similar to the original research. These findings are extremely significant, since the largest cost in Alzheimer's care is long-term nursing home use, averaging about \$50,000 per year in Minnesota.
    - Controlled research in non-Minnesota Veterans Administration outpatient clinics is demonstrating significantly better outcomes for caregivers in terms of reduced strain, depression and perception of unmet needs for their family member with Alzheimer's, when the clinics partner with Alzheimer's Association chapters to provide caregiver support. Publication of these results as well as medical cost comparisons between intervention and control groups is expected soon.<sup>33</sup>
  4. It will encourage medical providers to talk with their patients and their families regarding palliative, hospice and end-of-life care early in the disease, which means that patients and families can put plans in place for the future, and hurried decisions made without knowledge of the patients' preferences can be minimized.
    - In LaCrosse, Wisconsin, when the community organized to consistently identify the wishes of individuals for care at the end of their life and then respected those wishes, the community achieved their goal of respecting those choices 97 percent of the time.<sup>34</sup>

## Implementation timeline

The working group is committed to seeing that the recommendations contained in this report are implemented. The urgency of these actions cannot be overstated, as we stand on the threshold of a permanent shift in the age of our state's population, and a dramatic increase in the number of our citizens with Alzheimer's disease.

The working group believes that the action steps proposed would, if implemented, provide a strong impetus to activate the state's many sectors to begin transforming their services and programs to more effectively meet the needs of persons with Alzheimer's and their families.

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## Group responsible for implementation

To facilitate and monitor implementation, the working group proposes establishing a second generation Alzheimer's Disease Working Group, convened by the Alzheimer's Association with membership to include caregivers, individuals with early stage Alzheimer's, health and long-term care providers and key state agency and medical group representatives, and members from ethnic, immigrant and tribal communities.

This group, called Minnesota Prepares for Alzheimer's 2020 (MPA 2020), would monitor progress on the recommendations and legislative actions, provide a coordinating point for implementation activities, develop action steps for recommendations that do not require legislative action, hold dialogues with leaders and organizations in ethnic, immigrant and tribal communities, prepare a periodic progress report for the Governor and legislators and alert the state as new knowledge or breakthroughs become available.

### Cost of inaction is too great

The working group is acutely aware of the financial and budgetary situation facing the state during the 2011-2012 biennium. Money will be tight. But the cost of inaction is greater than the costs of taking the actions described here.

A recent report by the national Alzheimer's Association, based on a study completed for the association by The Lewin Group, indicates that, absent a breakthrough to delay the point of onset or slow the progression of Alzheimer's, the total annual cost attributable to Alzheimer's within the U.S. will top \$1 trillion per year by 2050. Delaying the onset of Alzheimer's by just five years would reduce this cost by almost 41 percent, or about half a trillion dollars. Slowing the progression of the disease could save almost \$200 billion per year compared to no change.

However, even if a cure were found today, Minnesota would still have nearly 100,000 citizens and their families needing education regarding the disease and support from informal and formal services for every day functioning. Their needs would not diminish.

The working group believes that Minnesota can respond to the soaring financial and human toll of Alzheimer's disease by establishing itself as the first state prepared for Alzheimer's disease, taking bold action now to improve care and support in the areas we have outlined. Through this proactive response, Minnesota will be able to dramatically reduce the human toll of Alzheimer's in the lives of its citizens and realize substantial cost savings for families, employers and state government.

*Through this proactive response, Minnesota will be able to dramatically reduce the human toll of Alzheimer's in the lives of its citizens and realize substantial cost savings for families, employers and state government.*

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# Appendix A

## Legislative Charge to the Alzheimer's Work Group

### Laws of MN, 2009, Chapter 159, Sec 110

#### Section 110. Alzheimer's Disease Working Group

Subdivision 1. Establishment; members. The Minnesota Board on Aging must appoint, unless otherwise provided, an Alzheimer's disease working group that consists of no more than 20 members including, but not limited to:

- (1) At least one caregiver of a person who has been diagnosed with Alzheimer's disease;
- (2) At least one person who has been diagnosed with Alzheimer's disease;
- (3) A representative of the nursing facility industry;
- (4) A representative of the assisted living industry;
- (5) A representative of the adult day services industry;
- (6) A representative of the medical care provider community;
- (7) A psychologist who specializes in dementia care;
- (8) An Alzheimer's researcher;
- (9) A representative of the Alzheimer's Association;
- (10) The commissioner of human services or a designee;
- (11) The commissioner of health or a designee;
- (12) The ombudsman for long-term care or a designee; and
- (13) At least two public members named by the governor.

The appointing authorities under this subdivision must complete their appointments no later than September 1, 2009.

Subd. 2. **Duties; recommendations.** The Alzheimer's disease working group must examine the array of needs of individuals diagnosed with Alzheimer's disease, services available to meet these needs, and the capacity of the state and current providers to meet these and future needs. The working group shall consider and make recommendations and findings on the following issues:

- (1) trends in the state's Alzheimer's population and service needs including, but not limited to:
  - (i) the state's role in long-term care, family caregiver support, and assistance to persons with early-stage and early-onset of Alzheimer's disease;
  - (ii) state policy regarding persons with Alzheimer's disease and dementia; and
  - (iii) establishment of a surveillance system to provide proper estimates of the number of persons in the state with Alzheimer's disease, and the changing population with dementia;
- (2) existing resources, services, and capacity including, but not limited to:
  - (i) type, cost, and availability of dementia services;
  - (ii) dementia-specific training requirements for long-term care staff;
  - (iii) quality care measures for residential care facilities;
  - (iv) availability of home and community-based resources for persons with Alzheimer's disease, including respite care;
  - (v) number and availability of long-term dementia units;
  - (vi) adequacy and appropriateness of geriatric psychiatric units for persons with behavior disorders associated with Alzheimer's and related dementia;
  - (vii) assisted living residential options for persons with dementia; and
  - (viii) state support of Alzheimer's research through Minnesota universities and other resources; and
- (3) needed policies or responses including, but not limited to, the provision of coordinated services and supports to persons and families living with Alzheimer's and related disorders, the capacity to meet these needs, and strategies to address identified gaps in services.

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Subd. 3. **Meetings.** The board must select a designee to convene the first meeting of the working group no later than September 1, 2009. Meetings of the working group must be open to the public, and to the extent practicable, technological means, such as Web casts, shall be used to reach the greatest number of people throughout the state. The members of the working group shall select a chair from their membership at the first meeting.

Subd. 4. **Report.** The Board on Aging must submit a report providing the findings and recommendations of the working group, including any draft legislation necessary to implement the recommendations, to the governor and chairs and ranking minority members of the legislative committees with jurisdiction over health care no later than January 15, 2011.

Subd. 5. **Private funding.** To the extent available, the board on aging may utilize funding provided by private foundations and other private funding sources to complete the duties of the Alzheimer's disease working group.

Subd. 6. **Expiration.** This section expires when the report under subdivision 4 is submitted.

May 19, 2009

## Appendix B

### Alzheimer's Disease Working Group Expert Team Members

The following individuals volunteered their time—from one meeting to several dozen hours of time—in order to join with appointed working group members and bring their special expertise and perspectives to the working group process.

	Name	Title/Affiliation
1.	Michelle Barclay	Vice President of Programs, Alzheimer's Association, Co-chair of Early Identification and support expert team
2.	Judy Berry	Founder, Dementia Care Foundation
3.	Marsha Berry	Professional Education Manager, Alzheimer's Association
4.	Brad Boevey, MD	Neurologist, Mayo College of Medicine
5.	Jenna Bowman	Advocacy Coordinator, Alzheimer's Association
6.	Connie Brown	Community Member
7.	Maria Cofrancesco, RN, CNP, CNS	Dementia Care Coordinator, Minneapolis VA Health Care System
8.	Diane Coplan	Community Member
9.	Susan Czapiewski, MD	Geropsychiatrist, Minneapolis VAMC and UMMC Memory Clinic
10.	Carol Feldheim, RN	Nurse Consultant, Tealwood Care Centers
11.	David Foster	Family Caregiver, Community Member, Co-chair of Achieving Quality in Services expert team
12.	Karen Gallagher	Social Worker, Park Nicollet Health System
13.	Joseph Gaugler, PhD	Associate Professor, Center on Aging, U of MN, School of Nursing
14.	David Goldberg	Early Stage Services Coordinator, Alzheimer's Association
15.	Mary Gorfine	Coordinator, Olmsted County Vital Aging Commission
16.	Bret Haake, MD, MBA	Assistant Medical Director of Neurosciences and Head of Department of Neurology at Regions, HealthPartners
17.	Gayle Hallin	Former Executive Director, Evercare Minnesota
18.	Leah Hanson, PhD	Co-director, Alzheimer's Research Center at Regions, HealthPartners
19.	Laura Hemmy, PhD	Assistant Professor, Department of Psychiatry, University of Minnesota
20.	John Hobday	CEO and Founder, HealthCare Interactive, Inc.
21.	Alvin Holm, MD	Geriatrician, HealthEast
22.	Kate Houston	Planning Director, Metropolitan Area Agency on Aging
23.	Robin Hunter, JD, CPA	Principal, Boeckermann, Grafstrom and Mayer
24.	Jeanne Jacobson	Director, Master of Arts in Nursing and Doctor of Nursing Practice Program, University of St. Catherine
25.	Linda Johnston	Director, Human Services, MN Chippewa Tribe
26.	Bob Karrick	Vice President and Chief Operating Officer, Smead Manufacturing Company
27.	Barb Keigan	Community Member
28.	Faten Khoury	Clinical Director and Medical Family Therapist, University of Minnesota
29.	Jessica Kirchoff	Occupational Therapist, North Memorial Home Care
30.	Cindy Leach	Housing Manager, The Alton Memory Care
31.	Andrine LeMieux, PhD, LP	Clinical Neuropsychologist, The Duluth Institute
32.	Jonathan Lips, JD	Attorney at Law, J.W. Lips, LLC, Chair, Financial issues expert team
33.	Angela Lunde	Education Outreach Coordinator, Mayo Clinic-ADRC
34.	Jeff Maloney	Chief Operating Officer, Evercare
35.	Connie Marsolek	Social Worker, Park Nicollet Health System

36.	<i>Olivia Mastry, JD</i>	<i>(Meeting facilitator), Health and Health Care Law Attorney, Community Member</i>
37.	<i>J. Riley McCarten, MD</i>	<i>Medical Director, Geriatric Research, Education and Clinical Center, Minneapolis VA Health Care System, Co-chair, Health and Healthcare expert team</i>
38.	<i>Siobhan McMahon, GNP</i>	<i>Nurse Practitioner Gerontology, St Mary's/Duluth Clinic</i>
39.	<i>Jen McNertney</i>	<i>Director of Advocacy for Housing &amp; Community Services, Aging Services of Minnesota</i>
40.	<i>Susan McPherson, PhD, ABPP, LP</i>	<i>Associate Professor of Neurology, University of Minnesota</i>
41.	<i>Lynne Morishita, GNP, MSN</i>	<i>Consultant in Geriatric Health Care</i>
42.	<i>Christine Mueller, PhD</i>	<i>Professor and Chair, Adult and Gerontological Health Cooperative, University of Minnesota</i>
43.	<i>Jan Mueller</i>	<i>(staff to working group), Field &amp; Advocacy Director, Alzheimer's Association</i>
44.	<i>Alice Neve</i>	<i>Librarian and Outreach Supervisor, St Paul Libraries</i>
45.	<i>Jane Pederson, MD, MSc</i>	<i>Director, Medical Affairs, Stratis Health</i>
46.	<i>Bob Power</i>	<i>Medical Economist, Private Consultant</i>
47.	<i>Tanya Rand</i>	<i>Social Worker, Bethesda Hospital's Outpatient Services, HealthEast</i>
48.	<i>Earl Reiland, JD</i>	<i>Merchant &amp; Gould P.C., Attorney, Community Member</i>
49.	<i>Patricio Reyes, MD</i>	<i>Program Director, Regions Center for Dementia and Alzheimer's Care, HealthPartners</i>
50.	<i>Karen Riddle, MD, OTR</i>	<i>Rehabilitation Doctor, North Memorial Home Care</i>
51.	<i>Kathryn Ringham</i>	<i>Medical Social Worker, Wilder Memory Loss Adult Day Program and Wilder Memory Club, Amherst H. Wilder Foundation</i>
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68.	<i>Robin Weis</i>	<i>Aging Program Director, Minnesota River Area Agency on Aging</i>
69.	<i>Maureen Wixsten</i>	<i>Clinical Nurse Specialist in Adult Health, Minneapolis VA Health Care System</i>
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# Appendix C

## Common types of dementia and their typical characteristics

Source: *Alzheimer's Disease 2010 Facts and Figures* (reprinted from that report)

Type of Dementia	Characteristics
Alzheimer's disease	<ul style="list-style-type: none"><li>* Most common type of dementia; accounts for an estimated 60 – 80 percent of cases.</li><li>* Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.</li><li>* Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles).</li></ul>
Vascular dementia (also called multi-infarct, post-stroke dementia or vascular cognitive impairment)	<ul style="list-style-type: none"><li>* Considered the second most common type of dementia.</li><li>* Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries.</li><li>* Symptoms often overlap those of Alzheimer's, although memory may not be as seriously affected.</li></ul>
Mixed dementia	<ul style="list-style-type: none"><li>* Characterized by the hallmark abnormalities of Alzheimer's and another type of dementia – most commonly vascular dementia, but also other types, such as dementia with Lewy bodies.</li><li>* Recent studies suggest that mixed dementia is more common than previously thought.</li></ul>
Dementia with Lewy bodies	<ul style="list-style-type: none"><li>* Pattern of decline may be similar to Alzheimer's, including problems with memory and judgment as well as behavior changes.</li><li>* Alertness and severity of cognitive symptoms may fluctuate daily.</li><li>* Visual hallucinations, muscle rigidity and tremors are common.</li><li>* Hallmarks include Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.</li></ul>
Parkinson's disease	<ul style="list-style-type: none"><li>* Many people who have Parkinson's (a disorder that usually involves movement problems) also develop dementia in later stages of the disease.</li><li>* The hallmark abnormality is Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.</li></ul>
Frontotemporal dementia	<ul style="list-style-type: none"><li>* Involves damage to brain cells, especially in the front and side regions of the brain.</li><li>* Typical symptoms include changes in personality and behavior, and difficulty with language</li><li>* No distinguishing microscopic abnormality is linked to all cases.</li><li>* Pick's disease, characterized by Pick's bodies, is one type of Frontotemporal dementia.</li></ul>
Creutzfeldt-Jakob disease	<ul style="list-style-type: none"><li>* Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.</li><li>* Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.</li><li>* Caused by the misfolding of prion protein throughout the brain.</li></ul>
Normal pressure hydrocephalus	<ul style="list-style-type: none"><li>* Caused by the buildup of fluid in the brain.</li><li>* Symptoms include difficulty walking, memory loss and inability to control urination.</li><li>* Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.</li></ul>

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## Appendix D

### Services Available to Meet Needs of Persons with Alzheimer's and Capacity of the State and Providers to Meet these Needs

#### Type, cost and availability of dementia services

The Minnesota Department of Human Services (DHS) has gathered local information about the current capacity and gaps in services, housing and nursing facility needs to support older persons in Minnesota every two years since 2001. All counties in Minnesota are asked to complete a survey of local capacity to meet long-term care needs of their older residents, including any significant gaps in services. This information is submitted to DHS, and staff summarizes and analyzes the data for planning and program development purposes.

It is important to note that the gaps analysis does not specifically address or consider the needs of older persons with Alzheimer's and other dementias. However, a number of the services identified by the survey are frequently sought and used by people with Alzheimer's and their caregivers, e.g., community and in-home services as well as housing with services, assisted living and nursing facilities. The results from the 2009 gaps analysis are included in the discussions of service capacity in the sections (below) on home and community-based services, assisted living and nursing facilities. Table 3 provides a summary of the current capacity in key service and housing options used by persons with Alzheimer's and other dementias.

#### Home and community-based services

Minnesota's home and community-based service system for older persons includes a wide variety of services, from preventive services to supportive services essential to help persons stay healthy, remain in their homes and age in place in their communities.

Of all these services, the ones most frequently utilized by persons with Alzheimer's and their caregivers include respite care, caregiver support, adult day health services and escorted transportation.

#### Respite care

Accessible and affordable respite care is perhaps the number one requested service by family caregivers of persons with Alzheimer's. Respite care can be provided in a home setting, a group setting such as in a community center or place of worship, or in a residential facility such as an assisted living or a nursing facility. It can also be provided either by paid staff or volunteers. Since 70 percent of those with Alzheimer's are being cared for in their homes or the homes of their caregivers, the need for respite is very high. It means that the caregiver can get away from the stresses of the caregiving role and do something for themselves.

To be effective, respite care must meet the unique needs of both the person and the caregiver, and thus, options are important. Unfortunately, the options are often limited. One of the key issues is affordability, especially for those persons who are not eligible for waiver services under Medical Assistance (MA).

#### Caregiver support services

This is a package of services that includes support groups for caregivers, training in how to provide care to a frail elder, and access to a caregiver coach who is a professional easily accessible to the caregiver to answer questions and provide options and suggestions. In researching the availability of support groups and caregiver coaching on MinnesotaHelp.info™, it became clear that this service is the most available of all the services for caregivers in Minnesota. Many of these programs are participating in the federally-funded demonstration projects administered by the Board on Aging to test the effectiveness of various models for caregiver support.

#### Adult day care and adult day health programs

Adult day care (or adult day health as it is also called) includes a continuum of programs, from a medical model or

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rehab-focused program, to a social model that offers social activities in a group setting with some individualized services. According to the MinnesotaHelp.info™ database, there are currently 80 adult day centers in the state. Most provide a daily schedule of activities that includes some help with activities of daily living (ADLs), meals, group and individual activities and transportation to and from the center. The demand is relatively small and the cost relatively high, but demand has been growing as more adult children use day care as “respite” while they work during the day.

## **Escorted transportation**

In nearly every assessment done of the service needs of older persons, transportation is the number one priority. Transportation service is used to get to needed community destinations and as a way to stay connected after a person is no longer able to drive. Escorted transportation is essential for many persons with Alzheimer’s since they inevitably will come to a point when they may lack the self-management skills to use transportation services independently. Some services, like Metro Mobility, allow and encourage an escort to ride along with the recipient. In volunteer driver programs, the volunteer driver often serves as an escort for the recipient. Unfortunately, the demand for transportation usually outstrips the supply of services available, and demand is expected to grow as persons in the older age groups become unable to drive themselves or their family members.

## **County gaps analysis for home and community-based services**

- The gaps analysis covers 45 home and community-based services.
- The gaps reported for in-home respite care and caregiver training and support have remained constant for the past few years.
- The percent of counties reporting gaps in out-of-home respite and adult day care has increased from 2007 to 2009 (from 47 percent to 58 percent for respite and from 44 percent to 51 percent for adult day care).
- A growing proportion of counties indicate that transportation is an increasing gap.
- These results indicate that while counties are experiencing expansions in some services, they are also experiencing decreases in services where they have not experienced gaps in the past.
- Funding reductions at all levels are affecting the supply of many services at the community level.

## **Memory care units in assisted living facilities**

Any senior housing in Minnesota that offers some type of service package to residents is considered to be a type of “housing with service establishment” and must be registered as such with the Minnesota Department of Health. The building itself must comply with applicable housing and safety codes, and the services must be provided by appropriately licensed providers. Residents usually pay a fixed monthly base fee that includes the rent and a “package” of services.

Some low-income, frail residents of housing with services establishments receive “customized living” services through the Medicaid Elderly Waiver (EW) program. Customized living is the name used for assisted living services provided through the EW program. EW, like other waiver programs, pays for needed individualized services only, not rent. In general, the percentage of EW recipients who use customized living services has not changed significantly since 2005, although the number has grown from 6,375 clients to 9,200. The majority of the recipients eligible for customized living are estimated to have some form of memory concerns, likely Alzheimer’s or other dementia.

## **County gaps analysis for senior housing**

When asked about gaps in specific types of housing, over half of counties reported there was not sufficient capacity across a variety of types of subsidized housing. Table 1 shows the percentage of counties reporting housing gaps in specific areas. The highest gaps are in the subsidized rental apartments with supervision and health services available, the type of housing most likely to serve low-income persons with Alzheimer’s.

**Table 1. Gaps in Housing Capacity in 2009**

	Counties Reporting Gaps			
	Subsidized		Market Rate	
	#	%	#	%
Rental Apartments with Supervision/Health Care Services	50	60%	32	38%
Rental Apartments with Support Services Only	48	57%	29	34%
Rental Apartments with No Services	33	39%	16	19%
Other housing options (such as Board & Care, Residential Care)	45	54%	43	51%
Adult family foster care	47	56%	41	48%
Corporate adult foster care	40	48%	43	51%

Source: Statewide Long Term Care Gaps Analysis Survey, 2009

These gaps are relevant because of Minnesota’s large supply of assisted living. Over the past twelve years there has been a steady increase in the availability of housing choices for older persons in Minnesota, particularly market rate options. The Department of Health’s registry of housing with services establishments keeps a running total of such establishments. In 2001, there were 780 housing providers in Minnesota that also offered service packages to residents. By 2010, this number had grown to 1,807 facilities, with approximately 78,000 units, 60,000 of which are assisted living. This gives Minnesota the highest number of assisted living in the nation, when measured by units per 1,000 elderly 65+. Of these 1,807 facilities, 103 report that they advertise themselves as memory care facilities. (There may be more that provide these services than report.)

### Memory care units within nursing facilities

According to the Department of Health, there are 186 memory care units within the nearly 400 nursing facilities in the state. (There may be more that provide these services than report.) The Minimum Data Set (MDS) data on the characteristics of persons in nursing facilities indicates that nearly three-fourths (71 percent) of residents have some degree of cognitive impairment, and it is likely that these residents have Alzheimer’s or other dementia. (See Table 2.)

**Table 2. Cognitive Impairment in Nursing Home Residents by State, 2007**

State	Total # Residents	Level of Cognitive Impairment (%)		
		None	Very Mild/ Mild	Severe
Minnesota	70,112	29	30	41
United States Total	3,196,923	31	27	42

Note: these figures include all individuals who spent any time in a nursing home in 2007. Percentages for each state may not sum to 100 percent because of rounding. Created from data from Nursing Home Data Compendium 2008 Edition

### County gaps analysis of nursing home memory care services

Counties were asked to report their perceptions of localized need for “specialty” services to meet unique long-term care needs in their service area. The largest gap reported was in the availability of dementia care specialty beds, where 56 percent of counties reported a gap. About half of counties (48 percent) reported a gap in heavy care, complex medical management beds. Nearly all counties reported sufficient capacity in post-acute rehabilitation beds with only 7 percent reporting a gap in this area.

Minnesota has closed approximately 12,000 nursing facility beds since 1994, and DHS staff who administer the nursing facility program are watching the supply of beds closely, because in some areas, the supply is limited. Overall, Minnesota still has more beds than the national average, but access and adequacy could become problems in some parts of the state. Under current law, if the supply of available beds slips below the state average, there are provisions for possible expansion of beds in that area.

**Table 3. Number and Cost of Key Services and Housing for Persons with Alzheimer’s and Caregivers**

Service	Estimated Number of Programs in Minnesota	Average Cost to Person or Caregiver
Respite services – in-home <sup>1</sup>	355	\$20.44/hour or \$92.08/day
Respite services – out-of-home <sup>2</sup>	616	\$20.44/hour or \$92.08/day
Caregiver Counseling <sup>3</sup>	52	Sliding fee scale or none
Caregiver Support Groups <sup>4</sup>	112	Sliding fee scale or none
Escorted Transportation <sup>5</sup>	136	Sliding fee scale, ticket or donation
Adult day care and day health <sup>6</sup>	135	\$40 - \$85/day
Assisted Living – memory care <sup>7</sup>	103	\$4,267/month
Nursing Facility – memory care <sup>8</sup>	186	\$219/day

**Geriatric psychiatry units**

According to MinnesotaHelp.info™, there are just eight geriatric psychiatry units providing service to persons with Alzheimer’s disease, other dementias or mental health issues that require inpatient hospitalization and assessment. Most are located within or administered by hospitals. They describe their services as geared toward serving those in crises and in immediate need of inpatient hospitalization for purposes of stabilization, assessment, diagnosis and development of a plan for next steps in treatment or placement. There is a growing need for facilities such as geriatric psychiatry units that will treat older persons with Alzheimer’s or other dementias who have been referred from assisted living or nursing facility memory care units because of difficult behavior. Often, these persons are denied readmission to that facility following their stay in the psychiatric unit. This situation leaves families, counties or health plans (whichever is the responsible party) with few or no options. Possible strategies to address this might involve looking at the pros/cons of expanding the supply of these units within hospitals, finding some incentives for certain nursing facilities to specialize more in this type of service, or increasing the ability of current nursing facilities with special units to care for and effectively manage persons with difficult behaviors.

1. In-home respite includes: home care, volunteer respite, homemaking, and companion programs. The count of 355 is based on a May 2010 query of the MinnesotaHelp.info database using the keyword “respite.” The cost is based on the July 2010 Elderly Waiver Service Rate Limits.
2. Out-of-home respite includes: assisted living and nursing facilities, adult day care, other group residential settings, and hospitals. The count of 616 is based on a May 2010 query of the MinnesotaHelp.info database using the keyword “respite.” The cost is based on the July 2010 Elderly Waiver Service Rate Limits.
3. The count of 52 is based on an August 2010 query of the MinnesotaHelp.info database using the keyword “caregiver.”
4. The count of 112 is based on an August 2010 query of the MinnesotaHelp.info database using the keyword “caregiver.”
5. The count of 136 is based on an August 2010 query of the MinnesotaHelp.info database using the keyword “transportation.” The programs selected for this count included features such as: assists passengers to and from vehicle, escorts available for appointments, escorts to door at destination.
6. The count is based on an August 2010 DHS Licensed Program List.
7. The count of 103 is based on an August 2010 query of the MinnesotaHelp.info database using the keyword “assisted living.” The programs selected for this count included features such as: dementia care, early stage memory care, memory loss, and special care programs for Alzheimer’s. The cost is the national average for Alzheimer’s specialty care in the assisted living setting reported in Alzheimer’s Disease 2009 Facts and Figures.
8. The cost is the national average for Alzheimer’s specialty care in the nursing facility setting reported in Alzheimer’s Disease 2009 Facts and Figures.

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As part of its movement to close large state hospitals, the state has built nine community behavioral health hospitals in communities around the state, where persons with acute mental health needs can be stabilized and treated on a short-term basis. Part of the strategic plan for these hospitals includes expanded intervention training for the staff of nearby facilities that serve older persons with behavioral issues, primarily those with Alzheimer's and other dementias, so that the facility staff can increase their ability to effectively manage their residents with difficult behaviors.

## Special services for those with young onset of Alzheimer's disease

According to the database contained in the MinnesotaHelp.info™ directory, there were 36 listings of agencies and programs to serve those with young onset of Alzheimer's disease. These include support groups, resources for screening and diagnosis, educational programs, day care programs, out-of-home respite programs and caregiver support programs. The programs were located in the metro areas of the state with a scattering of sites around the more rural portions of the state. There are gaps in services for this group. According to the focus group held with persons who have young onset of Alzheimer's, they are interested in getting more information on a variety of interventions aimed at improving disease knowledge and management, promoting physical, cognitive and mental health, delaying progression of the disease, reducing excess disability and enhancing their quality of life.

Persons with early stage Alzheimer's were recently deemed eligible for Social Security Disability Income under a humanitarian clause. This means they become eligible without the long delays that often occur for applicants to this program. Since the disease makes it increasingly difficult to work, eligibility for this income assistance program is a very important benefit.

## Special Grants and Demonstrations

There are some additional demonstration projects underway within DHS and the Board on Aging that are testing new models for services to persons with Alzheimer's and their caregivers.

## Minnesota Board on Aging Memory Care Initiatives

MBA has received federal funds to set up a number of innovative and evidence-based program models for persons with Alzheimer's and their caregivers.

**1. Memory Care Initiative** provides people in the earliest stages of dementia with optimal control over their lives to help sustain cognitive function, reduce premature decline and reduce emotional and psychological distress of family caregivers. The initiative is currently being pursued at eight locations throughout the state. At each site a care coach will:

- Identify people with early dementia and their caregivers
- Refer to the cooperating clinic for a complete medical work-up
- Engage in support planning with both the person with early dementia and their caregiver in cooperation with the clinic
- Provide ongoing coaching, education, support planning and services tailored to those in early stage dementia including Memory Club, exercise, nutrition, financial counseling referrals, driving guidance and other similar services

The goal is to screen 4,000 people, and to identify and serve 250 people with early stage dementia and their caregivers.

**2. Minnesota Family Memory Care** is the award-winning translation of the New York University (NYU) Caregiver Intervention, a model that was evaluated in a longitudinal randomized controlled trial conducted over 21 years at NYU. The study demonstrated the success of its model of enhanced support for caregivers by reducing caregiver

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depression, the effects of caregiving on physical health and reactions to problem behaviors caused by Alzheimer's disease, while postponing institutionalization of the person with dementia. The major mediator of these outcomes is improved support from family and friends and services of a certified caregiver coach. This model is being delivered by 13 providers across Minnesota.

**3. Tailored Care™ Caregiver Assessment Demonstration** is a caregiver assessment process for supporting family caregivers. T-Care™ is an evidence-based approach grounded in the caregiver identity theory, developed by Dr. Rhonda Montgomery of the University of Wisconsin-Milwaukee. The T-Care™ process uses a screen and thorough assessment to measure and score the caregiver's emotional levels and needs, and offers customized strategies via decision-making maps to address the identified emotional stress and needs. Currently, Minnesota has more than twenty certified caregiver coaches providing T-Care™ assessments and customized services at more than 20 locations. Minnesota is one of six states piloting this process.

**4. Powerful Tools for Caregivers** is an evidenced-based caregiver education intervention strategy based on the research of Kate Lorig et al., and the adaptation of Legacy Caregiver Services located in Oregon. Minnesota is promoting this through its already existing caregiver support programs around the state.

## Quality assurance and improvement

The state has a number of current requirements and initiatives in quality assurance and improvement that provide services to persons with Alzheimer's and their caregivers, and these are described below. The state is placing increased priority on performance measurement and is working to improve its efforts in monitoring and reporting on the quality of the services it funds.

### Statutory requirement for dementia training

Under Minnesota law, staff of licensed facilities that identify themselves as providing dementia or memory care must receive basic dementia care training. Licensed facilities under this law include nursing facilities, housing with services, home care agencies and adult day services. Additionally, under the Disclosure of Special Care Statute, licensed housing with services providers must provide written information to consumers of their services, including the dementia care training received by their staff members. The areas of required training include: 1) an explanation of Alzheimer's disease and related disorders; 2) assistance with activities of daily living; 3) problem-solving with challenging behaviors; and 4) communication skills.

### Quality measures for residential facilities

In January 2006, the departments of health and human services published a web-based nursing home report card. Hosted on the MDH website ([www.health.state.mn.us/nhreportcard](http://www.health.state.mn.us/nhreportcard)) the Minnesota nursing home report card is believed to be the most comprehensive nursing home report card in the nation.

It is interactive in that it allows users to view results for a specific facility, or, alternatively, to specify a location they are interested in and select the quality measures they consider most important. The report card then provides a list of all facilities that meet the geographic criteria and sorts the list according to the scores of those facilities on the seven quality measures, with emphasis placed on the measures prioritized by the user. The user can then select a facility from the list and see its scores on the seven quality measures, using a five star rating.

The report card averages approximately 2,000 unique visits per month. Seven quality measures have been developed and are currently in use:

- Quality of life and satisfaction
- Clinical outcomes
- Amount of direct care staffing
- Direct care staff retention

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- Use of temporary staff from outside pool agencies
  - Proportion of beds in single bed rooms
  - Inspection findings from certification surveys

When selecting the measures most important to them, report card users increasingly and overwhelmingly prioritize resident outcomes, i.e., quality of life and satisfaction, inspection findings, and clinical outcomes, over process or structural measures.

The departments are working on several enhancements to the report card at this time:

- Adding family satisfaction as a new quality measure
- Including non-MA facilities in the report card
- Incorporating features allowing users to focus on dementia and short-stay care
- Making actual data available in addition to the five star rating

Work has also begun on development of a report card for assisted living facilities that would be similar in many ways to the nursing home report card. Once that is completed, the plan is to develop a report card for the remainder of home and community-based services, which includes an estimated 5,000 agencies and programs.

## **Improving access and information**

The Minnesota Board on Aging has provided information and assistance to older persons and their families through the Area Agencies on Aging for over a decade. In response to 2001 long-term care legislation, the MBA developed an easy-to-use website called [MinnesotaHelp.info](http://MinnesotaHelp.info)<sup>TM</sup>. The MBA has recently worked to improve the quality of this website. One of the new features that users can now access is the use of key words to narrow their search for programs. These keywords now include Alzheimer's, dementia, early stage Alzheimer's and early onset. Staff also added questions related to Alzheimer's and other dementias to the online caregiver and consumer decision tools that are part of MinnesotaHelp.info<sup>TM</sup> and trained all the Senior LinkAge Line<sup>®</sup> staff on the use of these new tools to better serve users who have concerns about Alzheimer's disease.

The MBA has worked to improve the quality of service provided through its Senior LinkAge Line<sup>®</sup> service by expanding the toll-free telephone information and assistance service, improving the technology used to make the service available, bolstering in-person assistance provided by the service and creating linkages between the Senior LinkAge Line<sup>®</sup> and the assessment, screening and eligibility determination functions of the counties.

## **Performance incentive payment program (PIPP)**

In 2007, DHS initiated the Performance Incentive Payment Program (PIPP). PIPP is a voluntary, competitive program designed to reward innovative projects within nursing facilities that improve quality or efficiency or contribute to rebalancing long-term care. Selected projects receive temporary operating payment rate increases of up to 5 percent, under amendments to their contract with DHS. Of the money awarded, 80 percent is contingent upon implementing the program as described, and the remaining 20 percent is contingent upon achieving specified outcomes.

As of August 2010, 162 nursing facilities have participated in the program, representing over 60 different quality improvement projects. Several PIPP projects have addressed improved care of those with dementia. Some examples are described below.

- A nursing facility in St. Cloud is educating staff on validation theory. This approach provides a compassionate and personalized approach to assisting residents who are exhibiting a range of behaviors.
- Several nursing facilities in west central Minnesota implemented a strength training program to reduce anxiety and depression as well as improve physical functioning among their residents with dementia.

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- A nursing facility in the Metro Area enhanced several areas outside around the facility so that residents with dementia could safely be outdoors.
  - A large number of affiliated nursing facilities around the state developed and implemented a resident-centered program to assess and treat pain in residents with dementia.
  - Several nursing facilities in the Metro Area collaborated with a dance theatre company to implement a program of dancing to address mood and depression in residents with dementia.
  - Several nursing facilities in rural Minnesota implemented a music therapy program to address worsening behavior among residents with Alzheimer's.

The results of these small demonstrations are reported and shared among all the facilities to encourage replication of promising practices.

## **State support of Alzheimer's research through Minnesota universities and other resources**

The Minnesota Partnership for Biotechnology and Medical Genomics is a unique collaborative venture between the Mayo Clinic, University of Minnesota and State of Minnesota. The Partnership seeks to position Minnesota as a world leader in biotechnology and medical genomics applications that will result in important new medical discoveries, thereby improving health care for patients and supporting the development of new business and jobs in Minnesota. To learn more about the Partnership, visit its web site at [www.minnesotapartnership.info](http://www.minnesotapartnership.info).

Within this large and innovative collaborative effort, several Alzheimer's projects have been funded since 2003. They include:

- \$1.3 million for predicting Alzheimer's disease
- \$1.8 million for imaging Alzheimer's disease
- \$2.2 million for evaluating Alzheimer's drug efficacy using magnetic resonance techniques
- \$0.9 million for diagnosis of Alzheimer's by amyloid plaque imaging
- \$3.5 million for an advanced molecular neuroimaging infrastructure grant

This represents the only research specific to Alzheimer's that has been funded in large measure by State of Minnesota funding.

## **Importance of communities in preparing Minnesota for Alzheimer's**

To most persons, their communities provide the essentials of life: a place to live, connections with neighbors and friends nearby, local shops, places for social gatherings, places to work or volunteer, amenities like parks, libraries, places of worship, clinics and a variety of other features. Depending on the size of the community, some may have many more of these elements, others may have less. However defined, most people desire a sense of community where they can contribute and also be supported when they need it.

Communities play a critical role in supporting persons with Alzheimer's and their family caregivers, since they can provide assistance and surround the person with their support and include them in activities. Because of the disease, persons with Alzheimer's need the familiarity of the same physical location and familiar landmarks, people and places. In addition, the caregivers are more likely to reach out for support from trusted friends and neighbors if they live in a community where they feel connected.

Preparing communities to play this vital role in supporting persons with Alzheimer's and their caregivers is important work and a critical part of preparing Minnesota for the future. Fortunately, there are a number of initiatives in the state that bode well for integrating these efforts.

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## **MBA Communities for a Lifetime Initiative**

The MBA recently completed a legislative report on the concept and implementation of Communities for a Lifetime (CFL). This concept has been growing in popularity and refers to the features that communities need in order to be good places to grow up and grow old, and be supportive of persons of all ages and abilities. The report describes current efforts within communities to redesign physical infrastructures such as transportation and housing, strengthen social infrastructures including a sense of connection with neighbors and others in the community, and expand the service infrastructure, so that essential services and amenities are present, e.g., health facilities, parks, libraries, entertainment, grocery stores, pharmacies.

Based upon the recommendations in that report, MBA has created a website [www.mnlifetimecommunities.org](http://www.mnlifetimecommunities.org) that pulls together the resources that communities need to work on this effort. It also includes a list of neighborhoods, communities and counties that have a CFL initiative underway.

As this concept builds momentum, it seems natural to integrate the ideas for how communities can prepare for Alzheimer's into these efforts since they share a common vision of the vital role that communities can play in the lives of their residents of all ages and abilities. MBA also has made CFL a priority for the work of its designated Area Agencies on Aging, so there are natural linkages between the CFL work of these agencies and the caregiver support programs they fund.

## **Conclusion**

Minnesota has a number of long-term care and community services and programs that are currently available to serve all older persons, including those with Alzheimer's and their caregivers. Many of these programs are funded through public dollars; therefore they are targeted at persons who are low-income and in need of long-term care. The exception to this are the programs funded under the federal Older Americans Act that are available to all persons over 60 at all income levels, but targeted to those who are low-income (but not eligible for Medicaid), frail, minority, and isolated.

However, there are many gaps reported in home and community-based services and some facility-based services that serve persons with Alzheimer's and their caregivers. The largest gaps are in the services that are most often requested by caregivers, that is, affordable respite that meets their unique needs, and escorted transportation. In addition, counties report ongoing gaps in availability of affordable housing with health services and supervision as well as gaps in availability of nursing facilities that provide dementia units. There also appears to be a gap in available geriatric psychiatry units since there is a very limited supply of them around the state, and most serve as a crisis inpatient unit for many different populations.

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# Appendix E

## Focus Group Responses to Recommendations

The working group wanted to obtain more information on the unique needs of several groups within Minnesota. Once the group had drafted its preliminary recommendations, these were shared with four focus groups, one each for: 1) persons with early stage Alzheimer's disease; 2) persons from the African-American community; 3) persons from the Hmong community; and 4) persons from the American Indian community. Their responses are included below.

### Early stage Alzheimer's group

- The focus group members emphasized the need for more non-drug interventions for the disease, and for these to be reimbursed or covered by insurance or other funding.
- Examples of these interventions include brain fitness, arts, exercise, socialization, cognitive training.
- There needs to be more research on brain training and fitness, e.g., validate the effectiveness of brain fitness programs.
- There should be more education about warning signs.
- Family practice physicians should be identifying and diagnosing early stages of Alzheimer's more often.
- Medical records should include information on cognition and memory problems.
- Education about the disease and detection should begin at a young age, even high school.
- There should be mandated dementia training as part of medical school training and continuing medical education for all physicians.
- Stigma surrounding the disease needs to be reduced – Alzheimer's is not part of the typical pattern of aging.
- People with disease need to speak out more and be aware of opportunities to engage and advocate.

### Focus group with African-American community

- The focus group members saw Alzheimer's disease as part of normal aging.
- The African-American community is very committed to caring for their family members with Alzheimer's in their homes, and felt they would be unlikely to use formal community-based services to provide assistance.
- The focus group members indicated that there is distrust of government and even stronger distrust of insurance companies, fearing that a diagnosis of Alzheimer's will eliminate insurance coverage.
- Increasing awareness of the disease is considered very important.
- The group suggested that the best avenue for education about the disease within their community is through the church community.

### Focus group with Hmong community

- The focus group members said that in their culture, relatives are expected to care for their elders and elders are valued.
- Aging is seen as one big issue, and there is little understanding of specific diseases and their causes or symptoms.

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- Many still practice Shamanism and would see those with Alzheimer's as needing spiritual healing.
  - Many elders do not like medical tests and do not adhere to medication requirements.
  - Elders would most likely not participate in research studies due to distrust and transportation issues.
  - Paperwork is usually overwhelming due to issues of reading and understanding English.
  - Someone who provides education must look like them and speak their language.
  - They would probably not attend support groups because their type of communication is much less formal than that.
  - Hmong families are changing, with movement to greater use of services such as assisted living and nursing homes.
  - State support is critical and how the state listens to family members is very important.
  - They are concerned about low wages in nursing homes and believe that homes should have culturally appropriate staff.
  - Highest priority services are home and community-based services including culturally-based respite care.

### **Focus group with American Indian community**

- Focus group members said that Indian elders would be willing to participate in research on Alzheimer's to better understand memory issues and their impact on the community.
- To educate the community about Alzheimer's and memory issues, the members suggested use of storytelling along with scientific facts and videos followed by a talking circle.
- Presenters of information could be non-Indian, have an academic background, but need to build rapport with the members and teach in an atmosphere that is less like a classroom and more homey. Presenting information in a positive manner with an emphasis on wellness is also important, as well as promoting brain health through use of word search and puzzles, and teaching survival skills.
- Memory issues need to be addressed more than they are now.

In summary, there appear to be several common themes across the focus groups, including:

- The need for more education and information for the general community (not just older persons) to reduce stigma about Alzheimer's, although this needs to be done in ways that are culturally appropriate.
- More emphasis on survival skills and "non-drug" interventions that persons can use to more effectively cope with the symptoms of Alzheimer's disease.
- An array of services and programs is critical to supporting persons with Alzheimer's disease, so that each person and family can find the services that best support their unique situation.

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# Appendix F

## Charge to the Minnesota Prepares for Alzheimer's 2020 (MPA 2020)

### Group Charge

1. To monitor progress related to final recommendations of the Alzheimer's Disease Working Group (ADWG), including:
  - o Lead efforts to pass proposed legislation.
  - o Work with Minnesota state agencies on rule and regulation changes.
  - o Advocate for recommended changes within medical associations and academic institutions.
  - o Continue cost saving analysis as research data is made available.
2. Lead next steps towards transforming Minnesota into the first state in the nation prepared for Alzheimer's and other dementias.
3. Create awareness and education strategies for policymakers, consumers, communities and employers regarding relevant actions recommended in the report.

### Participation

- Former ADWG members, medical and long-term care providers, state agency staff (including Minnesota Department of Human Services, Minnesota Board of Aging, Minnesota Department of Health), representatives of health systems and health plans, universities, researchers, legislators, law enforcement officials, individuals living with early-stage dementia, caregivers, representatives from rural and diverse communities, business leaders and Alzheimer's Association staff and volunteers.
- Members may volunteer or be invited to participate.

### Leadership

- The Alzheimer's Association Minnesota—North Dakota will take initial and primary leadership of this newly formed group.
- A Steering Committee will be formed once initial membership is confirmed.
- Timeline
  - Recruitment during November and December 2010
  - Announce formation of group at press conference in January 2011
  - First meeting in February 2011
  - Meet quarterly – all meetings are open to the public and interested parties

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## Endnotes

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