



Presented to  
**Chet Culver, Governor**  
and the  
**Iowa General Assembly**  
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Prepared by the  
Department of Elder Affairs

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# Final Report

## Alzheimer's Disease Task Force

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### Executive Summary

To many, the words “Alzheimer’s disease” trigger a sense of fear and foreboding but little understanding of the reality of the disease. To those who attended the meetings of the Alzheimer’s Disease Task Force, the transformative power of the disease became palpable and sobering. The urgency surrounding the need for Iowa to mobilize a state response to this public health crisis was consistently reinforced through the testimony of presenters, the direct experiences shared by task force members, and most profoundly, by Iowans whose lives were shaped by Alzheimer’s disease.

The recommendations included herein are in response not solely to the legislative directives in Senate File 489, but also to the concerns and appeals voiced by those who participated in this public process. The scope of the task force’s work was enormous. Fully exploring every facet of the issues related to or impacted by Alzheimer’s disease was not possible within the timeframe of the task force’s deliberations. It was the personal and professional expertise that task force members brought to the table combined with the information provided through presenter testimony and written materials that formed the basis of this report to the Governor and the General Assembly.

The task force recommends that the following strategies (in no particular order) be undertaken within the next 1-2 years (Tier 1):

1. Establish an office for Alzheimer’s disease or related disorders within state government. This office would not replace or duplicate any services currently offered by the Area Agencies on Aging, the Alzheimer’s Association, or other agencies, but would act as a referral source to local services.
2. Increase and enhance training and education requirements about Alzheimer’s disease or related disorders for all direct care employees including, but not limited to, long-term care settings, assisted living, elder group homes, residential care, adult day facilities and home health care.
3. Broaden the spectrum of people who are required to receive training specific to Alzheimer’s disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer’s disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/monitoring, and ombudsmen.
4. Ensure that all recommendations coalesce with other initiatives and programs within the state, such as the Direct Care Worker Task Force Recommendations, Alzheimer’s Association, Area Agencies on Aging, the Hartford Center Grant, Iowa Respite and Crisis Care Coalition and the UI Center on Aging and Geriatric Education Center.



5. Support and assist the rapidly increasing numbers of Iowans with Alzheimer's disease or related disorder by providing a wide array of home and community based services such as adult day services, respite care, and affordable transportation as well as Assisted Living, occupational therapy, speech therapy, social work services, dieticians, and others as these may delay premature nursing facility placement.
6. Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel.
7. Implement a statewide campaign to educate healthcare providers regarding early detection instruments, such as AD8 and Mini-Cog, as early detection could prepare patients and families for what to expect.
8. Make Medicaid Waivers a significant factor in helping address the many needs of Iowans dealing with problems associated with Alzheimer's disease or related disorder, such as adult day services, assisted living, respite care, occupational therapy, speech therapy, social work services, dieticians, and affordable transportation as a means to delay premature institutionalization.
9. Given that the Medicaid Waiver is a long process, undertake a three step approach to address the needs of persons with Alzheimer's disease or related dementia:
  - Step 1:* Allow individuals with a diagnosis of early on-set Alzheimer's disease or related disorders to be served in excess of the current maximum number of clients under the Ill and Handicapped Waiver.
  - Step 2:* Increase the expenditure limits under the Elderly Waiver to give parity with other waivers including but not limited to the Ill and Handicapped Waiver, the Brain Injury Waiver and the Mental Retardation Waiver for persons with a diagnosis of Alzheimer's disease or related disorder. (This recommendation affects patients older than 65.)
  - Step 3:* Establish an Alzheimer's disease or related disorder specific waiver to place greater importance on the issue and needs comparable to the Brain Injury Waiver and the HIV/Aids waiver and without regard to the age of the person with Alzheimer's disease or related disorder.
10. Compile an analysis of Iowa's population by county and age to determine current utilization and future service needs of caregivers and persons with Alzheimer's disease or related disorder to support development of programs and services.
11. Review current trends and the impact in the Long Term Care rebalancing efforts affecting persons with Alzheimer's disease or related disorder.
12. Modify existing community needs assessment process to include questions that would identify and quantify at-risk people with Alzheimer's disease or related disorder.



13. Enhance capacity of services to meet the needs of persons with Alzheimer's disease or related disorder
14. Establish Quality Care measures with system benchmarks for facility and community based care for persons with Alzheimer's disease or related disorder.
15. Address the preparedness of the workforce to provide care and services in support of persons with Alzheimer's disease or related disorder and their caregivers.
16. Establish Alzheimer's disease or related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer's disease or related disorder and their caregivers.
17. Convene a workgroup on a regular basis to address psychogeriatric needs of persons with Alzheimer's disease or related disorders in Iowa.
18. To keep Iowans healthier and reduce the risk for developing Alzheimer's disease or related disorders:
  - a. Provide physical and mental activity programs using evidence-based programs designed for older adults such as Enhance Fitness, Eat Better & Move More, and Healthy Aging.
  - b. Provide chronic disease self management programs using evidence-based health promotion programs such as Stanford Chronic Disease Self Management.
  - c. Promote dietary quality for older Iowans through provision of nutrition education programs such as Eat Better & Move More.
  - d. Provide nutrition counseling by registered dietitians to older adults determined to be at high nutrition risk.
  - e. Provide brain health education programs to help Iowans reduce their risk of Alzheimer's disease or related disorders.

The task force recommends the following strategies (in no particular order) be undertaken within the next 3-5 years (Tier 2):

19. Create an optional specialized certification for health and human services professionals to provide quality care and improve the quality of life for people with Alzheimer's disease or related disorders.
20. Increase the spectrum of educational resources available by using on-line courses and community colleges, and make subsidized educational opportunities available for those wishing to specialize in this field.



21. Determine implication of funding and policy on niche populations such as Down's syndrome and young onset Alzheimer's disease or related disorder.

The task force recommends the following strategy be undertaken within the next 6-10 years (Tier 3):

22. Correlate stages of Alzheimer's disease or related disorder with interventions to assist caregivers and service providers to make care decisions and to navigate the delivery system through the:
  - a) Identification of intervention
  - b) Identification of service needs
  - c) Identification of safety needs (including home environments)
  - d) Identification of caregiver needs

### **About This Report**

Following an overview of the history of the task force and background information on Alzheimer's disease, the report is divided into four sections. These sections correspond to the delineation of four subcommittees into which task force members were divided.

It should be noted that the term "Alzheimer's Disease" is used to encompass not only Alzheimer's disease but also additional brain disorders such as vascular dementia, mixed dementia, mild cognitive impairment, dementia with Lewy bodies, and other types of dementia.

Interspersed throughout the report are verbatim comments received from Iowans who responded to on-line surveys about how Alzheimer's disease has affected their lives. Their words poignantly give voice to the emotions, frustrations, and hopes of Iowans who are personally experiencing the impact of Alzheimer's disease. A copy of the Department of Elder Affairs survey can be found in Appendix A.



### **Task Force History and Process**

The task force was established with the passage of Senate File 489, a copy of which is attached as Appendix B. Signed by Governor Culver on April 27, 2007, the legislation called for a task force to “assess the current and future impact of Alzheimer's disease and related disorders on the residents of the state; examine the existing industries, services, and resources addressing the needs of persons with Alzheimer's disease or related disorders, their families, and their caregivers; and develop a strategy to mobilize a state response to this public health crisis.”

The legislation defined the types of entities and individuals that would comprise the task force. Membership was made up of ten representatives of private sector industries, advocacy agencies, and individuals directly affected by Alzheimer's disease or related dementia, four legislators, and four state agency directors or designees. For a list of taskforce members, see Appendix C.

The formal work of the task force began on September 24 at which time the task force reviewed the group's charge, established operational protocols, and heard testimony from advocacy groups and individuals. Time was allocated for public comment during each meeting of the task force. At the November 19<sup>th</sup> session, four subcommittees were formed – Education and Training, Funding and Reimbursement, Services and Housing, and Wellness and Disease Management. The subcommittees continued their discussions at the December 10 meeting which culminated in a set of draft recommendations for consideration by the full task force. In a conference call meeting on December 20, task force members refined then finalized the language of the recommendations that follow.

### **Alzheimer's Disease Background Information**

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM – IV – TR) Alzheimer's disease is a form of dementia that is characterized by memory impairment and one other cognitive disorder such as aphasia (inability to produce and understand speech), apraxia (the inability to perform complex movements), agnosia (the total or partial loss of the ability to recognize familiar people or objects) or disruption in executive functioning to such a degree as to cause impairment in work and or social functioning. The 2007, Alzheimer's Disease Facts and Figures defines dementia as a “group of disorders” that cause decline in at least two of the following cognitive functions: memory; ability to generate understandable speech or





comprehend the spoken word or written language; ability to plan and carry out complex tasks, and distortion of visual processes.

There are nine specific types of dementia that have a range of impact on daily functioning from mild to severe:

1. Mild cognitive impairment (MCI) symptoms include memory loss, difficulty with language or other cognitive functions serious enough to be noticeable, but not severe enough to interfere with daily activities.
2. Normal pressure hydrocephalus is brain damage caused from the buildup of fluid on the brain.
3. Creutzfeldt-Jakob disease is a rapidly fatal disorder that not only includes memory dysfunction but involves coordination and behavioral changes.
4. Frontotemporal dementia is characterized by two patterns of symptoms involving changes in personality and behavior as well as considerable language problems.
5. Lewy bodies is similar in pattern to Alzheimer's disease (difficulty with memory, confusion and poor judgment) however, alertness and severity of symptoms change from day to day.
6. Parkinson's disease may result in dementia in later stages of the disease with similar characteristic as Lewy body dementia.
7. Mixed dementia is a mix of Alzheimer's disease and vascular dementia.
8. Vascular dementia is also known as multi-infarct dementia caused by reduced blood flow to the brain due to emboli blocking small arteries.
9. Alzheimer's disease is the most common form of dementia. Fifty to 75% of dementia diagnoses are Alzheimer's disease. Initially, the most common symptom is difficulty learning new information. As the brain damage occurs, there is a progression of symptoms from confusion, poor judgment, and language difficulties to the final stage of total loss of function, inability to care for self and ultimately death.



### Prevalence

#### National

The Alzheimer's Association released a statistical report of the United States data on Alzheimer's disease and other dementias in 2007. In summary, the report identifies that Alzheimer's disease is the most common type of dementia. The estimated 5.1 million Americans with this disease by age group revealed the following breakdown:

- Age 65-74 - 2% or 300,000 people
- Age 75-84 - 19% or 2,400,000 people
- Over Age 85 - 42% or 2,200,000 people

According to the report, every 72 seconds someone in America develops the disease and by mid-century, someone will develop Alzheimer's disease every 33 seconds. By 2050, with the advent of the baby boomer generation the number of individuals with Alzheimer's disease could range from 11 million to 16 million.

The Alzheimer's Association report further identifies that 29% of Medicare beneficiaries age 65+ with Alzheimer's disease or other dementias also receive Medicaid benefits. About half live in the nursing home and half in the community. Of the community-based people with Alzheimer's disease, 84% who were at high risk of nursing home placement had assets that would pay for less than a year's stay in a facility. "When baby boomers with severe disabilities or disease like Alzheimer's disease begin to reach the median age for admission to a nursing home in 2025, Medicaid long-term care spending will skyrocket. Medicaid costs for nursing home care alone will climb from \$21 billion in 2005 to \$38 billion in 2025." (Alzheimer's Disease Facts and Figures, 2007)

#### Iowa

In Iowa in 2000, there were nearly 65,000 people with a diagnosis of Alzheimer's disease and a potential 6% increase by 2010 resulting in an estimated 69,000 people. The State Library of Iowa, State Data Center revealed that in 2007 the number of Iowans 85 and older was 2.5% of Iowa's population. This is significant as the 85-and-over population has the highest disability rate of any age group. An AARP study revealed that the



preference of nearly all older Iowans (95%) is to remain in their own home (AARP, Iowa Home and Community-Based Long-Term Care: An AARP Survey, 2002.)

Iowa's long-term care financing and delivery system is biased toward institutional care. In State Fiscal Year 2006, only 1.6% of the 2.5 billion Medicaid expenditures in Iowa for people age 65 and older went to Iowa's 1915c Elderly Waiver program which is a home and community based service delivery system designed to support older Iowan's (age 65+) who are at the nursing home level of care and who want to remain in their own home.

### **Caregiving**

Caregivers provide enormous amounts of unpaid time in their caregiving role. If paid, it is estimated that the amount of time spent providing care nationwide would be worth close to \$83 billion in 2005 (Alzheimer's Disease Fact and Figures, 2007.) In fact, the report indicates that close to 10 million Americans care for a person with Alzheimer's disease. Furthermore, 29% of caregivers 60+ years and older not only care for someone with a dementia, but also have one or more serious medical conditions themselves. Iowa's estimates for 2005 were 93,556 caregivers of people with Alzheimer's disease or related dementia who provided 80,757,917 hours of unpaid care per year at a value of \$789,812,426.

The report, "Families Care: Alzheimer's Caregiving in the United States, 2004," reports that the typical individual caring for someone with Alzheimer's is a woman, age 48, married, employed, has some college education and no children in the home. Half of the Alzheimer's caregivers work full-time. Most often, the caregiver is a relative and the most common relationship between caregiver and care-receiver is child and parent. The typical Alzheimer's care recipient is a 78 year old, widowed female. However, a third of Alzheimer's care recipients are 85 years old and older.

Time spent in care giving produces high incidents of stress, poor health and increased depression. Twenty-five percent of caregivers of people with Alzheimer's report their care giving is stressful, but only fifteen percent of caregivers of non-dementia people report stress. Two-thirds of working caregivers of people with Alzheimer's disease or related disorders missed work because of care giving duties; eight percent turn down promotions



and seven percent lost job benefits. (Alzheimer's Disease Facts and Figures, 2007) The caregiver of someone with ADRD provides assistance with activities of daily living (ADLs) and more likely to help with the most difficult ADLs, i.e. incontinence, bathing and feeding. Twenty-three percent of Alzheimer's caregivers provided care for 20 or more hours per week, 71% have cared for the recipient for more than a year and 32% have made a commitment of five years or more ("Families Care: Alzheimer's Caregiving in the United States, 2004.") Furthermore, there are personal sacrifices of time for family, friends, hobbies, social activities and exercise for the caregiver.

In the September 2006 report, "Caregivers in Decline", a study conducted by Evercare for the National Alliance for Caregiving demonstrated the tremendous impact caregiving has on the physical and mental health of the caregiver. Caregivers in general, reported that their physical health declined because of providing care and the rating of their health was only fair to poor. Of the caregivers surveyed, half are assisting in three or more activities of daily living. The caregiver who spends 40 or more hours weekly attending to their care-recipient reported their health became a "lot worse" as a result of caregiving than the caregiver who spent 20 hours per week or less providing care. Three-quarters of the caregivers in poor health felt they did not have a choice whether or not to provide care. As reported by the survey, the following are the most common aspects of health deterioration: loss of energy and sleep, stress and/or panic attacks, pain, aching, depression, headaches, and weight loss/gain. Depression was reported by 91% of the caregivers in decline; 90% report feelings of increased stress; 51% take medications as a result of providing care; 10% report abusing alcohol or prescription drugs; 82% report inadequate sleep, 63% poor eating habits; 58% report decreased exercise. In addition, 52% of caregivers do less preventative health care than they did prior to caregiving.

In January 2007, the Urban Institute, for the U.S. Department of Health and Human Services released a report that indicated that the physical strain from caregiving was the most important predictor of high stress followed by disturbed sleep and care receiver problem behaviors which lead to admission into a nursing home. A conclusion drawn from this report is that strategies for reducing caregiver stress should include respite, caregiver training and more information about assistive technology and how to access such devices as well as managing care recipient behaviors that are disruptive.

Rural caregiving has unique challenges. In the Easter Seals/National Alliance for Caregiving report "Caregiving in Rural America," people in rural areas have limited health and social services, in-home support services, public transportation options and business opportunities. This report cites that about 11% of rural caregivers have annual incomes



under \$15,000, 17% between \$15,000 and \$29,000; 34% between \$30,000 and \$49,000; 18% between \$50,000 and \$74,000; 8% between \$75,000 and \$100,000; and 11% over \$100,000 annually. Rural caregivers are less likely to use formal services that might ease their caregiver work. Twenty-two percent of rural caregivers use an aide or nurse through an agency, and only 8% of rural caregivers use other types of paid help. Twenty-nine percent of rural caregivers utilize transportation services (if transportation services are available to them.)

### References:

AARP. *Iowa Home and Community-Based Long-Term Care: An AARP Survey*. (Washington, D. C.: AARP Knowledge Management, 2002.)

Alzheimer's Association and National Alliance for Caregiving.

*Families Care: Alzheimer's Caregiving in the United States 2004* (Washington, D.C.: 2004), accessible at [www.alz.org](http://www.alz.org); search "families care."

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American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision. Washington, D.C., American psychiatric Association, 2000. Pages 147 – 157.

Easter Seals and National Alliance for Caregiving. *Caregiving in Rural America*, 2006, accessible at [www.easterseals.com](http://www.easterseals.com); search "Caregiving in Rural America."

Evercare and National Alliance for Caregiving. *Caregivers in Decline. A Close-up Look at the Health Risks of Caregiving for a Loved One* (Minnetonka, MN, 2006).

Spillman, Brenda C.; Long, Sharon K. *Does High Caregiver Stress Lead to Nursing Home Entry?* Urban Institute prepared for Office of Disability, Aging and Long-Term Care Policy Office of the Assistant Secretary for Planning and Evaluation U.S. Department of Health and Human Services, 2007.

State Library of Iowa, State Data Center Program, 800-248-4483, <http://www.iowadatacenter.org>.

### **Analysis of Department of Elder Affairs Alzheimer's Disease Survey**

In November, 2007, the Department of Elder Affairs contracted with the Department of Administrative Services (DAS) to develop a web-based survey that would collect information from Iowans about how Alzheimer's disease had directly affected their lives. The survey tool was designed to collect primarily qualitative information, thereby allowing respondents the maximum amount of latitude to express their thoughts and ideas. Quantitative information was gathered in the form of a ranking of the most pressing areas of need in Iowa as scored by those who completed the survey.



Within just a few days of the survey's release, over 100 lowans had responded. Their often emotional words poignantly expressed the realities of coping with the impact of Alzheimer's disease, and did so in a way more powerful than numbers or statistics. The survey will continue to be posted on the department's webpage, <http://www.state.ia.us/elderaffairs/#survey> through May 2008 to serve as an on-going avenue for lowans to share their experiences and recommendations.

The Department of Elder Affairs contracted with Department of Administrative Services to conduct an analysis of the data received. The following is a synopsis of the DAS analysis.

### *Review of Findings*

In summary, the results of the analysis of survey responses indicated that the experiences and recommendations as conveyed by respondents were consistent with the discussions and findings of the Alzheimer's Task Force. There were no significant departures. When respondents ranked the most pressing area of need that should be addressed in Iowa, the scoring of the seven areas was statistically very close. *Access to Services* received the largest tally at 17.06% of total weighted voting. *Information about the Types of Services Available* was ranked at a very close second with a score of 16.9%. The remaining differences in ranking were negligible.

<b>Service</b>	<b>Ranking</b>
Access to services	17.06%
Information about the types of services available and how to use them	16.9%
Affordability of services	15.89%
Education and training	15.89%
Quality of services	15.24%
Support for families and caregivers	15.2%
Other	3.84%



## Alzheimer's Disease Task Force

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The following table details the weighted ranking used for the analysis. The first table shows a count, or how many times each ranking was chosen for each of the areas by individual participants.

	<b>Access</b>	<b>Information</b>	<b>Affordability</b>	<b>Ed./ Training</b>	<b>Quality</b>	<b>Family Support</b>	<b>Other Needs</b>
7	21	13	15	11	15	12	7
6	18	19	11	18	12	11	1
5	13	19	17	13	14	14	0
4	9	9	18	11	18	25	2
3	17	12	13	20	12	11	3
2	6	22	11	19	10	10	1
1	3	2	4	1	2	3	21

Based on the above table, a weighted score was calculated by multiplying the count of each ranking chosen by the appropriate rank. Each need was then summed to provide a numeric score and percentage ratio as seen in the table below.



Rank	Access	Information	Affordability	Ed./ Training	Quality	Family Support	Other Needs
7	147	91	105	77	105	84	49
6	108	114	66	108	72	66	6
5	65	95	85	65	70	70	0
4	36	36	72	44	72	100	8
3	51	36	39	60	36	33	9
2	12	44	22	38	20	20	2
1	3	2	4	1	2	3	21
Totals	422	418	393	393	377	376	95
%	17.06%	16.90%	15.89%	15.89%	15.24%	15.20%	3.84%

When looking solely at those items that received the highest ranking of 6 or 7, *Access to Services* did rank higher at 21.29%. *Information about the Types of Services Available* remained the second most pressing area with 17.11%. *Education and Training* was third with 15.44% due in part to the large number of people who ranked it with a “6” (the second most pressing area of need.)

*Access to Services* was seen by respondents as the most pressing need overall. Health care professionals and those in public service consistently identified *Access to Services* as the most pressing need. A sampling of the qualitative responses follows.





Comments by	Comment
Health care provider	<ul style="list-style-type: none"> <li>As a healthcare provider who has worked in the DSM metro and now in rural Iowa, I have noticed a lack of services available for rural community members.</li> </ul>
	<ul style="list-style-type: none"> <li>I am a health care provider and I have repeatedly seen families/spouses resort to nursing home placement when they are exhausted and/or unable to manage the care of their loved one. There is very, very little in-between care in rural Iowa (e.g., in-home support, specialized outreach). The services simply don't seem to exist or they are not connecting with families in need.</li> </ul>
	<ul style="list-style-type: none"> <li>I have presented to many community groups on the topic of Alzheimer's and find a shortage of adult day, respite and quality long term care services in most counties throughout Iowa. Few home care agencies provide their home care staff with dementia care training.</li> </ul>
Public employee	<ul style="list-style-type: none"> <li>It seems that the only services available in local areas are the nursing homes. There are no support groups locally in the small rural areas.</li> </ul>
Family member	<ul style="list-style-type: none"> <li>It is very difficult to find facilities that are able to care for Alzheimer residents due to their wandering or their behaviors. More and more facilities are choosing to close their Alzheimer units due to survey issues.</li> </ul>
	<ul style="list-style-type: none"> <li>Access for service is available if you know where to look. The local Alzheimer's chapter is the best place, but this information needs to be communicated better through the media and through medical professionals.</li> </ul>

Of the comments made, many focused on the *Availability of Services* and *Access to Services* in rural communities. People discussed the need to travel in order to receive service and care. At the same time, many of the comments regarding *Access to Services* as well as recommendations to address access revolved around information available. The following table highlights individual recommendations that focus on *Access to Services*. These comments reflect the relationship between access and information pertaining to services.



Comments by	Comment
Health care provider	<ul style="list-style-type: none"> <li>When physicians diagnose this type of condition they need to immediately make a referral to a clinical manager who provides them with information that puts all of the information into one place, then they can start the thought process for later on down the line.</li> </ul>
	<ul style="list-style-type: none"> <li>More info about how/where to find a support group &amp; assistance. Radio, TV or news paper adds. Something that comes into the home.</li> </ul>
	<ul style="list-style-type: none"> <li>An 800 number to help locate local services for all areas in Iowa.</li> </ul>
	<ul style="list-style-type: none"> <li>Physicians need to be educated about what is available and how to access services and then educate their patients and families. They should begin the education as to what services are available and what might be needed when the patient is in the office or hospital room.</li> </ul>
Public employee	<ul style="list-style-type: none"> <li>Perhaps localized conferences where family members can get updated information. Can funding be given to nursing homes to provide for more support services?</li> </ul>
Family member	<ul style="list-style-type: none"> <li>Publicity and public information.....We need to de-mystify this in the mind of the public. We still have some mentality that only weak persons are "mentally ill". Services needed include KNOWLEDGE OF WHAT IS AVAILABLE and WHERE, respite care, financial management for the patient's business, be aware that the patient is just ripe for financial exploitation by outsiders or, worse yet, family members.</li> </ul>
	<ul style="list-style-type: none"> <li>There needs to be more emphasis on rural areas, esp. with diagnosing, ongoing care and respite. Can you work with existing agencies, such as Area Agencies on Aging, parish nurses, the Alzheimer's Association to first go into a community and lay groundwork about the disease, then come in with a mobile clinic that would make monthly visits, etc?</li> </ul>

Based on the results and comments between *Access to Service* and *Information about the Types of Services Available*, there appears to be a relationship between the two. Individuals cannot get to services about which they know nothing. Families rated information as a higher need than access to services. The weighted score of public employees and health care providers pushed *Access to Services* just above *Information about the Types of Services Available* in ranking. Selected comments regarding the need for information follow.



Comments by	Comment
Family member	<ul style="list-style-type: none"> <li>There just isn't a lot unless you want to spend hours on the internet. There needs to be more printed material sent out. The only thing I ever get is a please donate.</li> </ul>
	<ul style="list-style-type: none"> <li>I need an advocate to keep me informed on types of services that are available and affordable for us. I am still quite ignorant of all that is out there. Everything seems so segmented. I feel so uninformed about services that would be helpful to us. I need someone or an agency to give me advice on how to plan for the future and how to deal with the progression of the disease.</li> </ul>
	<ul style="list-style-type: none"> <li>I am not as familiar anymore with the services offered specifically for Alzheimer's but that is why we have agencies to point us in the right directions such as the Alzheimer's Association, Area Agencies on Aging, Hospice, Adult Day Centers, Assisted Livings, Nursing Homes, Etc. So a person doesn't necessarily need to know the exact types of services available just someone/someplace to call to get information.</li> </ul>
Family member	<ul style="list-style-type: none"> <li>Make brochures and materials in simple easy to understand terms. Also maybe have some testimonies from families as to the care of their loved one. With this disease everyone reacts differently so just easy to understand steps of what to do.</li> </ul>
Health care provider	<ul style="list-style-type: none"> <li>More materials in waiting rooms and for physicians</li> </ul>
	<ul style="list-style-type: none"> <li>Make sure that information is in public areas i.e. – Drs' office waiting areas. Make sure it is there and getting refreshed and put out ASAP.</li> </ul>
	<ul style="list-style-type: none"> <li>Again, I have not found any one place to start asking for services in my local area.</li> </ul>
	<ul style="list-style-type: none"> <li>Not much information available</li> </ul>

### *Demographic Information*

Demographic information was requested as a portion of the survey. The four key demographic areas collected include the following:

- Identity of the respondent



- Age range of the respondent
- Rural/Urban location of the respondent (based on county)<sup>1</sup>
- Sex of respondent

Analysis of the demographic data was not considered predictive due to the percentage of respondents who did not answer the demographic questions in the survey. *Identity* was the only survey question that had 100% participation.

The survey asked respondents to identify their role or relationship to persons with Alzheimer's disease or dementia. Options included a person with Alzheimer's disease or dementia, a spouse or partner of a person with Alzheimer's disease or dementia, an immediate family member, a non-family caregiver, a healthcare provider, or a public employee. The options of spouse and family member were combined for the analysis of the survey as were non-family caregiver and health care provider due to the low participation by particular identification groups. The weighted rating of each identification group is seen in the table below.

	Family	Provider	Public Employee	Other	Grand Total
Rating of Access	171	211	43	4	429
Rating of Information	190	189	34	5	418
Rating of Affordability	172	176	38	7	393
Rating of Education	162	195	34	2	393
Rating of Quality	173	176	31	3	383
Rating of Family Support	156	190	29	1	376
Rating of Other Needs	39	30	20	6	95
<b>Count of Respondents</b>	<b>44</b>	<b>47</b>	<b>12</b>	<b>1</b>	<b>104</b>
% of Respondents	42.31%	45.19%	11.54%	0.96%	100%

<sup>1</sup> Rural/urban county determination is according to the State Data Center of Iowa.

<http://www.iowadatacenter.org/aboutdata/statisticalareas/>



The survey requested an age range be chosen by each respondent. The majority of respondents opted not to answer the question. Nevertheless the weighted rating of each age group is provided in the table below.

	No Answer	Under 35	35-49	50-64	Over 65	Grand Total
Rating of Access	172	27	77	125	21	422
Rating of Information	178	45	61	118	16	418
Rating of Affordability	146	29	56	139	23	393
Rating of Education	150	51	57	116	19	393
Rating of Quality	165	24	67	104	17	377
Rating of Family Support	149	34	62	116	15	376
Rating of Other Needs	31	10	12	38	4	95
<b>Count of Respondents</b>	<b>41</b>	<b>9</b>	<b>16</b>	<b>32</b>	<b>5</b>	<b>103</b>
% of Respondents	39.81%	8.74%	15.53%	31.07%	4.85%	100%

The survey requested the respondents' county as a demographic identifier. Based on the county entered, it was determined whether they were considered in a metropolitan area or rural area as seen by the State Data Center of Iowa. While the State Data Center of Iowa may identify a county as metropolitan, it does not take into account those individuals who still live in a rural area of a metropolitan county. As with other demographic questions, the majority of respondents did not provide county information. The weighted rating of each group is provided in the table below for informational purposes only.



	No Answer	Urban	Rural	Grand Total
Rating of Access	178	147	97	422
Rating of Information	185	162	71	418
Rating of Affordability	165	154	74	393
Rating of Education	155	140	98	393
Rating of Quality	176	121	80	377
Rating of Family Support	157	143	76	376
Rating of Other Needs	38	44	13	95
<b>Count of Respondents</b>	<b>46</b>	<b>38</b>	<b>20</b>	<b>104</b>
% of Respondents	44.23%	36.54%	19.23%	100%

The survey also asked the gender of respondents. Again, a high number of participants did not choose to answer this question. For reference, the weighted rating is provided below.

	No Answer	Female	Male	Grand Total
Rating of Access	97	178	147	422
Rating of Information	71	185	162	418
Rating of Affordability	74	165	154	393
Rating of Education	98	155	140	393
Rating of Quality	80	176	121	377
Rating of Family Support	76	157	143	376
Rating of Other Needs	13	38	44	95
<b>Count of Respondents</b>	<b>41</b>	<b>51</b>	<b>11</b>	<b>103</b>
% of Respondents	39.81%	49.51%	10.68%	100%



### SECTION 1: Education and training

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*"There seems to be a stigma attached to the disease in the small communities. Somehow there needs to be some dialogue out there that breaks the stigma so you don't have to feel like your loved one wants to hide in a shell."*

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*"I do not think health care providers, direct care providers, or even family members are receiving adequate information on the care and treatment for their loved ones or patients. There are a lot of myths and misconceptions about persons with dementia. It will take a paradigm shift to change the perception that persons with dementia can not live purposeful and meaningful lives."*

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The need for both public and professional education was repeated over and over again as the task force looked at existing services, resources, and the capacity of Iowa's health care delivery systems to assist persons with Alzheimer's disease and their caregivers. Presentations from providers and trade associations aligned with those of consumers and advocacy groups on the issue of the importance of education and training. The consistent message was that the unique care needs of persons with Alzheimer's or dementia can only be met when caregivers (both professional and less formal) possess the requisite skills and expertise.

The task force's examination of the type, cost, and availability of dementia services, the availability of home and community-based resources for persons with Alzheimer's disease, respite care for families, and similar topics reinforced the need for consistent, expansive education and training. Specific recommendations from the Education and Training subcommittee are as follows:

- Establish an office for Alzheimer's disease or related disorders within state government. This office would not replace or duplicate any services currently offered by the Area Agencies on Aging, the Alzheimer's Association, or other agencies, but would act as a referral source to local services. (Tier 1)

This office would:

- a) Increase public awareness for services currently available at the local or state level.
- b) Collaborate with various stakeholders including serving as a point of contact for people diagnosed with the disease, caregivers, professionals and consumers for information, education, training and referrals.
- c) Create a senior alert program for local, regional or statewide notification of missing senior adults.



- d) Coordinate efforts to continue the work of this task force and research the work of experts in both national and international settings.
- e) Create an advocacy system for people not currently living in long-term care facilities who have been diagnosed with Alzheimer's disease or related disorder and their families.
- f) Be guided by a multi-disciplinary commission (board) to continue the work of this task force.
- Increase and enhance training and education requirements about Alzheimer's disease or related disorders for all direct care employees including, but not limited to, long-term care settings, assisted living, elder group homes, residential care, adult day service facilities and home health care. (Tier 1)
  - a) Establish or broaden the number of hours for training for direct care staff to a minimum of 8 hours classroom instruction and a minimum of 8 hours of supervised interactive experience.
  - b) Establish or broaden the number of continuing education/in-service hours for direct care workers on the topic of Alzheimer's disease or related disorders to a minimum of 8 hours annually.
  - c) Add a competency component following Alzheimer's disease or related disorders training.
  - d) Establish a standard curriculum model that will include, but not be limited to: the diagnostic process, the progression of the disease, communication skills (including the person with the diagnosis, family, friends and caregivers), family stress and challenges, nutrition and dining information, activities, daily life skills, caregiver stress, the importance of building relationships and understanding the personal history, expected challenging behaviors and non-pharmacologic interventions, and medication management.
  - e) Establish a certification process for trainers and educators of the standard curriculum model.
- Broaden the spectrum of people who are required to receive training specific to Alzheimer's disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer's disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/monitoring, and ombudsmen. (Tier 1)
- Create an optional specialized certification for health and human services professionals to provide quality care and improve the quality of life for people with Alzheimer's disease or related disorders. (Tier 2)
- Increase the spectrum of educational resources available by using on-line courses, community colleges and make subsidized educational opportunities available for those wishing to specialize in this field. (Tier 2)





- Ensure that all task force recommendations coalesce with other initiatives and programs within the state, such as the Direct Care Worker Task Force Recommendations, Alzheimer's Association, Area Agencies on Aging, the Hartford Center Grant, Iowa Respite and Crisis Care Coalition and the UI Center on Aging and Geriatric Education Center. (Tier 1)

### SECTION 2: Funding and Reimbursement

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*"As long as you have the right type of health care coverage, you are okay. If you don't, expect your family to go broke, especially if you are relatively young and in good health otherwise."*

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*"I was forced to retire to care for my husband in our home. We are on a fixed income and I fear the expense of everything and being able to stay above board with expenses. Affordability for this middle-class family is a daily worry for me."*

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As articulated in the two survey responses above and others, the cost of caring for a person with Alzheimer's disease is beyond what most families can afford and more than a single state program could provide. Funding and reimbursement related in some way to many of the presentations to the task force. The members looked at topics such as projected trends in the state's population of persons with Alzheimer's disease, the unique challenges of lowans with early-stage and early onset of Alzheimer's disease or related disorders, and efforts to define quality care. The Funding and Reimbursement subcommittee developed the following recommendations:

- Support and assist the rapidly increasing numbers of lowans with Alzheimer's disease or related disorder by providing a wide array of home and community based services such as adult day services, respite care, and affordable transportation as well as assisted living, occupational therapy, speech therapy, social work services, dieticians, and others as these may delay premature nursing facility placement. (Tier 1)
- Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel. (Tier 1)
- Implement a statewide campaign to educate health and human services professionals regarding early detection instruments, such as AD8 and Mini-Cog, as early detection could prepare patients and families for what to expect. (Tier 1)



- Make Medicaid Waivers a significant factor in helping address the many needs of Iowans dealing with problems associated with Alzheimer's disease or related disorder, such as adult day services, assisted living, respite care, occupational therapy, speech therapy, social work services, dieticians, and affordable transportation as a means to delay premature institutionalization. (Tier 1)
- Given that the Medicaid Waiver is a long process, undertake a three-step approach to address the needs of persons with Alzheimer's disease or related dementia:
  - Step 1:* Allow individuals with a diagnosis of early on-set Alzheimer's disease or related disorders to be served in excess of the current maximum number of clients under the Ill and Handicap Waiver.
  - Step 2:* Increase the expenditure limits under the Elderly Waiver to give parity with other waivers including but not limited to the Ill and Handicapped Waiver, the Brain Injury Waiver, and the Mental Retardation Waiver for persons with a diagnosis of Alzheimer's disease or related disorder. (This recommendation affects patients older than 65)
  - Step 3:* Establish an Alzheimer's disease or related disorder specific waiver to place greater importance on the issue and needs comparable to the Brain Injury Waiver and the HIV/Aids waiver and without regard to the age of the person with Alzheimer's disease or related disorder. (Tier 1)
- Determine the implications of funding and policy on niche populations including Down's syndrome and Young onset Alzheimer's disease or related disorder. (Tier 2)

### SECTION 3: Services and Housing

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*"We are all too tired, and mom carries the biggest burden... We need help and don't know where to turn, sometimes church members sit in, and we're thankful for the relief, but our batteries don't feel recharged for very long."*

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*"I am a health care provider and I have repeatedly seen families/spouses resort to nursing home placement when they are exhausted and/or unable to manage the care of their loved one. There is very, very little in-between care in rural Iowa (e.g., in-home support, specialized outreach). The services simply don't seem to exist or they are not connecting with families in need."*

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The members of the task force repeatedly heard about the immediate need to expand support for persons and families living with Alzheimer's disease. Discussions and presentations covered the full spectrum of the components of service delivery such as assisted living options for persons with dementia, availability of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's disease, and the distribution of long-term care institutional services across the state.

An analysis of the data received through the Department of Elder Affairs website survey showed that "access to services" and "information about the types of services available" were ranked by respondents as the most pressing areas of need in Iowa. To begin to address service needs and gaps across the state, the Services and Housing subcommittee developed the following recommendations:

- Compile an analysis of Iowa's population by county and age to determine current utilization and future service needs of caregivers and persons with Alzheimer's disease or related disorder to support development of programs and services. (Tier 1)
- Review current trends and the impact in the Long Term Care rebalancing efforts affecting persons with Alzheimer's disease or related disorder. (Tier 1)
  - a) Bed occupancy, length of stay in a nursing facility, increase number in elderly waiver, acuity level of nursing facility residents, growth of assisted living programs.
  - b) Determine impact of Direct Care Worker shortages on availability and access to services.
  - c) Availability of adult day services.
  - d) Senior Living Coordinating Unit (SLCU) long-range plan (need to ensure strategies to include those to support service for persons with Alzheimer's disease or related disorder and their caregivers).
- Modify the existing community needs assessment process to include questions that would identify and quantify at-risk people with Alzheimer's disease or related disorder. This would include local public health community needs assessment, Area Agency on Aging area planning process, and other agencies that receive federal and state funding for services to Iowa's aging population. (Tier 1)
- Enhance the capacity of services to meet the needs of persons with Alzheimer's disease or related disorder (Tier 1).
  - a) Examine current administrative rules for nursing facilities, CCDI, assisted living, adult day services, home and community-based services, and Medicaid elderly waiver case management programs (administered by the departments of Human Services, Elder Affairs and Public Health).
  - b) Develop recommendations which reflect Alzheimer's disease or related disorder capable and friendly practices.
  - c) Provide technical assistance to current service providers to enable the diversification of their service base.



- d) Examine the caps on waiver funding.
- e) Review current re-imbusement rates across all state programs.
- f) Ensure the availability of trained workers for facility and community based services.
- g) Task the Senior Living Coordinating Unit (SLCU) to formally examine the findings of the University of Iowa's Adult Day Services study (Sanders and Saunders), make recommendations, and track implementation progress across the Unit agencies.
- Establish Quality Care measures with system benchmarks for facility and community based care for persons with Alzheimer's disease or related disorder. (Tier 1)
- Correlate stages of Alzheimer's disease or related disorder with interventions to assist caregivers and service providers to make care decisions and to navigate the delivery system through the: (Tier 3)
  - a) Identification of intervention
  - b) Identification of service needs
  - c) Identification of safety needs (including home environments)
  - d) Identification of caregiver needs
- Determine the implications of funding and policy on niche populations such as Down's syndrome and young onset Alzheimer's disease or related disorder. (Tier 2)
- Address the preparedness of the workforce to provide care and services in support of persons with Alzheimer's disease or related disorder and their caregivers. (Tier 1)
  - a) Recruit and retain workers across care settings.
  - b) Train caregivers across disciplines to meet the unique needs of persons with Alzheimer's disease or related disorder.
  - c) Maximize the utilization of information technology to expand the access and availability of health professionals.
  - d) Promote the interdisciplinary team approach for planning and care delivery.
  - e) Integrate strategies for planned environmental interventions to aid staff, caregiver and person with Alzheimer's disease or related disorder.

### **SECTION 4 – Wellness and Disease Management**

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*“Our family got no support from anyone. We were just left to try to accept Mom's disease as another dynamic we had to deal with. We had to provide support to each other.”*

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*“We had a horrible experience with my Father's dementia. He turned into a Jekyll & Hyde character and there was nowhere we could turn for help...I will never forget the hell we went through and the helpless feeling as there was nobody that would listen or help us in our small town.” (AARP survey)*

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Developing a strategy to mobilize a state response to the growth in the number of Iowans with Alzheimer's disease calls for both short-term and long-term interventions. The task force recognized the role prevention and disease management can play in reducing the long-term incidence of Alzheimer's disease. The existing need for specialized expertise was also evident during task force discussions about the almost insurmountable difficulties that can be encountered in Iowa when trying to help individuals with Alzheimer's disease who are facing a mental health crisis. As an outgrowth of these deliberations, the Wellness and Disease Management subcommittee outlined the recommendations that follow.

- Establish Alzheimer's disease and related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer's disease or related disorder and their caregivers. The public could initially access information about the Centers through an 800-number manned by a non-profit entity (such as the Alzheimer's Association). The ideal center would have physician services, social services, nursing, and special interest in the care of persons with Alzheimer's disease or related disorder.

The state would provide funding to support establishment of new centers. Various organizations focused on patient needs in this area could join forces to ensure efficiency and effectiveness. For example, existing memory centers could joint venture with the Alzheimer's Association and mental health advocate organizations to establish multiple centers across the state that would provide easy access to comprehensive services. These services would include history, physical, lab, x-ray, social support, and treatment. (Tier 1)

- Convene a workgroup on a regular basis to address psychogeriatric needs of persons with Alzheimer's disease in Iowa. The workgroup would be tasked with identifying mechanisms for funding of in-patient mental health services, expanding the statewide availability of services, establishing education pathways for providers, and enhancing the availability of emergency crisis intervention. (Tier 1)
- To keep Iowans healthier and reduce the risk for developing Alzheimer's disease or related disorder.
  - a) Provide physical and mental activity programs using evidence-based programs designed for older adults such as EnhanceFitness, Eat Better & Move More, and Healthy Aging.
  - b) Provide chronic disease self management programs using evidence-based health promotion programs such as Stanford Chronic Disease Self Management.
  - c) Promote dietary quality for older Iowans through provision of nutrition education programs such as Eat Better & Move More.
  - d) Provide nutrition counseling by registered dietitians to older adults determined to be at high nutrition risk.
  - e) Provide brain health education programs to help Iowans reduce their risk of Alzheimer's disease or related disorders. (Tier 1)

## Appendices

### Appendix A: Department of Elder Affairs On-line Survey Tool

For over 65,000 Iowans, Alzheimer's disease is a daily personal reality. For each individual with the disease, there are countless family members, friends, or other caregivers who are personally or professionally committed to providing needed support and compassion.

If your life has been touched by Alzheimer's disease or related dementias, the Alzheimer's disease Task Force would like to hear from you. The Iowa Legislature established the Task Force to "assess the current and future impact of Alzheimer's disease and related disorders on the residents of the state; examine the existing industries, services, and resources addressing the needs of persons with Alzheimer's disease or related disorders, their families, and their caregivers; and develop a strategy to mobilize a state response to this public health crisis."

The most critical direction for the Task Force will come from the personal stories of Iowans who have witnessed first-hand the impact of Alzheimer's disease or dementia on their lives. Please take a few minutes to share your experience and any suggestions you have about how to improve the services and resources in Iowa that are available to support persons with Alzheimer's disease or related dementias. The survey will first ask you to describe your personal experiences relating to services and support for persons with Alzheimer's disease. You will then be asked for your specific recommendations for improving Alzheimer's or dementia care in Iowa. Through your responses, you can become part of shaping the future course of dementia care in Iowa. Thank you!

Please enter the following information about yourself for assistance in data gathering:

- 1) Iowa county in which you live:
- 2) Gender
- 3) Age
- 4) Ethnicity
- 5) Is English your second language? If yes, what is your native language?
- 6) I would like to be contacted with more information directly: First name, last name, telephone number, E-mail address.
  
- 7) Please describe yourself (drop down options: a) Person with Alzheimer's Disease or dementia, b) spouse or partner of person with Alzheimer's Disease or dementia, c) son, daughter, or other family member of a person with Alzheimer's Disease or dementia, d) non-family caregiver of a person with Alzheimer's Disease or dementia, e) health care provider, f) public employee or official, g) Other.
  
- 8) For persons impacted by Alzheimer's disease or other dementia, what do you believe is the most pressing area of need in Iowa? (drop down options: a) Information about the types of services available and how to use them, b) access to services, c) quality of services, d) affordability of services, e) support for families and caregivers, f) education and training, g) other

For those items you ranked as most pressing on the previous page, please respond to the following:

- 9) In your own words, describe your experience regarding *access to services* for lowans with Alzheimer's disease or dementia. (Open text field)
- 10) In your own words, describe your experience regarding *quality of services* for lowans with Alzheimer's disease or dementia. (Open text field)
- 11) In your own words, describe your experience regarding *affordability of services* for lowans with Alzheimer's disease or dementia. (Open text field)
- 12) In your own words, describe your experience regarding *support for families and caregivers of lowans* with Alzheimer's disease or dementia. (Open text field)
- 13) In your own words, describe your experience regarding *education and training* about Alzheimer's disease or dementia. (Open text field)
- 14) In your own words, describe your experience regarding *information about the types of services available and how to use them* as related to Alzheimer's disease or dementia. (Open text field)
- 15) In your own words, describe any *other personal experiences* with receiving or providing assistance or services. (Open text field)

For those items you ranked as most pressing on page two, please respond to the following questions:

- 16) What specific recommendations do you have about how to better address *access to services* for lowans with Alzheimer's disease or dementia? Please be as specific as possible about what you would like to see happen. (Open text field)
- 17) What specific recommendations do you have about how to better address *quality of service* for lowans with Alzheimer's disease or dementia? Please be as specific as possible about what you would like to see happen. (Open text field)
- 18) What specific recommendations do you have about how to better address *affordability of services* for lowans with Alzheimer's disease or dementia? Please be as specific as possible about what you would like to see happen. (Open text field)
- 19) What specific recommendations do you have about how to better address *support for families and caregivers* of lowans with Alzheimer's disease or dementia? Please be as specific as possible about what you would like to see happen. (Open text field)
- 20) What specific recommendations do you have about how to better address *education and training* for lowans with Alzheimer's disease or dementia? Please be as specific as possible about what you would like to see happen. (Open text field)
- 21) What specific recommendations do you have about how to better address *information about the types of services available and how to use them* in regard to Alzheimer's disease or dementia? Please be as specific as possible about what you would like to see happen. (Open text field)
- 22) What specific recommendations do you have about how to better address *any other issues* with Alzheimer's disease or dementia? Please be as specific as possible about what you would like to see happen. (Open text field)

## Appendix B: Senate File 489

### Section 1. ALZHEIMER'S DISEASE TASK FORCE.

1. The Alzheimer's disease task force is established. The task force shall consist of the following members:
  - a. The joint chairpersons of the legislative health and human services appropriations subcommittee and the chairs of the human resources standing committees of the senate and the house of representatives.
  - b. The following members appointed by the governor:
    - (1) One person with Alzheimer's disease.
    - (2) One caregiver of a person 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 health care provider community.
    - (7) A person who conducts Alzheimer's disease research.
    - (8) A representative of the Alzheimer's association.
    - (9) A representative of Iowa AARP.
    - (10) A licensed health care provider specializing in the practice of gerontology.
  - c. The director, or the director's designee, of each of the following agencies:
    - (1) The department of elder affairs.
    - (2) The department of human services.
    - (3) The department of public health.
    - (4) The department of workforce development.
    - (5) The department of inspections and appeals.
2. The department of elder affairs shall convene the taskforce and provide necessary administrative support for the task force.
3. The task force shall assess the current and future impact of Alzheimer's disease and related disorders on the residents of the state; examine the existing industries, services, and resources addressing the needs of persons with Alzheimer's disease or related disorders, their families, and their caregivers; and develop a strategy to mobilize a state response to this public health crisis.
4. The task force shall include an examination of the following in its assessment and recommendations:
  - a. Trends in the state's population of persons with Alzheimer's disease or related disorders and the needs of such persons including but not limited to:
    - 1) The state role in long-term care, family caregiver support, and assistance to persons with early-stage and early onset of Alzheimer's disease or related disorders.
    - 2) State policy regarding persons with Alzheimer's disease or related disorders.
  - b. Existing services, resources, and capacity including but not limited to:
    - 1) The type, cost, and availability of dementia services.
    - 2) Dementia-specific training requirements for long-term care staff.
    - 3) Quality care measures for residential care facilities.
    - 4) The capacity of public safety and law enforcement agencies to respond to persons with Alzheimer's disease or related disorders.
    - 5) The availability of home and community-based resources for persons with Alzheimer's disease or related disorders and respite care to assist families.
    - 6) An inventory of long-term care dementia care units.
    - 7) The adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's disease and related dementia.



- 8) Assisted living residential options for persons with dementia.
  - 9) State support of research of Alzheimer's disease and related disorders through the state's institutions of higher education and other resources.
- c. Needed state policies or responses including but not limited to directions for the provision of clear and coordinated services and support to persons and families living with Alzheimer's disease or related disorders, and strategies to address any identified gaps in services.

5. All meetings of the task force shall comply with chapter 21 and the task force shall utilize technological means, such as web casts, to gather feedback on its discussions and recommendations from persons and families affected by Alzheimer's disease and related disorders and from the general public.

6. The task force shall submit a report of its findings and date-specific recommendations to the general assembly and the governor in the form of a state Alzheimer's disease and related disorders plan by January 1, 2008. The task force shall be dissolved upon the submission of the plan.

## Appendix C: Task Force Members

Category defined in SF 489	Name	Position
Joint chairpersons of the legislative health and human services appropriations sub-committee	Rep. Ro Foege (D) Senator Jack Hatch (D)	
Chair of Senate Human Resources Committee	Senator Amanda Ragan (D)	
Chair of House Human Resources Committee	Rep. Mark Smith (D)	
Person with Alzheimer's disease	Barbara Barker	Consumer
Caregiver of a person with Alzheimer's disease	Linda Linderbaum	Retired teacher, Solon
Representative of the nursing facility industry	Don Chensvold	Health Care of Iowa, Inc – Cedar Rapids
Representative of the assisted living industry	Linda Larkin	Agemark Corporation - Ft. Madison
Representative of the adult day services industry	Renee Grummer-Miller, MSW, LISW	Ageing Service – Cedar Rapids
Representative of the health care provider community	Joann Simpson, ARNP	Alzheimer's support group facilitator. Alegent Health Mercy Hospital, Corning
A person who conducts Alzheimer's research	Dr. Mehrdad Razavi	Neurologist, lead physician at the Memory Clinic, McFarland Clinic, PC - Marshalltown
Representative of the Alzheimer's Association	Pat Gill	Board member with Big Sioux Chapter, former state legislator
Representative of AARP	Becky Groff	AARP Associate State Director  Community Outreach

Licensed health care provider specializing in the practice of gerontology	Robert L. Bender II, M.D.	Medical Director, The Johnny & Romie Orr Center for Healthy Aging and Memory Loss
Representatives of Iowa Dept. of Elder Affairs	John McCalley	
Iowa Dept of Human Services	Jennifer Steenblock	
Iowa Dept of Public Health	Carol Peterson	
Workforce Development	Tony Dietsch	
Iowa Dept of Inspections and Appeals	Kathy Sutton	

**Appendix D** — List of websites for more information about Alzheimer's disease and caregiver issues.

### **Alzheimer's Association**

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

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Its mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. This website includes links to local chapter who provide a variety of programs and services for people impacted by Alzheimer's disease.

### **Alzheimer's Foundation of America**

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

The mission of the Alzheimer's Foundation of America is "to provide optimal care and services to individuals confronting dementia, and to their caregivers and families through member organizations dedicated to improving quality of life." The AFA's toll-free hotline provides information, counseling by licensed social workers and referrals to community resources across the nation.

### **Alzheimer's Disease Centers (ADCs) Directory. National Institutes of Health**

<http://www.nia.nih.gov/Alzheimers/ResearchInformation/ResearchCenters/>

Alzheimer's Disease Centers offer diagnosis and medical management; clinical research and drug trials; and information about the disease, services and resources.

### **ADEAR. Alzheimer's Disease Education and Referral Center**

<http://www.nia.nih.gov/alzheimers>

ADEAR maintains information on Alzheimer's disease research, diagnosis, treatment, clinical trials and federal government programs and resources. AD Lib, ADEAR's literature database, has nearly 8,500 materials related to Alzheimer's disease that includes fact sheets, textbook chapters, journal articles, brochures, teaching manuals, directories, videos and other media, bibliographies, program descriptions, monographs, newsletters and reports.

### **Alzheimer's Disease International (ADI)**

<http://www.alz.co.uk>

ADI is an international membership group of Alzheimer associations. The ADI site links to member association sites throughout the world. It also provides information in several languages, statistics on the number of people with dementia worldwide, and the implications for the distribution of research funding, especially in developing countries.

### **Alzheimer Research Forum**

<http://www.alzforum.org>

This website reports on the latest scientific findings, from basic research to clinical trials; creates and maintains public databases of essential research data and reagents; and produces discussion forums to promote debate, speed the dissemination of new ideas, and break down barriers across the numerous disciplines that can contribute to the global effort to cure Alzheimer's disease.

## **Alzheimer Society of Canada**

[www.alzheimer.ca](http://www.alzheimer.ca)

The Alzheimer Society of Canada is a nationwide, not-for-profit health organization dedicated to helping people affected by Alzheimer's disease. The Society develops and provides support and educational programs for people with the disease, their families and their caregivers.

## **Fisher Center for Alzheimer's Research**

<http://www.alzinfo.org>

Fisher's site is a comprehensive portal for caregivers, family members, people living with Alzheimer's, and the general public.

## **Mayo Clinic Alzheimer's Disease Center**

<http://www.mayoclinic.com>

The Mayo Clinic Alzheimer's Disease Center has easy to understand, practical in-depth information on Alzheimer's and caregiving.

## **MedicineNet**

[http://www.medicinenet.com/alzheimers\\_disease/article.htm](http://www.medicinenet.com/alzheimers_disease/article.htm)

MedicineNet.com is an online, healthcare media publishing company. It provides easy-to-read, in-depth, authoritative medical information for consumers via its robust, user-friendly, interactive web site.

## **MedlinePlus**

<http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>

MedlinePlus will direct you to information to help answer health questions. MedlinePlus brings together authoritative information from the National Library of Medicine, the National Institutes of Health, and other government agencies and health-related organizations. MedlinePlus also has extensive information about drugs, an illustrated medical encyclopedia, interactive patient tutorials, and latest health news.

## **Wem MD.com Alzheimer's Health Center**

<http://www.webmd.com/alzheimers/default.htm>

This site has a broad range of information, with an emphasis on information for individuals who are concerned about memory problems or have Alzheimer's disease.

## **Iowa Department of Elder Affairs**

<http://www.state.ia.us/elderaffairs>

Family and informal caregivers are the backbone of our long-term care system. The vast majority of long-term care in Iowa and the nation is provided informally and privately at no public cost. Often at great sacrifice, families keep a loved one at home, avoiding more costly institutional care. Most caregivers are reluctant to use formal help. They often provide care with little support, experience adverse consequences to their own physical and emotional well-being, and use formal services only when faced with a crisis. But, even the most self-sufficient people may need information and direct services to best meet the needs of both aging family members and themselves. This Family Caregiver section will provide links to information and resources that can help individuals and caregivers.

## **LifeLongLinks**

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

The LifeLong Links Web site provides a place to start for consumers and providers who are thinking about and planning for long-term living. LifeLong Links also connects informed consumers and providers with a coordinated entry point to Iowa's information and referral resources: Iowa COMPASS, the Iowa Association of Area Agencies on Aging, Iowa Family Caregiver Support Program, and Iowa 2-1-1.

## **Iowa Family Caregiver**

<http://www.iowafamilycaregiver.org>

A collaborative effort of the area agencies on aging, the Iowa Family Caregiver Support Program puts people in touch with essential services to help them in their caregiving role and to meet the needs of the older loved one. Information specialists, experienced and knowledgeable in the field of aging, will listen to requests or concerns and explain sources of help based on individual circumstances.

## **Family Caregiver Alliance, National Center on Caregiving**

<http://www.caregiver.org>

Family Caregiver Alliance (FCA), founded 30 years ago in 1977, serves as a public voice for these caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

## **National Alliance for Caregiving**

<http://www.caregiving.org>

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

## **National Family Caregivers Association**

<http://www.nfcacares.org>

NFCA offers a virtual library of information and educational materials ranging from national educational campaigns to tips and guides for family caregivers, information on agencies and organizations which provide caregiver support, to communicating effectively workshops.

## **Family Care America**

<http://www.familycareamerica.com>

The *National Caregivers Library* is one of the most extensive online libraries for caregivers that exist today. It consists of hundreds of articles, forms, checklists and links to topic-specific external resources. The library is organized into the eighteen Caregivers Resources categories, which appear to the immediate left on the screen. Clicking on any category will lead to a list of sub-categories which in turn, lead to lists of articles and other resources.

## **Eldercare Locator**

<http://www.eldercare.gov>

Eldercare Locator is a public service of the U.S. Administration on Aging. The Eldercare Locator is the first step to finding resources for older adults in any U.S. community. Just one phone call or Website visit provides an instant connection to resources that enable older persons to live independently in their communities. The service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers.

## **AARP**

<http://www.aarp.org/families/caregiving>

This website provides a Guide to Caring which contains information and links on such topic areas as "Planning Ahead," "Providing Care at Home," and "Information and Resources for Caregivers."

## **Senior Health Insurance Information Program**

<http://www.shiip.state.ia.us>

Senior Health Insurance Information Program can help people find answers to the important questions about Medicare, Medicare supplement insurance, long term care insurance, and other health insurance issues. Created in 1990 by the State of Iowa [Insurance Division](#), SHIIP has helped thousands of people on Medicare sort through confusing health insurance information.

## **Family Caregiving – It's Not All Up to You**

[www.familycaregiving101.org](http://www.familycaregiving101.org)

This site is designed to provide caregivers with the basic tools, skills and information they need to protect their own physical and mental health while they provide high quality care for their loved one. It is also a place for family caregivers to return again and again as new levels of caregiving are reached. Advertising

messages, crafted with the assistance of family caregivers themselves, assure caregivers across America that they are not alone, and encourage caregivers to take better care of themselves and their loved one by visiting the site and asking for help.

*Note: The Iowa Department of Elder Affairs does not control or guarantee the accuracy, timeliness or completeness of this information.*