

**The Final Report of the
Task Force on the Effect of
Alzheimer's Disease
in Oklahoma**

Executive Summary

On April 29, 2008, Governor Brad Henry signed into law Senate Bill 2186 establishing the Task Force on the Effect of Alzheimer's disease in Oklahoma to "assess the current and future impact of Alzheimer's disease; examine the existing industries, services and resources addressing the needs of persons living with Alzheimer's disease, their families and caregivers; and to develop a strategy to mobilize a state response to this public health crisis."

The task force studied the current infrastructure in the state and reviewed services available to those with Alzheimer's disease and their caregivers. Based on these findings, the task force brought forth recommendations to fill gaps in services and address the needs of the growing number of those diagnosed with the disease and the unique challenges it presents.

According to the Alzheimer's Association's *2009 Facts and Figures* report, more than 5 million people are currently living with Alzheimer's disease in the United States. In Oklahoma, there were an estimated 62,000 people living with Alzheimer's disease as of the year 2000 and this number is estimated to grow to 74,000 Oklahomans by 2010, an increase of 19 percent.¹ There is currently no cure for Alzheimer's disease.

With life expectancy in the United States increasing and "baby-boomers" reaching retirement age, the prevalence of Alzheimer's disease and other dementias will increase exponentially beyond age 65. The number of people affected by Alzheimer's disease, the most prevalent form of dementia, is growing at a faster rate than the progress being made in discovering the means to cope with this emerging epidemic. According to the Centers for Disease Control and Prevention, Alzheimer's deaths have grown 47 percent since 2000, while most other terminal diseases have seen a decrease in percentage of deaths.

The approaching crisis in the national health care system stems not only from the growing number of older people at risk for dementia, but also the rising cost of labor intensive care. Neither the general public nor its policy makers appreciates the magnitude of the pending public health disaster. Alzheimer's disease currently costs the United State government nearly \$148 billion a year. The average annual cost of care per person is estimated to be between \$40,000 to \$60,000, with nearly 500,000 new patients every year.²

The statistics indicate that by the year 2050, the United States will have more than 16 million individuals, up from five million today, affected by Alzheimer's disease and requiring medical care and institutionalization.³ The patterns of growth in the aging population are going to profoundly affect how care is provided for people with Alzheimer's disease.

These patterns will reach their full impact as the "baby-boom" generation ages into late life 20 to 30 years from now. These trends, which foretell the devastating toll of dementia, have already begun to shape the future strategic plans of many public and private organizations.

Almost 10 million Americans provide unpaid care for a person with Alzheimer's disease or related dementias. In 2008 alone, caregivers provided 8.5 billion hours of unpaid care, a contribution valued at \$94 billion. In Oklahoma, it is estimated that there are currently 113,475 caregivers providing 97,951,999 hours of unpaid care to a loved one with Alzheimer's disease. The market value of unpaid care in Oklahoma alone is \$1,087,267,190.⁴

One study of family and other unpaid caregivers of people with Alzheimer's and related dementias found that 57 percent were employed full-time or part-time. Of those employed caregivers, two-thirds said they had to go in late, leave early or take time off because of caregiving. Eight percent had to quit work entirely.⁵

While there are a number of services available to those with Alzheimer's disease and related dementias in Oklahoma, there are still significant steps to be taken to provide adequate and dignified care. It is estimated that 70 percent of people with Alzheimer's disease live at home, where care is generally paid for out-of-pocket by their families, presenting a unique set of challenges to this population.⁶ While there are existing resources in the state, often caregivers are overwhelmed and unable to identify or search for these services and many programs face gaps in service, often due to funding issues.

It is worth noting that remarkable progress has been made in the last 30 years in understanding Alzheimer's disease. Today the field has access to a rich array of talents, tools, ideas, knowledge, and experiences from diverse disciplines, providing unique opportunities for quantum leaps in uncovering cause(s), treatments, and new models of care. New discoveries and leads have begun to provide some measure of hope for interventions that could delay the onset of disabling symptoms and enable individuals to continue functioning independently for longer periods of time.

It is with this in mind, that the Task Force on the Effect of Alzheimer's disease in Oklahoma has generated twenty-three recommendations addressing three main areas: promoting and improving standards of care; identifying and promoting support services; and, creating a formal system for recording statistics. The complete list of recommendations include the following:

- **Establish and fund a statewide information and referral system for those with Alzheimer's disease, their caregivers and their families to connect with local case management, support services and information.**
- **Medical and direct care staff at any nursing home, assisted living facility, adult day center, skilled nursing facility, home health agency or hospice agency that is licensed by the state or receiving state funding should be required by law to complete four hours of in-service training per year in Alzheimer's and dementia related care.**
- **Create culturally competent public service announcements to raise the level of public education about brain health and the warning signs of Alzheimer's and dementia, some of which should specifically target populations with disproportionately higher rates of these diseases.**
- **Revise Disclosure Form 613 with the Oklahoma Department of Health to include specific information that qualifies the facility as a specialized care facility. Facilities should not be allowed to advertise an Alzheimer's unit until the disclosure form has**

been approved designating their unit as such. The form must specify minimum standards a facility must maintain to be designated as an Alzheimer's care unit.

- **Require that the diagnosis of Alzheimer's disease and related dementias be made an essential competency in state medical schools by 2012, while also providing incentives to physicians to complete dementia-specific modules in the re-licensing process (every 3 years).**
- **Create a student loan forgiveness program for medical school students who specialize in geriatrics and practice in the state of Oklahoma.**
- **Dedicate a funding source for all future long-term care services.**
- **Increase the daily reimbursement rate for funding for Adult Day Center services, as well as increase the number of locations across the state.**
- **Provide enhanced funding to compensate facilities that expend dollars for staff education related to Alzheimer's care.**
- **Implement an automatic reminder on Electronic Medical Records requiring physicians' offices to provide referral of diagnosed patients to the Alzheimer's Association upon diagnosis of Alzheimer's disease or related dementias.**

In addition, due to the complex nature of these issues, the Task Force recommends that the Governor appoint a Cabinet-level Secretary of Aging and the Legislature form a single committee in both the Senate and House of Representatives to handle all aging-specific legislation.

¹ 2009 Alzheimer's Disease Facts and Figures Report, Alzheimer's Association, Pg 23.

² Virginia Commission on Alzheimer's Disease and Related Disorders – Strategic Plan, Pg. 1.

³ 2009 Alzheimer's Disease Facts and Figures Report, Alzheimer's Association, Pg. 19.

⁴ 2009 Alzheimer's Disease Facts and Figures Report, Alzheimer's Association, Pg 43.

⁵ The MetLife Caregiving Cost Study: Productivity Losses to U.S. Businesses; MetLife Mature Market Institute National Alliance for Caregiving, July 2006.

⁶ Texas Council on Alzheimer's disease and related disorders, 2006 Bi-Annual Report.