



## Summary of Report to the Legislature

*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.*

*—From The Age of Alzheimer's, op-ed by Sandra Day O'Connor and others  
New York Times, October 27, 2010*

### Impact of Alzheimer's disease in Minnesota

Between 2010 and 2050, the number of Minnesotans with Alzheimer's disease will soar from 90,000 to 200,000. As Minnesota experiences an historic increase in its older population over the next 40 years, the number of people with Alzheimer's disease and other dementias is expected to double for people ages 75-84 and triple for those over age 85. Alzheimer's disease does not discriminate since it affects all people regardless of race and ethnicity.

The total cost of care for these individuals could reach an estimated \$20 billion per year in Minnesota by 2050, most of that spent in the Medicaid budget for assisted living and nursing home care when families have exhausted their personal and financial resources.

Efforts to find effective treatments and a cure for Alzheimer's must continue. However, Minnesota should begin now to implement evidence-based strategies proven to reduce suffering and provide near-term cost savings if:

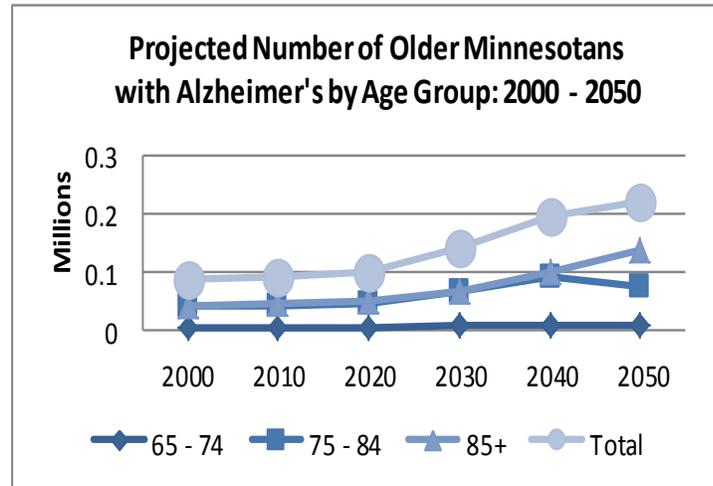
- The disease is diagnosed early.
- Medical care is well managed.
- All providers meet standards for dementia care.
- Nursing home placement is delayed through strong support of family caregivers.
- Patients and their families have a plan for palliative, hospice and end-of-life care.

This report recommends actions that would transform our medical and long term care systems and communities in ways that would achieve these results.

## Human and financial toll

The rise of 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. Alzheimer's disease takes a human toll in that it is the fifth leading cause of death among persons over age 65 and the sixth leading cause of death for all ages in the United States.

Beyond the stigma and disability for the affected person, perhaps more than any other disease, Alzheimer's human toll extends to families. An estimated 10 million individuals in the U.S. provide unpaid care to persons with Alzheimer's or other dementias. In 2009, 200,000 Minnesotans caring for family members with Alzheimer's provided an estimated 223 million hours of unpaid care, which represents a value of \$2.6 billion. Over half of these caregivers are working adults who experience lost productivity, work days and income. These caregivers report high levels of stress, chronic illness and depression.



## Financial burden borne by all

Alzheimer's also brings with it a financial burden that is borne by all. Without changes, from 2010 to 2050, the total costs of care for Americans age 65 and older with Alzheimer's disease will increase five-fold, from \$172 billion to \$1.08 trillion per year. (*The Lewin Group, 2010*) In Minnesota alone, these costs could reach \$20 billion, most of that being Medicaid dollars. (*DHS estimate, 2010*)

These dollar amounts represent the direct costs of care to all, including Medicare, Medicaid, private insurance and the out-of-pocket costs of individuals. The average cost for care for those with the disease versus those without it is three times greater for Medicare and nine times greater for Medical Assistance programs.

Average Per Person Payments by Source for Health and Long-Term Care Services, Medicare Beneficiaries Aged 65 and Older, with and without Alzheimers Disease and 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 total payments exactly due to rounding  
 Source: Alzheimer's Association. 2010 Facts and Figures

## **Alzheimer's Disease Working Group**

To more fully understand and address the mounting Alzheimer's crisis in Minnesota, the 2009 Minnesota Legislature called on the Minnesota Board on Aging to establish the Alzheimer's Disease Working Group to study the status of Alzheimer's disease in Minnesota and make recommendations to the Legislature for needed policy and program changes that will prepare the state for the future. This legislation was enacted as a result of advocacy efforts of the Alzheimer's Association Minnesota—North Dakota to assess the state's readiness for a major increase in the incidence of Alzheimer's disease.

The legislation required the working group to examine the needs of individuals with Alzheimer's disease, the services available to meet the needs, and the capacity of the state and providers to meet current and future challenges. 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.

## **Priority Recommendations**

In response to its legislative mandate, and to reduce the human and fiscal toll of Alzheimer's disease, the working group has developed a set of priority recommendations. The recommendations are framed by the overarching vision that Minnesota must be prepared for the budgetary, social and personal impacts of Alzheimer's disease through a comprehensive, person-centered approach to the disease that is reinforced through transformation of the systems that touch the lives of persons with Alzheimer's and their caregivers.

## Priority Recommendations

### 1. Identify Alzheimer's Early

#### **What is the problem**

- ▶ Medical providers do not assess the cognitive health of their patients regularly.
- ▶ Individuals are not aware of the importance of early identification of dementia.

#### **Why is this important**

- ▶ Early identification improves the ability to manage the disease.
- ▶ The person and family can plan for the future before the disease progresses.
- ▶ Research now points to the potential for dramatic financial savings to the state in reduced long-term care, to Medicare in medical services and to families and communities when Alzheimer's is identified early and disease management begins immediately. (See table below showing benefits identified by Weimer and Sager, 2009.)

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
<b>Interventions:</b>			
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 saves due to early intervention Source: David L Weimer and Mark A. Sager, <i>Early identification and treatment of Alzheimer's disease: social and fiscal outcomes. Alzheimer's and Dementia</i> 5 (2009). 215 – 226.			

#### **Recommendations**

1. Assess the cognitive health of all Medicare patients at the new annual wellness visit included as a new 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 and awareness campaigns.
3. Provide information about the disease to patients with early stage Alzheimer's as soon as possible after diagnosis.

#### **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 working with persons with Alzheimer's and other dementias and researchers, and b) affected individuals with mild cognitive impairment or dementia and their families. (Full version of this legislative action is included in the research section on page 11.)

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

### What is the problem

- ▶ Ineffective management of medical care provided to the Alzheimer's patient leads to high levels of costly health care and earlier nursing home placement.
- ▶ Up to now, there has been no funding stream to pay medical providers for the type of care most effective for those with Alzheimer's.
- ▶ There has been little attention to the advance planning needs of Alzheimer's patients and their families.

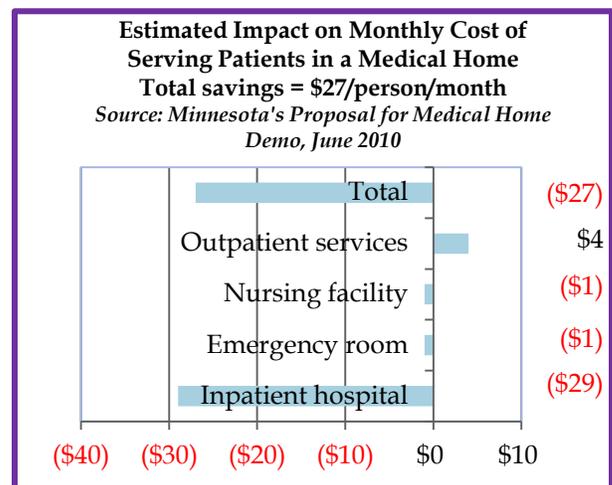
### Why is this important

- ▶ Good care for Alzheimer's requires a team approach, which is the basis for the health care home model.
- ▶ Physicians can play a critical role in helping their patients and their families talk about palliative care and end-of-life care.
- ▶ Research has shown the health care home model reduces disparities in health care outcomes.

### 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 care transitions.
2. 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.
3. Provide assistance to patients and families in making critical decisions regarding care, including palliative, hospice and end-of-life care, in a culturally appropriate manner.

### Legislative Actions to Implement Recommendations



*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.*

1. The Minnesota Board on Aging shall offer information about all stages of Alzheimer's (with special attention to early stage), and information for individuals and family members about improving disease knowledge and management, promoting overall physical and cognitive health and enhancing quality of life, through its consumer assistance service or through links to other information. This information will 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 should 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 should be posted on the recommended Dementia Clearinghouse website.

### 3. Achieve Quality and Competence in Dementia Care

#### **What is the problem**

- ▶ Caregivers face many barriers in navigating the available options for services for their family member with Alzheimer's and for themselves throughout the whole course of the disease.
- ▶ There are few accepted quality standards that families can use to judge the quality of dementia care of health and long-term care providers and little information about providers that meet accepted standards.

#### **Why is this important**

- ▶ Families need specific, accurate and comparable information about services in order to determine which options are most appropriate for their relative with Alzheimer's.
- ▶ Strong, tailored support for family caregivers has been shown to prolong caregiving and delay nursing home placement by 18 months compared to traditional supports for caregivers, resulting in major cost savings of at least \$50,000 per year in nursing home costs.

#### **Recommendations**

1. Provide easy access to information about services across all stages of the disease, in order to smooth transitions between services and settings and ensure transfer of essential clinical records.

2. Adopt the Alzheimer's Association Dementia Care Practice Recommendations as the "gold standard" for dementia care in Minnesota, and make information about these standards widely available to all caregivers, paid and unpaid. (These recommendations provide a comprehensive set of standards for patient care, staffing and training, and environmental requirements for high quality care of those with Alzheimer's and other dementias.)
3. Create and disseminate a flexible curriculum for caregiver education, based on these standards, and create a system of credentialing, public recognition and rewarding providers that are "dementia competent," including appropriate cultural competence.

Service Quality Evaluation Matrix: Questions to Ask <sup>i</sup>
Are resources available in your community?
Are resources well-known, accessible, 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 Working Group)</i>

### 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

### What is the problem

- ▶ Communities need guidance in how to prepare for growing numbers of their residents with Alzheimer's and other dementias.
- ▶ 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.

### Why is this important

- ▶ Communities are an essential source of affordable and nearby support for persons with Alzheimer's and their caregivers.
- ▶ As the number of persons with Alzheimer's in communities grows, the general public needs accurate information about the disease and the impact of the disease on individuals, their caregivers and their communities.

### **Recommendations**

1. Create and disseminate a list of key elements that communities 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 to help them assess their progress toward development of these key elements.
3. Develop, enhance and improve the variety and supply of informal and formal support for caregivers of persons with Alzheimer's including the concept of "community as caregiver."
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 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 in its communities for a lifetime website. Best practice models for ethnic, immigrant and tribal communities should also be provided on this website.

## **5. Train Medical Providers in Dementia Care**

*"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,*

### **What is the problem**

► Physicians currently receive only two hours of training in dementia care at the University of Minnesota medical school and have no requirements for dementia training in their continuing education classes. The curricula for other health professionals lack adequate coverage of these topics as well.

### **Why is this important**

► Since medical providers will be caring for a much older population with a higher incidence of Alzheimer's in the future, it is important that they have a good understanding of dementia and its management.

### **Recommendations**

1. Mandate the inclusion of information on Alzheimer's and other dementias in the training curriculum and continuing education requirements for 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 disease management.
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.

### **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 geriatrics 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**

### ***What is the problem***

- ▶ The growth in the numbers of individuals with Alzheimer's will take a huge financial toll, reaching an annual cost of an estimated \$20 billion in Minnesota by 2050.
- ▶ Because very few families have the level of resources required to pay for the intensive care that individuals with Alzheimer's need, much of the cost will be borne by state and federal governments.

### ***Why is this important***

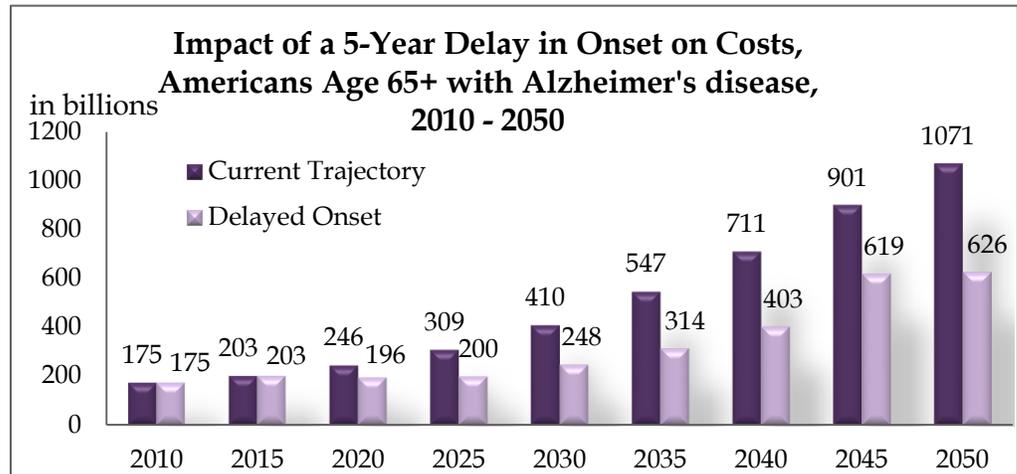
- ▶ Given the dire projections about the future growth in the cost of Alzheimer's, the general public and policymakers need to be educated about these costs and the financial burden it represents.
- ▶ We need to intensify our efforts to identify and implement evidence-based strategies that offer cost savings in the care of Alzheimer's patients.

### ***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., aggressive detection, caregiver support models, better care management.
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.
3. Include Alzheimer's care in the recently awarded Medicare demonstration of the health care home (a.k.a. medical home), in Minnesota beginning 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 component 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.

## 7. Intensify Research and Surveillance

### **What is the problem**

- ▶ More volunteers are needed to participate in Alzheimer's research underway in Minnesota, including individuals from ethnic, immigrant and tribal communities.
- ▶ We still do not have evidence-based prevention, treatment or possible cures for Alzheimer's.

### **Why is this important**

- ▶ Knowing more about Alzheimer's and the course of the disease increases the likelihood that individuals will volunteer for research trials and this will advance treatments and the search for a cure.

### **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 screenings to collect statewide data to develop more accurate state prevalence data.
3. Increase the number of individuals from diverse communities involved in community research studies on Alzheimer's.
4. Continue aggressive research for prevention, treatments and a cure for Alzheimer's.

### Action Steps 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 working with persons with Alzheimer's disease and other dementias, and researchers, and b) affected individuals with mild cognitive impairment or dementia and their families.
  - For the professionals and researchers, the website should 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.
  - For individuals affected with the disease and their families, the website should provide educational resources regarding risk factors and potential prevention of 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.

*"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*

## Conclusions 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, providing support for caregivers and preparing 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 improves the quality of life for affected individuals and their families.

#### A. 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. (References to the following research studies are included in the full report's endnotes.)

1. It will provide incentives for physicians to do cognitive screening 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 Clinics show strong feasibility of screening protocols and promising results when dementia is identified and care planning and management is begun immediately. Results are to be published when ready.<sup>ii</sup>
  - A recent study completed in Wisconsin estimated a savings of \$10,000 per person identified through early identification and screening.
2. It will educate and train all allied health professionals within their primary curriculum and in 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 and rates of conversion to Mild Cognitive Impairment (MCI) from normal functioning and from MCI to dementia and the related health and long-term care costs associated with all stages of the process.
  - The state's own proposal to Medicare for a 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 or other dementias.
3. It will make evidence-based strategies for providing support to caregivers universally available in the state, which will mean caregivers will care longer, which will result in dramatic savings in

*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 improves the quality of life for affected individuals and their families.*

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 care in an Alzheimer's Disease Research Center. This intervention is currently being translated into rural and urban program sites in Minnesota. The Minnesota sites are demonstrating positive outcomes for caregivers that are similar to the original research. These findings are extremely significant, since the largest cost for Alzheimer's care is long-term nursing home use.
  - 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 medical clinics partner with Alzheimer's Association chapters to provide care. Publication of these results as well as medical cost comparisons between intervention and control groups is expected soon.
4. It will encourage physicians to talk with their patients and their families regarding palliative, hospice and end-of-life care early in the disease, which means that plans can be put in place and hurried decisions made without knowledge of the patients' preferences can be minimized.
- In LaCrosse, Wisconsin, when the community organized to consistently identify individual wishes for care at the end of their life and then respected those wishes, the community achieved their goal of respecting the person's choices 97 percent of the time.

### **B. 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.

### **C. Group responsible for implementation**

To facilitate and monitor implementation, the working group also 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, including members from diverse communities.

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

the Governor and legislators on progress and alert the state as new knowledge or breakthroughs become available.

**D. 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 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 the "nothing changes" scenario 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 breakthrough.

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.

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

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 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 many of its citizens and realize substantial cost savings for families, employers and state government.

### Alzheimer's Disease Working Group

	<b>Name</b>	<b>Title/Affiliation</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
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 J. 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 Schoepfoerster, MD	Geriatrician, Geriatric Services of Minnesota
19.	Carol Shapiro	Caregiver, Community Member
20.	John Thomas, MD	Medical Director, Hospice of the Red River Valley

**Chair and Co-chairs of Expert Teams**

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**Achieving Quality**

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Deb Holtz

**Early Identification and Support**

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**Dementia-Competent Communities**

Gerise Thompson

Catherine Sampson

**Research**

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**Financial Issues**

Jonathan Lips, JD

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