

**Alzheimer's Disease Response Strategy  
Submitted to the Iowa General Assembly  
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## Executive Summary

The Alzheimer's Foundation of America's recently released report is entitled *No Time to Waste*. This is all too true for the US and for Iowa. Nationally, the discussion is focused on terms like "epidemic" and "crisis," with millions of Americans currently diagnosed with Alzheimer's disease (AD) and millions more expected to be diagnosed in the coming years. The baby boomer population is projected to push social and medical service systems beyond current capacities, and the cost of the disease to American society is estimated to total \$20 trillion by 2050<sup>1</sup>. Dollar figures do not capture the emotional and physical toll that Alzheimer's disease and related dementias takes on the individuals who are diagnosed and the millions of caregivers that struggle daily to meet their needs. Iowa faces especially unique challenges because of its aging population, fragmented service systems, lack of accurate data on the problem, and a growing shortage of the workforce necessary to support the increasing demand.

The Alzheimer's Workgroup was established in 2011 with the Iowa General Assembly's passage of House File 390. The legislation requires a strategy to respond to the needs of Iowans with Alzheimer's disease and other forms of dementia. Workgroup members struggled to find a balance between the need to comprehensively address one of the biggest challenges facing the current generation, and the need to think practically about what is doable within the current economic climate.

The five guiding principles that frame the response strategy are:

- Efficiently utilize services within limited resources and funding, and expand partnerships between public and private entities
- Invest in evidence-based interventions
- Aim to provide standardized and consistent access to multiple, individualized services and supports
- Recognize that Alzheimer's disease and related dementias are best addressed with a social model of supports, not a medical model of treatment
- Start building the foundation to prepare for long-term investments and comprehensive supports in the future

The response strategy goals outlined in this report are:

- 1. Develop the Infrastructure Necessary to Support and Fund Alzheimer's Activities**
- 2. Address Stigma with Awareness and Education**
- 3. Provide Immediate Information and Resources**
- 4. Address Workforce Challenges Specific to Alzheimer's and Dementia Needs**
- 5. Increase Access to Services Most in Need**
- 6. Improve Data Collection on Alzheimer's Disease in Iowa**

## Background

The Alzheimer's Workgroup was established in September of 2011 as a result of the passage of House File 390, which required the workgroup to "design a strategy to respond to the needs of Iowans with Alzheimer's disease and other forms of dementia." Specifically, the workgroup was tasked with developing action steps, a timeline for implementation, and identification of the parties responsible for the activities. In addition, the workgroup was required to include recommendations for:

- The location of an office for Alzheimer's disease and other forms of dementia within state government.
- Instituting the public and private partnership necessary to most efficiently and effectively implement the response strategy and provide continuing collaboration.
- Ongoing data collection and funding to support the response strategy.

This is not the first time that the General Assembly identified Alzheimer's disease and related disorders as needing significant attention and planning. Legislation passed in 2007 (SF489) established a task force that developed recommendations in four categories: education and training; funding and reimbursement; services and housing; and wellness and disease management. The workgroup reviewed the 2007 task force report and recommendations as part of its work in developing this report.

The Alzheimer's Workgroup met twice in-person and once via teleconference to develop the response strategy and recommendations in this document.

## Work Group Members

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## **About Alzheimer's and Dementia in Iowa**

Dementia is diagnosed according to criteria that are established in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*.<sup>ii</sup> The criteria include a decline in memory along with a decline in cognitive abilities such as speaking or in understanding language; in recognizing or identifying objects; in exercising motor function; or in problem solving. In order for a diagnosis to be made, the decline in cognitive abilities must be severe enough to interfere with daily life.<sup>iii</sup>

Alzheimer's Disease is a "progressive and fatal brain disorder that causes problems with memory, thinking and behavior."<sup>iv</sup> It is the most common dementia, accounting for 60 to 80 percent of cases. Besides AD, other forms of dementia include:

- Vascular dementia
- Parkinson's disease
- Dementia with Lewy bodies
- Frontotemporal dementia
- Crutzfeldt-Jakob disease
- Normal pressure hydrocephalus
- Mixed dementia<sup>iii</sup>

For purposes of the Alzheimer's Disease Response Strategy for Iowa, the work to address AD includes work to address these related forms of dementia.

### *What is the impact?*

The impact of AD is staggering in actual costs of providing care, in the emotional and financial toll on patients and families, and in the projected need for services and costs for the future. One in eight people aged 65 and older and nearly half of people aged 85 and older have AD. In the United States 5.4 million people have AD, including 200,000 people under age 65 with younger onset of the disease. Sixty-nine thousand Iowans have AD, and the prevalence of AD in Iowa is expected to increase 18 percent by 2025.<sup>iii</sup>

While AD is substantially underreported as a cause of death, we know that it is the sixth leading cause of death overall and the fifth leading cause of death among older Americans. It is common for an individual with AD to have other health conditions, and the AD often contributes to making the other health conditions worse.<sup>iii</sup> For Iowans, it was the fifth leading cause of death in 2009. That year, Iowans died from Alzheimer's at a rate of 42 deaths per 100,000 population<sup>v</sup> (compared to the national average of 24.7 deaths per 100,000).<sup>iii</sup>

Health care costs for people with AD are three times higher than those without. Medicare and Medicaid cover about 70 percent of this cost, which is estimated at \$183 billion annually (including health care, long-term care, and hospice). This annual cost is expected to increase to \$1.1 trillion by 2050.<sup>iii</sup> In fact, “between 2010 and 2050, the costs to Medicare of caring for someone with Alzheimer’s will increase over 600 percent — and the cost to families in out-of-pocket costs will grow more than 400 percent.”<sup>iv</sup> “Over the next 40 years, Alzheimer’s will cost America over \$20 trillion, enough to pay off the national debt and still send a \$20,000 check to every man, woman and child in America.”<sup>iv</sup> And these costs only capture paid caregiving and do not include the unpaid caregiving that represents the vast majority of care for this population.

#### *What is “younger-onset”?*

When AD is diagnosed in a person under the age of 65, this is called “younger-onset” AD. About 200,000 people in the United States are diagnosed with younger-onset AD.<sup>iii</sup> The impact of younger-onset AD to the individual and their family during the years when a person is of employment age can be financially devastating and puts significant strain on family and informal support systems. Individuals and families experience barriers to services and supports that are designed, often by regulation, to serve a population that is older.

#### *What are the Challenges of Addressing Alzheimer’s Disease in the Population?*

Misperceptions and stigma prevent AD from being diagnosed. Patients and caregivers may delay reporting signs and symptoms of the disease, and they may not continue to report changes as the disease progresses. In some cases, providers may be reluctant to conduct full screening for the disease and may not believe a diagnosis will be productive or helpful for the patient. Lack of funding for services can also be a barrier on a number of levels. For people with young-onset or people with developmental disabilities, the challenges often include difficulty navigating a service system that was created for older individuals and not designed to meet their needs.<sup>vi</sup>

#### Challenges from Iowans’ Perspectives

In August, 2011, a series of listening sessions was conducted by the Alzheimer’s Association in conjunction with the National Alzheimer’s Project Act (NAPA).<sup>vii</sup> During these sessions, people with AD, caregivers, and family members provided their perspectives regarding the most critical issues associated with the disease. Themes from Iowans attending sessions included:

- Difficulty in getting a diagnosis, especially for younger-onset
- The need for training for physicians and other professional health care providers
- More funding for federal research
- Quality of care in facilities (staffing ratios, activities, turnover rates, etc.)
- Availability and accessibility of services

### Fragmentation

Families may not be aware of available services or understand how to access them. Some services for people with AD and educational and supportive resources for their families have been designed to allow for local flexibility and may vary based on where they live. While this creates services that meet local needs, it means that services that are available in one location may not be available to someone with similar needs in another community. Difficulty in interpreting eligibility requirements can be another issue. . Services for some programs are available at age 60, but other programs require a minimum age of 65. Income and resources are considered in eligibility determination for Medicaid, and the details of the rules can be confusing to family members.

### Workforce

Issues with workforce shortages and training in the health and long-term care systems are cause for concern for the overall system as a whole. The aging population and the increased demands it places on care systems is a key factor. The Institute of Medicine's (IOM) April 2008 report entitled *Retooling for an Aging America: Building the Health Care Workforce* calls for "immediate investments in enhancing the geriatric competencies of the entire workforce, increasing the recruitment and retention of geriatric specialists and caregivers, and improving the way that care for older adults is delivered."<sup>viii</sup> The shortage and training issues impact care for people with AD in direct and specific ways from the day-to-day hands-on care that is provided, to primary medical care they receive, to specialty physician care.

Direct care professionals are individuals who provide supportive services and care to people experiencing illnesses or disabilities and receive compensation for such services.<sup>ix</sup> The Iowa Direct Care Worker Advisory Council estimates that there are 55,000 direct care professionals in the state.<sup>ix</sup> It is estimated that these workers provide 70 to 80 percent of all the hands-on long-term care and personal assistance for the elderly, those with disabilities, and those with chronic conditions.<sup>x</sup> The rapidly growing demand for home and community-based services, along with the increasing elderly population, mean this workforce is only expected to grow. The categories of "nurse aides" and "home health aides" are in the top 10 for anticipated growth in Iowa between 2008 and 2018.<sup>xi</sup> During this timeframe, Iowa Workforce Development estimates a need for an additional 11,000 direct care professionals.<sup>xii</sup> As Iowa monitors the expected demand for this workforce, it is important to focus on ways to prevent attrition and to avoid the cost of turnover.

Increasing shortages in primary care, particularly in rural areas, have been an ongoing concern for many years. In Iowa, 62 counties have primary care shortage areas.<sup>xiii</sup> Primary care

clinicians are critical to the initial diagnosis of AD and for ongoing medical care for patients. Primary care practices are also an initial point of information for family members. The pressures caused by lack of primary care clinicians mean that the system cannot consistently respond timely and thoroughly to patient and family needs. It may also mean that clinicians have not received specialized or updated training specific to AD.

Beyond shortages in primary care, Iowa also experiences shortages in areas of specialty care often needed by patients with AD. In 2007, the Task Force on the Iowa Physician Workforce found that two areas of physician care in greatest need were psychiatry and neurology.<sup>xiv</sup> These are two areas of specialty physician care most needed by people with AD. In Iowa, 90 counties are mental health professional shortage areas,<sup>xv</sup> a direct reflection of psychiatrist to population ratio. A key component to meeting the needs of people with AD and family members is addressing both workforce shortages and workforce training needs at all levels in the system.

#### *What Resources are Available for Patients, Families, and Caregivers?*

The Alzheimer's Association is a national organization that "works on a global, national and local level to enhance care and support for all those affected by Alzheimer's and related dementias."<sup>xvi</sup> In Iowa, local offices are located in Burlington, Cedar Falls, Cedar Rapids, Council Bluffs, Creston, Davenport, Dubuque, Fort Dodge, Sioux City, Waterloo, and West Des Moines.<sup>vi</sup> The Alzheimer's Association is available 24 hours per day, 7 days per week, providing information and referral.<sup>xvii</sup> The Alzheimer's Association also provides:

- Support groups for caregivers and people with AD
- Care consultation
- Community and professional education
- Online resources – education, chat rooms, information, care planning tools and others
- Safety services including Medic Alert + Safe Return and Comfort Zone
- Lending libraries

Area Agencies on Aging (AAAs) were established under the Older Americans Act (OAA) in 1973 to respond to the needs of Americans aged 60 and over in every local community. Iowa has AAAs covering all 99 counties.<sup>xviii</sup> Funded by approximately 50% federal, 10% state, and 40% local contributions, AAAs strive to meet the needs of the rapidly-growing number of older Iowans through the following activities:

- Assess current needs of older Iowans
- Assess available services, programs, and institutions
- Develop plans to help address service gaps via the Senior Living Program
- Assure access to services, programs, and institutions

- Advocate for the needs of older Iowans
- Finance and administer contracts to direct providers of services
- Provide a central leadership role for older Iowans
- Provide information and assistance services for older Iowans and their caregivers<sup>xviii</sup>

Medicaid Home and Community Based Services (HCBS) Waivers include “a comprehensive range of home and community services that provide alternatives to unnecessary institutional care” and “enable people with significant disabilities to live in their communities and offer consumers more control over the services they receive.”<sup>xix</sup> The services are funded through the Medicaid program which is a combination of federal and state funding. In Iowa, Medicaid funding is approximately 63 percent federal funds and 37 percent state funds. Service providers are located across the state. Seven waivers offer different types of services and have different eligibility criteria. Services available under the Elderly Waiver in Iowa include:

- |                                    |                                |
|------------------------------------|--------------------------------|
| • Adult Day Care                   | • Homemaker                    |
| • Assistive Devices                | • Mental Health Outreach       |
| • Case Management                  | • Nursing                      |
| • Chore                            | • Nutritional Counseling       |
| • Consumer Directed Attendant Care | • Personal Emergency Response  |
| • Home & Vehicle Modification      | • Respite                      |
| • Home Delivered Meals             | • Senior Companion             |
| • Home Health Aide                 | • Transportation <sup>xx</sup> |

It is important to note two things about HCBS service availability: there are eligibility requirements, including income eligibility, that not all Iowans meet; and there are caps on the number of individuals that are allowed to participate in some waivers in Iowa, meaning that individuals may need to stay on a waiting list for a period of time before services become available.

Alzheimer’s Special Care Units (SCUs) in nursing facilities and assisted living settings provide enhanced security and services specific to the unique needs of people with dementia. These units provide enhanced support and supervision, activities targeted to the needs of people with dementia.<sup>xxi</sup> Service providers are located across the state.

## Overview of the Response Strategy

After reviewing the statistics related to the state of Alzheimer's disease and related dementias in Iowa, the Alzheimer's Workgroup identified several contextual factors that are important to a discussion about how Iowa addresses AD in Iowa:

- There is limited resources and funding available at the state and federal levels;
- There is a lack of comprehensive data on AD in Iowa, and therefore little knowledge about the unique needs of this targeted population;
- Fragmented service systems often mean individuals and families have difficulty accessing information and resources, and there are not consistent services and supports available;
- Iowa faces significant workforce challenges, including shortages for specific specialties and professions, as well as a need for more and better training related to AD;
- Stigma about Alzheimer's and dementia is believed to be pervasive and unless addressed, will impede any efforts to improve overall system supports for AD.

As a result of discussion about the current context, the workgroup identified five guiding principles that frame the recommendations. As Iowa develops and implements this response strategy, it must:

1. *Efficiently utilize services within limited resources and funding, and expand partnerships.* Partnerships would include public (federal, state and local government agencies) and private entities (including community-based, non-profit, faith-based, health-care, long-term care, and other organizations and individuals).
2. *Invest in evidence-based interventions.* Current research demonstrates proven interventions for AD, and new research indicates the effectiveness of early diagnosis and intervention. Iowa should use its limited resources to target proven strategies.
3. *Aim to provide standardized and consistent access to multiple, individualized services and supports.* The response strategy starts with improving access to information and referral, and home and community-based services.
4. *Recognize that Alzheimer's disease and related dementias are best addressed with a social model of supports, not a medical model of treatment.* A social model incorporates strategies such as delaying onset through healthy behaviors; improving long-term health; and providing psychosocial supports and education for individuals and family caregivers.
5. *Start building the foundation.* Strategies will include addressing stigma, collecting data, addressing workforce barriers, and creating a state-level infrastructure that will prepare Iowa for long-term investments and comprehensive supports in the future.

## **Response Strategy**

The response strategy lists each overarching goal and specific objectives, followed by action steps and timeline. Refer to page 18 for a one-page reference of all of the activities and timelines. Each goal also addresses who should be responsible for completing the activities and additional considerations related to funding. Ultimately, most of the goals rely on follow-through of the first recommendation to develop a public/private infrastructure to implement Alzheimer's activities. The six goals within the strategy are:

- 1) Develop the Infrastructure Necessary to Support and Fund Alzheimer's Activities
  - a. Establish an AD coordinator position and multidisciplinary advisory group.
- 2) Address Stigma with Awareness and Education
  - a. Implement a public awareness campaign about AD and related dementias.
  - b. Promote evidence-based practices in assessment and diagnosis among the medical community.
- 3) Provide Immediate Information and Resources
  - a. Support the expansion of Aging and Disability Resource Centers (ADRCs) in Iowa.
  - b. Ensure that ADRCs and other information and referral sources are dementia-capable.
  - c. Inform community networks of referral sources for dementia.
- 4) Address Workforce Challenges Specific to AD Needs
  - a. Invest in state-level efforts to improve recruitment and retention of targeted professions, including psychiatrists, gerontologists, neurologists and direct care professionals.
  - b. Revisit the recommendations of the 2010 Iowa Dementia Education Project. In collaboration with the Direct Care Workforce Initiative and the Mental Health Redesign recommendations, take steps to implement curriculum recommendations for direct care professionals and expand the project to other staff that interact with individuals with AD.
- 5) Increase Access to Services Most in Need
  - a. Review the availability of home and community based services, reduce barriers to accessing them, and ensure providers are dementia-capable.
  - b. Develop telemedicine capabilities to allow professionals serving individuals with cognitive impairment to access mental health advice and services.
- 6) Improve Data Collection on AD in Iowa
  - a. Utilize existing assessment tools to collect additional data on the population.
  - b. Identify unique needs and issues for early-onset Alzheimer's and develop plan to address early-onset in Iowa.

**Goal 1: Develop the Infrastructure Necessary to Support and Fund Alzheimer’s Activities**

Objective:

- A. Establish an AD coordinator position and multidisciplinary advisory group.

House File 390 required the workgroup to specifically identify a location for a state office on Alzheimer’s disease and related dementias. For development of the response strategy, the workgroup discussed the purpose of a state office, its role, and how it would partner with private agencies to avoid duplication of services and leverage existing funding and resources. The position and advisory group are necessary to provide coordination and partnership in a fragmented system that is currently minimally responsive to individual and family needs for information, resources and supports.

Ultimately, the workgroup recommends a coordinator position (1 full-time equivalent) to be located within the Iowa Department of Public Health. Support for this included IDPH’s ability to take on a more widespread range of responsibility including data collection and capacity to increase public awareness. The group also discussed that this is a public health issue and is not confined only to those who are aging. The coordinator will collaborate with an advisory group that should include representation from:

- Iowa Department on Aging
- Iowa Department of Human Services (Iowa Medicaid Enterprise)
- Iowa Department of Inspections and Appeals
- Iowa Department of Public Safety
- Iowa Workforce Development
- Alzheimer’s Association
- Iowa CareGivers Association
- AARP - Iowa
- Iowa Association of Area Agencies on Aging
- Faith-based entities
- Community-based organizations
- Paid and unpaid caregivers
- Individuals experiencing AD and their families

The state agencies participating in the advisory group will be expected to identify a staff person to work in partnership with the AD Coordinator, other state agencies, and the private partners to provide information and support as requested and within resources available.

The AD Coordinator will:

- Research and respond to funding opportunities
- Lead and coordinate data collection efforts among public and private entities, and disseminate information
- Coordinate a public awareness campaign, including identification of partners

- Promote AD evidence-based practices, including caregiver education, physician practice standards, and others
- Act as a liaison to the Aging and Disability Resource Centers, Area Agencies on Aging, state and national Alzheimer’s Association chapters, and others to ensure Alzheimer’s disease and related dementias are appropriately addressed statewide
- Track relevant workforce projections in coordination with Iowa Workforce Development, the Health and Long Term Care Access Advisory Council and other existing efforts
- Create accountability among all entities responsible for providing services and supports for individuals with AD and their families
- Act as a state-level subject matter expert; build and maintain relationships at state, federal and local levels
- Provide staff support to the advisory group

Action Steps	Timeline
Pass legislation to establish and fund the coordinator position (1 FTE) and provide appropriations to support the position, the advisory group, and targeted action steps outlined in the recommendation(s).	May 2012
Hire coordinator	October 2012

**Goal 2: Address Stigma with Awareness and Education**

Objectives:

- Implement a public awareness campaign about Alzheimer’s disease and related dementias.
- Promote evidence-based practices in assessment and diagnosis among the medical community.

Stigma is prevalent and underlies many of the challenges related to accessing services for Alzheimer’s disease and related dementias. Individuals are afraid to ask their physicians about memory loss, and family members are hesitant to ask for help until they are in crisis and emotionally and physically exhausted. “That’s the double stigma of Alzheimer’s—ashamed that you have it in your family, ashamed that you can’t cope.”<sup>i</sup> These factors delay diagnose and increase fear and embarrassment, while placing additional stress on families coping with the illness without needed supports. The purpose of a public awareness campaign would be to ‘de-mystify’ the disease by encouraging Iowans to think about addressing it like they do heart disease and cancer.

In addition to a public awareness campaign, targeted education to physicians is necessary to promote best practices in diagnosis and referral. The Physician Consortium for Performance Improvement (PCPI) is currently drafting a Dementia Performance Measurement Set to assist physicians and other health care professionals in improving quality of care for the AD population. The draft measures encompass activities such as performing cognitive assessments, determining functional status, managing symptoms, conducting palliative care counseling and advance care planning, and providing caregiver education and support.<sup>xxii</sup> Once finalized the performance measures should be distributed widely and promoting as best practice in Iowa.

Action Steps	Timeline
Develop a public/private advisory group for awareness campaign	January 2013
Disseminate PCPI dementia performance measure set to groups and individuals	March 2013
Set goals and outcomes for the public awareness campaign	March 2013
Seek funding for the public awareness campaign	March 2013
Develop awareness campaign messaging and work with partners to disseminate	June 2013

This activity is expected to be led by the Iowa Department of Public Health’s coordinator position in partnership with the AD advisory group and additional partners as identified for this project. For the public awareness campaign specifically, the workgroup recommends including individuals with AD and their families, caregivers, health care and long-term care professionals, police and fire representatives, schools, faith-based and community-based organizations, and health insurance and pharmaceutical companies. Funding should be sought from a variety of sources, including state, federal and private agencies.

**Goal 3: Provide Immediate Information and Resources to Individuals and Families**

Objectives:

- A. Support the expansion of Aging and Disability Resource Centers (ADRCs) in Iowa.
- B. Ensure that ADRCs and other information and referral sources are dementia-capable.
- C. Inform community networks of referral sources for dementia.

Getting a diagnosis is an extremely difficult experience for families; they are overwhelmed and often do not receive information about how to access services and supports. In an effort to utilize existing services and funding and create partnerships statewide, the workgroup recommends that existing information and referral services are expanded. This would include educating community networks about how to respond to dementia-related issues and questions, and providing information about referral sources for this population. The Iowa

chapters of the Alzheimer’s Association offer 24/7 referral services, and it should be a priority to raise lowans’ awareness of the information and referral services already available.

The Aging and Disability Resource Centers (ADRC) model, as a vehicle to accessing long-term community care supports and services, has been developing in Iowa since 2004 through Administration on Aging Title IV discretionary funding opportunities. Information and referral services are one of the pillar services of the ADRC, which are provided by Alliance for Information & Referral Services certified specialists. Information and referral services utilize multiple databases to assist consumers in finding needed services and supports, as well as provide access to additional services for which the consumer might be eligible. Expansion of ADRC services throughout Iowa will occur during the next five years.

Action Steps	Timeline
Conduct informal outreach by private entities and partners to share information with referral centers about dementia and Alzheimer’s	January 2012
Establish relationship and work with advisory group to develop materials to distribute to information and referral centers	June 2013
Begin regular dissemination of information and communication with information and referral centers	September 2013

It is expected that the AD Coordinator would work closely with ADRCs, the state Alzheimer’s Association chapters, and other referral sources. Before the coordinator position is established, the workgroup anticipates that partners will inform their networks about the need to ensure dementia-capability within the information and referral systems. No additional funding is needed for this activity as it would primarily be done through the coordinator FTE and in partnership with private organizations and other state agencies.

**Goal 4: Address Workforce Challenges Specific to AD Needs**

Objectives:

- A. Invest in state-level efforts to improve recruitment and retention of targeted professions, including psychiatrists, gerontologists, neurologists and direct care professionals.
- B. Revisit the recommendations of the 2010 Iowa Dementia Education Project. In collaboration with the Direct Care Workforce Initiative and the Mental Health Redesign recommendations, take steps to implement curriculum recommendations for direct care professionals and expand the project to other staff that interact with individuals with AD.

As stated in the section of this report entitled *About Alzheimer’s and Dementia*, most of Iowa’s 99 counties are designated as health professional shortage areas with shortages in primary care and specialty areas, particularly direct care, gerontology, neurology and psychiatry. Alzheimer’s disease and related dementias are complex and challenging disorders, and Iowa must ensure that individuals with AD not only have access to needed services and professionals, but also that those professionals are properly trained and educated.

Action Steps	Timeline
Revisit the 2010 curriculum recommendations and review existing administrative rules related to dementia training to identify alignment with current rules, the Direct Care Workforce Initiative, and the Mental Health Redesign effort	January 2013
Identify workgroup (as part of AD Advisory Group) to identify common training needs for ancillary staff	June 2013
Submit and pass rules to implement 2010 Alzheimer’s curriculum recommendations that align with dementia training requirements	September 2013
Review existing recruitment and retention programs and identify opportunities to improve access and services for AD	September 2013

No specific costs have been identified for these activities. The coordinator and advisory group recommended in Goal 1 would primarily be responsible for conducting the action steps. Once the advisory group is established, a first priority will be to review the curriculum recommendations and begin the work of reviewing existing rules related to dementia training in anticipation of developing administrative rules for implementation.

**Goal 5: Increase Access to Services Most in Need**

Objectives:

- A. Review the availability of home and community based services, reduce barriers to accessing them, and ensure providers are dementia-capable.
- B. Develop telemedicine capabilities to allow professionals serving individuals with cognitive impairment to access mental health advice and services.

Improving access to home and community-based services not only benefits the individual with AD by allowing them to stay at home with family, but it also saves costs to the state by delaying or eliminating the need for institutionalization. Services that are often essential for individuals with AD and their families include housekeeping/chore, home health care, meals, transportation, adult day, and respite. Adult day services in particular have been declining in Iowa, and yet adult day and respite services are noted by families as ‘lifesaving’ services that allowed them to perform normal activities like going to work and running errands.

In addition, new technology has allowed individuals in rural or underserved parts of Iowa to receive advice and services from highly skilled and in-demand health care professionals through telemedicine capabilities. With a severe mental health workforce shortage, promoting telemedicine for mental health services is a priority for Iowa.

Action Steps	Timeline
Review the current fee structure for adult day agencies registering with the Iowa Department of Inspections and Appeals	June 2012
Assess barriers to increased implementation of HCBS	December 2013
Identify partners for expanding and promoting telemedicine capabilities to serve individuals with AD in Iowa	January 2014
Develop strategic plan for expanding and promoting telemedicine capabilities for AD in Iowa in cooperation with efforts of the Health and Long Term Care Access Advisory Council	June 2014

The Iowa Department of Inspections and Appeals is the primary agency that would be responsible for the review of the fee structure for adult day services. The other action steps listed here would be conducted by the coordinator and advisory group with targeted partners involved as needed.

***Goal 6: Improve Data Collection on Alzheimer’s Disease in Iowa***

Objectives:

- A. Utilize existing assessment tools to collect additional data on the population.
- B. Identify unique needs and issues for younger-onset Alzheimer’s and develop plan to address younger-onset in Iowa.

The lack of data on this population was a significant challenge for the Alzheimer’s Workgroup. Data serves many purposes: better identification of the population and related issues in Iowa; planning for services and funding; and supporting research on the disease. Initially, the workgroup identified opportunities to add assessment questions to existing tools to capture better information about this population at little or no cost. Unfortunately, since Alzheimer’s disease is often not listed as the primary diagnosis, there is no existing data set that would provide this kind of information in Iowa. The questions should assist Iowa in future planning for Alzheimer’s in Iowa by determining how individuals are currently accessing services and funding and what barriers exist related to identification and treatment.

Following is a list of current assessment tools that should be reviewed to determine how additional questions related to Alzheimer’s might be incorporated.

- The Iowa Department of Public Health’s Behavioral Risk Factor Surveillance System (BRFSS), which has already incorporated questions about cognitive impairment
- The National Aging Programs Information System (NAPIS), which is required reporting for any services provided through the Older Americans Act
- The Iowa Department of Public Health’s Community Health Needs Assessment and Health Improvement Plans (CHNA & HIP), which are conducted every five years by all 99 counties in Iowa
- The Medicare Wellness Visit, which recently added cognitive impairment questions to the assessment

Although younger-onset Alzheimer’s affects a small percentage of the overall population of individuals with AD, the impact is compounded by the fact that these individuals are often ineligible for funding and services targeted to older Iowans. Individuals with disabilities, such as Down Syndrome, are at a higher risk of developing Alzheimer’s disease and related dementias at a younger age. Therefore, the developmental disability population is specifically targeted in the action step related to drafting a plan for younger-onset Alzheimer’s. The AD Coordinator and advisory group should make it a priority to utilize the data collected from the assessment tools to inform planning for younger-onset Alzheimer’s in Iowa.

Action Steps	Timeline
Draft assessment questions and incorporate into assessment tools	January 2013
Begin analysis of data collected through assessment tools	September 2013
Update assessment questions and continue ongoing data collection and analysis	January 2014
Draft plan for addressing younger-onset Alzheimer’s in Iowa, including a specific focus on the developmental disability population	June 2014

It is important to note for planning purposes that identification and incorporation of additional assessment questions are not expected to cost any additional money, but ongoing analysis of the compiled data will likely take some additional funding to complete. The plan for addressing younger-onset Alzheimer’s in Iowa will be conducted by the AD advisory group.

## Overview of Action Steps and Timeline

Action Steps	Timeline
Conduct informal outreach by private entities and partners to share information with referral centers about dementia and Alzheimer's	January 2012
Pass legislation to establish and fund the coordinator position (1 FTE) and provide appropriations to support the position, the Advisory Group, and targeted action steps outlined in the recommendation(s).	May 2012
Hires coordinator	October 2012
Develop a public/private advisory group for public awareness campaign	January 2013
Draft assessment questions and incorporate into assessment tools	January 2013
Revisit the 2010 curriculum recommendations and review existing administrative rules related to dementia training to identify alignment with current rules, the Direct Care Workforce Initiative, and the Mental Health Redesign effort	January 2013
Disseminate PCPI dementia performance measure set to groups and individuals	March 2013
Set goals and outcomes for the public awareness campaign	March 2013
Seek funding for the public awareness campaign	March 2013
Develop awareness campaign messaging and work with partners to disseminate	June 2013
Establish relationships with information and referral centers and works with advisory group to develop materials to distribute	June 2013
Identify workgroup (as part of AD Advisory Group) to identify common training needs for ancillary staff	June 2013
Submit and pass rules to implement 2010 Alzheimer's curriculum recommendations that align with dementia training requirements	September 2013
Begin regular dissemination of information and communication with information and referral centers	September 2013
Begin analysis of data collected through assessment tools	September 2013
Review existing recruitment and retention programs and identify opportunities to improve access and services for AD	September 2013
Assess barriers to increased implementation of HCBS	December 2013
Identify partners for expanding and promoting telemedicine capabilities to serve individuals with AD in Iowa	January 2014
Update assessment questions and continue ongoing data collection and analysis	January 2014
Draft plan for addressing younger-onset Alzheimer's in Iowa	June 2014
Develop strategic plan for expanding and promoting telemedicine capabilities for AD in Iowa in cooperation with efforts of the Health and Long-Term Care Access Advisory Council	June 2014

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