



STATE OF INDIANA
OFFICE OF THE GOVERNOR
State House, Second Floor
Indianapolis, Indiana 46204

Michael R. Pence
Governor

Many health issues face our state, but Alzheimer's disease is especially challenging for Hoosier families, communities and health care providers. In 2011, Governor Mitch Daniels showed his commitment to fighting the state's growing Alzheimer's crisis by appointing the Governor's Task Force on Alzheimer's Disease. I am pleased to be able to build on the previous administration's dedication to our great state's aging population and present you with the Indiana Plan for Alzheimer's Disease and Related Dementias.

The State Plan creates the infrastructure and accountability necessary to build dementia-capable programs for the 120,000 Hoosiers currently living with Alzheimer's and the many hundreds of thousands who will be diagnosed in the future. The plan outlines aggressive strategies to address awareness, planning, diagnosis, quality of care, public safety and research. More than one thousand Hoosiers participated in the process of creating the plan, and dozens of experts provided input to the task force that produced the final document.

I urge you to study the recommendations set forth in the Indiana Plan for Alzheimer's Disease and Related Dementias and consider how you can join me in the fight against this growing epidemic. Together, we can work to improve the lives of hundreds of thousands of Hoosiers.

Sincerely,

Mike Pence
Governor of Indiana

Indiana Plan for Alzheimer's Disease and Related Dementias

2013-2017

**Sixth Leading
Cause
of Death**



**Skyrocketing
Cost of
Care**

**Increasing
Mortality
Rates**

**No Prevention, Cure or
Way to Slow Progression**

Table of Contents

	Page Number
Background	2
Introduction and Facts about Alzheimer’s Disease – Why a State Plan? Indiana Plan Development Process –Task Force, Speakers, Surveys, Forums	
Plan Summary: Vision and Ten Priorities for Action	12
<hr/>	
Goal A: Raise Awareness about Alzheimer’s Disease and What Individuals Can Do to Support Those with Alzheimer’s Disease	14
A1. Action Plan to Raise Public Awareness of Alzheimer’s Disease A2. Action Plan to Maintain and Improve Brain Health A3. Action Plan to Improve Legal and Financial Planning A4. Action Plan to Assist Unpaid Caregivers	
<hr/>	
Goal B: Connect Patients and Families to Services on a Timely Basis	18
B1. Action Plan to Increase Early Detection and Diagnosis of AD B2. Action Plan to Improve Care Coordination and Case Management	
<hr/>	
Goal C: Improve the Quality of Care for Individuals with Alzheimer’s Disease or Dementia	20
C1. Action Plan to Address Alzheimer’s and Dementia Care Issues in Health Facility Regulations C2. Action Plan to Expand Health Care System Capacity and Funding C3. Action Plan to Improve Dementia Training and Supply of Health Care Professionals	
<hr/>	
Goal D: Increase Public Safety for People with Alzheimer’s Disease and Their Families	24
D1. Action Plan to Ensure Availability of Dementia Training for Public Safety Workers D2. Action Plan to Improve Driving Safety D3. Action Plan to Protect Cognitively Impaired Adults from Fraud, Abuse, and Neglect	
<hr/>	
Goal E: Enhance Research and Data about Alzheimer’s Disease	26
E1. Action Plan to Increase Research E2. Action Plan to Improve Data Collection	
<hr/>	
Goal F: Implement the Plan Effectively	29
F1. Action Plan to Improve State Infrastructure for Implementing the AD Plan F2. Action Plan to Integrate Indiana AD Plan with Related Plans	
<hr/>	
Excerpts from the National Plan	31



BACKGROUND

Introduction to the Indiana Plan

In 2011, the Indiana General Assembly directed the Indiana Alzheimer's Disease and Related Senile Dementia Task Force ("Task Force") to develop a state plan for Alzheimer's disease or related senile dementia. This *Indiana Plan for Alzheimer's Disease and Dementia* ("State Plan") consists of recommendations from the Task Force for consideration by a combination of public and private partners. These are not mandates but rather recommendations.

What is Alzheimer's Disease and Dementia?

"Dementia" is an umbrella term describing a variety of diseases and conditions that develop when nerve cells in the brain die or no longer function normally. Alzheimer's disease is the most common type of dementia, accounting for an estimated 60-80 percent of cases. Some other types of dementia include Lewy body, frontotemporal, mixed, and vascular dementia.

Symptoms develop over time. Warning signs of Alzheimer's include these:

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

For more information about warning signs visit www.alz.org/10signs.

Alzheimer's is not a normal part of aging, although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. Alzheimer's is not just a disease of old age, however. Up to five percent of people with the disease have young-onset Alzheimer's (also known as early-onset), which can appear in people in their 40s or 50s. This population has a set of needs different from those over 65, and those affected may experience difficulty accessing accurate and timely diagnosis and needed services due to their age.

Alzheimer's and most types of dementia are progressive diseases in which symptoms gradually worsen over time. In the early stages of Alzheimer's the most well-known symptom is mild memory loss, although other symptoms may be apparent and initially subtle, causing confusion or concern for family and friends. Other symptoms can include word-finding problems, trouble performing tasks such as paying bills, personality changes or emotional symptoms of depression, anxiety, or irritability. By late-stage Alzheimer's, individuals lose the ability to carry on a conversation, respond to their environment, and care for themselves in every aspect of their lives.

National data indicate that older African Americans are about twice as likely to develop Alzheimer's as older Caucasians, and Latinos are about one and one-half times as likely to develop Alzheimer's as older Caucasians. Individuals with Down's syndrome are at extremely high risk for developing Alzheimer's due to a genetic link between these two conditions.



Photo courtesy of the Alzheimer's Association

Alzheimer's is the sixth leading cause of death in the United States. Those with Alzheimer's live an average of eight years after their symptoms become noticeable to others, but survival can range from four to 20 years, depending on age and other health conditions.

Alzheimer's has no cure at this time, but treatments for symptoms are available and research continues. Although current Alzheimer's treatments cannot stop the disease from progressing, they can temporarily slow the worsening of dementia symptoms and improve quality of life for some people with Alzheimer's and their caregivers. Today, there is a worldwide effort underway to find better ways to treat the disease, delay its onset, and prevent it from developing.

(Adapted from the Oregon State Plan using materials produced by the Alzheimer's Association)

Facts about Alzheimer's Disease – Why a State Plan?

The following facts and figures, published by the Alzheimer's Association and summarized in its Factsheet of March 2012, illustrate why it has become imperative for Indiana to have a plan for addressing Alzheimer's disease and related dementias.

2012 Alzheimer's Disease Facts and Figures (see www.alz.org/facts)

The number of people with Alzheimer's disease is growing – and fast.

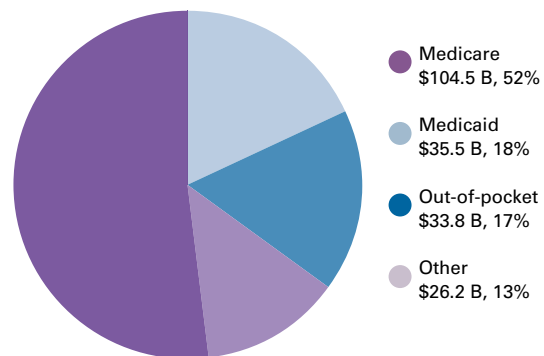
- Today, more than 5 million Americans are living with Alzheimer's disease, including 120,000 Hoosiers.
- By 2050, up to 16 million Americans will have the disease.

The graying of America will be expensive, and Alzheimer's is a major reason why.

- In 2012, the direct costs of caring for those with Alzheimer's to American society totaled an estimated \$200 billion, including \$140 billion in costs to Medicare and Medicaid.
- Average per-person Medicare costs for those with Alzheimer's and other dementias are three times higher than for those without these conditions.
- Unless something is done, the costs of Alzheimer's in 2050 are estimated to total \$1.1 trillion (in today's dollars). Costs to Medicare and Medicaid will increase nearly 500 percent.

2012 Costs of Alzheimer's = \$200 billion

Total cost: \$200 Billion (B)



*Data are in 2012 dollars.

Created from data from the application of The Lewin Model^{A17} to data from the Medicare Current Beneficiary Survey for 2008.⁽¹²⁸⁾ "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

Alzheimer's makes treating other diseases more expensive – increasing costs across the health care system.

- Most people with Alzheimer's have one or more other serious medical conditions, and dementia complicates management of these conditions. For example, a person with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who has diabetes but not Alzheimer's.

Many people with Alzheimer’s live alone – and are left to fend for themselves.

- An estimated 800,000 individuals with Alzheimer’s (more than one in seven) live alone, and up to half of them do not have an identifiable caregiver.
- People with Alzheimer’s and other dementias who live alone are exposed to higher risks – including inadequate self-care, malnutrition, untreated medical conditions, falls, wandering from home unattended, and accidental deaths – compared to those who do not live alone.



Photo courtesy of the Alzheimer’s Association

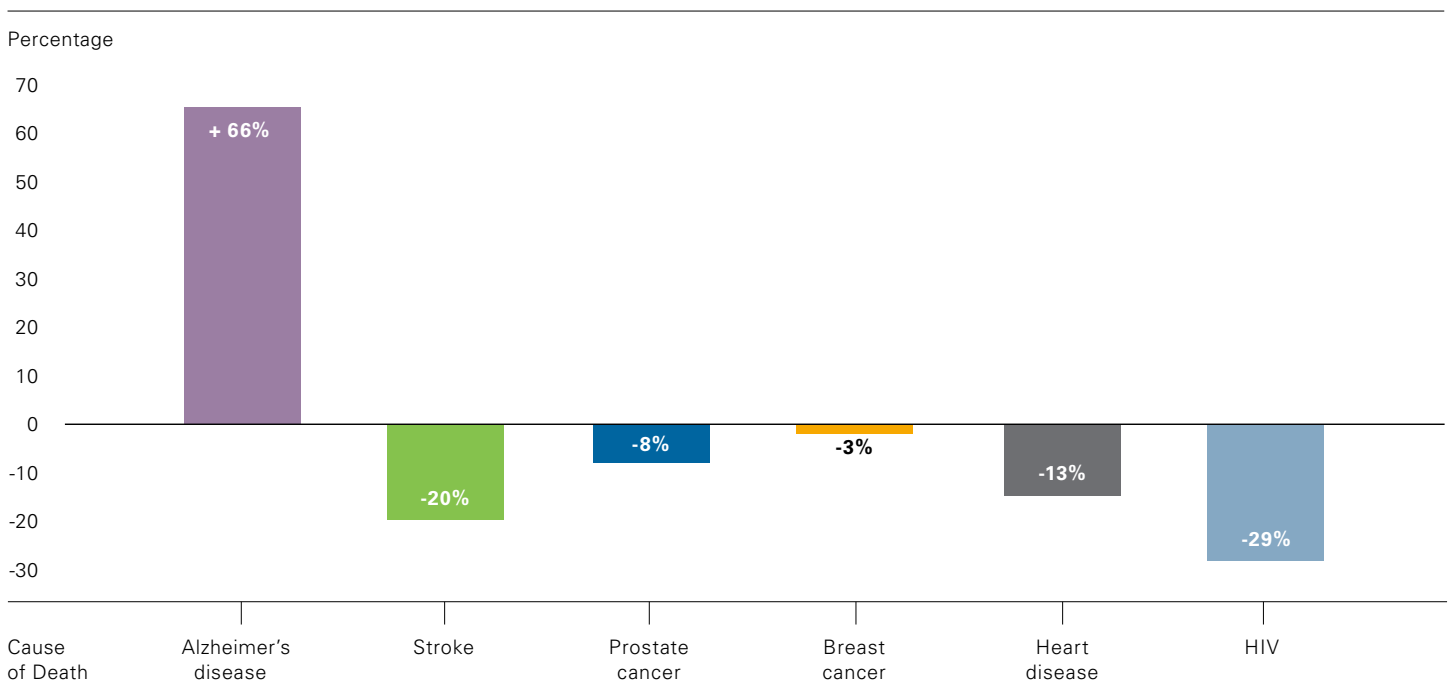
With Alzheimer’s, it is not just those with the disease who suffer – it’s also their caregivers.

- In 2011, 15.2 million family and friends nationwide provided 17.4 billion hours of unpaid care to those with Alzheimer’s and other dementias – care valued at \$210.5 billion.
- Due to the physical and emotional toll of caregiving on their own health, Alzheimer’s and dementia caregivers across the U.S. had \$8.7 billion in additional health care costs in 2011.

Alzheimer’s is not just memory loss – Alzheimer’s kills.

- Alzheimer’s disease is the sixth leading cause of death in the United States and the fifth leading cause of death for those aged 65 and older.
- Alzheimer’s is the only cause of death among the top 10 in America without a way to prevent, cure or even slow its progression.
- Deaths from Alzheimer’s increased 66 percent between 2000 and 2008, while deaths from other major diseases decreased as shown below.

Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2008



Created from data from the National Center for Health Statistics⁽⁸⁷⁾ and Miniño et al.⁽⁸²⁾

Number of Indiana Deaths Due to Alzheimer's Disease in 2008: 1,971

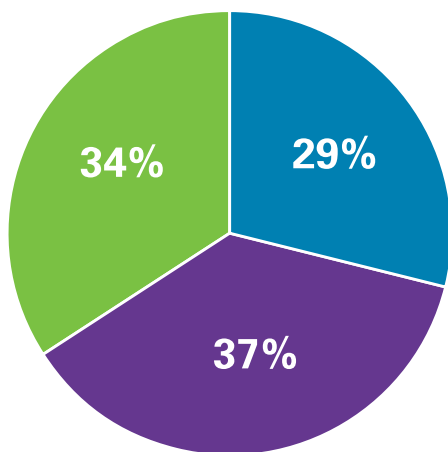
Number of Hoosiers Aged 65 and Older with Alzheimer's by Age					
Year	65-74	75-84	85+	Total	% Chg from 2000
2000	6,600	54,000	42,000	100,000	-
2010	5,900	55,000	54,000	120,000	20%
2020	7,000	56,000	58,000	120,000	20%
2025	8,400	65,000	60,000	130,000	30%

Number of Alzheimer's & Dementia Caregivers, Hours of Unpaid Care, Economic Value of Care				
Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care	Higher Health Costs of Caregivers
2011	326,151	371,420,588	\$4,501,617,522	\$180,794,933

Cognitive Impairment in Indiana Nursing Home Residents, 2009

Total Nursing Home Residents

84,063



Level of Cognitive Impairment

- severe/moderate
- mild/very mild
- none

Summary

Alzheimer's is a devastating disease that causes changes in one's memory, behavior, and ability to think clearly. It is the sixth leading cause of death in America, and the only one for which there is no way to cure, prevent, or slow its progression. From 2000 to 2010, the number of Hoosiers with AD increased 20%, and the number is expected to increase further as the population ages. Currently, about 120,000 Hoosiers live with Alzheimer's, and 326,000 informal caregivers provide them with unpaid care valued at \$4.5 billion.

Other State and National Plans

Given these statistics and the impact of Alzheimer's disease on families, caregivers, and taxpayers, the national Alzheimer's Association has urged all states to adopt a plan. So far (2012), about half of all states have adopted a plan.

In May 2012, the federal government adopted the National Alzheimer's Plan pursuant to the National Alzheimer's Project Act (napa.alz.org). The Indiana Plan complements the National Plan.

Indiana Plan

Through implementation of the Indiana plan, we expect to have a positive impact on all stakeholders in Indiana, from caregivers to government. The Task Force that developed this plan includes state legislators, non-profit organizations, state government agencies, academic researchers, issue experts, physicians, care providers, and family caregivers. It is the product of professional expertise, personal experience and public input. As new needs arise or new resources become available, it should be amended to reflect these changes.

This plan was developed to ensure that Hoosiers with Alzheimer's disease and related dementias as well as their caregivers have the information and support they need, and that services are delivered as effectively and efficiently as possible.

The plan's development is described next.



Photo courtesy of the Alzheimer's Association



Development of the Indiana Plan

Indiana Alzheimer's Disease and Related Senile Dementia Task Force

Creation

In 1992, the Indiana General Assembly created the Alzheimer's Disease and Related Senile Dementia Task Force. The statute was codified at Indiana Code (IC) 12-10-5-10. In 2011, the Indiana General Assembly amended the statute to require that the Task Force develop a state plan concerning the provision of services in the area of Alzheimer's disease or related senile dementia. The statute became effective July 1, 2011, and provided for the expiration of the Task Force on December 31, 2013.

Members of the Task Force

Appointments to the Task Force were made by Governor Daniels. The following were members of the Task Force:

Member Categories	Name / Title / Organization
Voting Members	
Representative of an Alzheimer's Disease support organization	Chair of Task Force Michael Sullivan, Director of Public Policy and Advocacy Alzheimer's Association Greater Indiana Chapter
Representative of an Alzheimer's Disease support organization	Stephen W. Adair, J.D.
Physician with an unlimited license to practice medicine under IC 25-22.5	Ann Marie Hake, M.D.
Psychologist with a license to practice psychology under IC 25-33	Frederick Unverzagt, Ph.D.
Health care provider that serves persons with Alzheimer's Disease	Vice Chair of Task Force Jana Powell, M.S.N., F.N.P.
Health care provider that serves persons with Alzheimer's Disease	Rosella Bennett
Parent, spouse, brother or sister afflicted with Alzheimer's Disease	Scott Bennington
Individual with expertise in Alzheimer's Disease	Cathy Schubert, M.D.
Individual with expertise in Alzheimer's Disease	Kathy Segrist, Ph.D.
Individual with expertise in Alzheimer's Disease	Ellen Dunnigan, M.S., CCC-SLP, Alzheimer's Care Group
FSSA Division of Aging Representative	Faith Laird, Director, Division of Aging Indiana Family and Social Services Administration
State Department of Health Representative	Terry Whitson, Assistant Commissioner Indiana State Department of Health
FSSA Division on Mental Health and Addiction Representative	Charlie Boyle/Lynn Smith
Ex Officio Members	
Legislator	Senator Tim Skinner
Legislator	Senator Jean Leising
Legislator	Rep. David Yarde/Rep. Mike Speedy
Legislator	Rep. John Day



Process for the Indiana Plan

Task Force Meetings

The Task Force conducted its first meeting on March 25, 2011. Throughout 2011 and 2012, the Task Force met regularly to learn more about Alzheimer's disease and draft a state plan. The Task Force heard from a series of experts, agencies, and organizations about issues related to Alzheimer's disease and dementia. The Task Force extends a special thanks to speakers and advisors, including the following:

Speaker/Advisor	Topic
Ellen Kershaw, Greater Kentucky and Southern Indiana Chapter of the Alzheimer's Association	Kentucky State Plan for Alzheimer's Disease
Linda Stemnock, Indiana State Department of Health	Behavioral Risk Factor Surveillance System
Catherine Morrison, National Alzheimer's Association	Data collection and public policy
Faith Laird, Family and Social Services Administration	Role of FSSA including Aging Division
Terry Whitson, Indiana State Department of Health	Role of ISDH including health facility regulation
Mike Splaine, Splaine Consulting, former Director of State Policy for the National Alzheimer's Association	Other state and national plans
Kelli Tungate, Central Indiana Council on Aging	Role of Area Agencies on Aging and Aging and Disability Resource Centers
Kristen LeEace, Indiana Association of Area Agencies on Aging	Role of AAAs and ADRCs; home and community-based care
Ann Marie Hake, M.D., Eli Lilly and Indiana University School of Medicine	Overview of Alzheimer's brain science and medicine
Steve Leak and Graig Lubsen, Bureau of Motor Vehicles	Driving safety and dementia
Rusty Goodpaster, Indiana Law Enforcement Academy Steve Helman, Indiana State Police Michael Garvey, Bruce Bare, and John Buckman, Indiana Department of Homeland Security	Dementia training for public safety officials
Linda Altmeyer and Tina Brooks, Alzheimer's Association of Greater Indiana	Training for public safety officials and caregivers
Jim Leich, LeadingAge Indiana (formerly Indiana Association of Homes and Services for the Aging)	Long-term care and continuum of care
Patrick Calkins, FSSA Adult Protective Services	Elder safety and adult protective services
Mary Austrom, Indiana Alzheimer's Disease Center	Medical education and training
Steve Adair, Beers Mellers Backs & Salin LLP	Legal and financial issues related to dementia
Gail Sprigler, Bellarmine University	Task force survey results and gap analysis
Carol Kramer, C. Kramer and Company	Task force meetings and plan development
Kristen Brand, FSSA Division of Aging	Home and community-based services
Matt Naikelis, FSSA Division of Aging	Program Director, Division of Aging, Indiana Family and Social Services Administration

Public Input Sessions

Input sessions were held in Fort Wayne, Indianapolis and Bloomington in August and September 2011. More than **150 participants** provided input, with these concerns emerging:

- Need for improved **services or mix** of services, including living wages, more staff, adult day care, home and community-based care, physical therapy for balance/falling, hospice, staged care in nursing homes, adult foster care, elder law, better drug alternatives
- Need for **training** of families, professionals, and generalists, including health professionals and public safety personnel
- Need for more **research** and funding for research
- Need for **care coordination**
- Concerns about **cost/financial issues** for families
- Need for better **diagnosis**
- Concerns about **workforce issues** for early onset and for caregivers
- Concern about **early-onset** issues

- Need for more **information/awareness** for caregivers in stressful situations
- Need for help with **driving** issues

Electronic Survey

An **electronic survey** was posted online throughout summer and fall 2011 and was distributed widely to the mailing lists of task force members and the organizations they represent. A total of 946 usable responses gauging satisfaction with services were collected. Hundreds of respondents also provided open-ended comments/suggestions. Respondents included people with Alzheimer’s disease (1%), family caregivers (62%), non-family caregivers (2%), professional caregivers/providers (33%), and public employees/officials (2%) from 84 of Indiana’s 92 counties. A brief summary follows:

Satisfaction with:	Very Satisfied or Satisfied	Very Dissatisfied or Dissatisfied	Don’t Know/NA	Comments	Responses N=
Affordability of dementia care	18.6%	56.5%	24.8%	196	801
Dementia care service options	31.6%	52.4%	18.0%	263	844
Education and training	31.5%	52.4%	16.0%	226	787
Support for families/caregivers	39.1%	45.8%	15.1%	189	797
Safety measures	32.0%	42.2%	25.8%	170	784
Access to dementia care	36.7%	37.1%	26.2%	157	804
Access to public information	52.9%	31.8%	15.3%	212	847

Summary of Plan Development

Task force meetings, public input, and electronic surveys yielded a variety of concerns and suggestions for Indiana to become a more dementia-friendly state. These concerns and suggestions were reviewed by task force members throughout 2012 and taken into consideration when developing this Plan.



Key to Abbreviations

- AAA/ADRC Area Agency on Aging/Aging and Disability Resource Center
- Alz Assn Alzheimer's Association (Greater Indiana, Greater Cincinnati, and Greater Kentucky and Southern Indiana Chapters)
- ACG Alzheimer's Care Group
- AoA Administration on Aging
- APS Adult Protective Services
- BMV Bureau of Motor Vehicles
- BRFSS Behavioral Risk Factor Surveillance System
- FSSA Family and Social Services Administration (Division of Aging, Division of Mental Health & Addictions, Office of Medicaid Policy and Planning, Adult Protective Services, etc).
- IADC Indiana Alzheimer Disease Center at IU School of Medicine
- IDND Indianapolis Discovery Network for Dementia
- IHIE Indiana Health Information Exchange
- ILEA Indiana Law Enforcement Academy
- ISDH Indiana State Department of Health
- LTC Long Term Care (nursing homes)
- NGO Non-governmental organization



Implementation of the Plan

The Task Force has begun to identify lead agencies and partners for this plan, but the list is far from inclusive and other interested parties will be invited and included. The lead agency is not expected to solely implement the recommendation, but will serve as the coordinator of partners to accomplish the goal and report back to the implementation oversight body. Several state, non-profit, and private agencies have already been identified to fulfill roles outlined in the Indiana Plan.



Photo courtesy of the Alzheimer's Association

Lead partners to implement these recommendations include:

- Indiana Family and Social Services Administration Division on Aging
- Indiana State Department of Health
- Alzheimer's Association (Greater Indiana, Greater Cincinnati, and Greater Kentucky and Southern Indiana Chapters)
- Indiana Alzheimer Disease Center at Indiana University

Additional state partners include:

- Indiana Department of Homeland Security
- Indiana Law Enforcement Academy
- Bureau of Motor Vehicles
- Area Agencies on Aging/Aging and Disability Resource Centers
- Adult Protective Services
- Other public and private entities



Photo courtesy of the Alzheimer's Association



Photo courtesy of the Alzheimer's Association



Indiana Plan for Alzheimer's Disease & Dementia

Vision for Indiana: A Dementia-Friendly State Ten Priorities for Action in 2013-2017

Goal A: Raise Awareness about Alzheimer's Disease and What Individuals Can Do to Support Those with Alzheimer's Disease

Priority 1 – Raise public awareness of Alzheimer's disease	Lead	Partners
Improve public access to current evidence-based information about Alzheimer's disease, support services, and Alzheimer's care.	Alz Assn	Alz Assn, FSSA, IADC, ISDH, NGOs

Goal B: Connect Patients and Families to Services on a Timely Basis

Priority 2 – Improve care and case management system	Lead	Partners
Improve the statewide care coordination system for Alzheimer's disease and dementia.	AAA/ADRC	AAA/ADRCs, Alz Assn, ACG, FSSA

Goal C: Improve the Quality of Care for Individuals with Alzheimer's Disease or Dementia

Priority 3 – Address Alzheimer's and dementia care issues in health care facility regulations	Lead	Partners
Provide input on Alzheimer's disease and dementia care issues in health care facilities when the State is updating regulations or developing quality improvement projects.	Alz Assn	Alz Assn, ISDH, FSSA, ACG, NGOs
Priority 4 – Ensure availability of Alzheimer's training for health care providers	Lead	Partners
Provide free or low-cost e-learning modules for health care providers on Alzheimer's disease and dementia care.	Alz Assn	Alz Assn, Ivy Tech, ACG, ISDH

Goal D: Increase Public Safety for People with Alzheimer's Disease and Their Families

Priority 5 – Ensure availability of dementia-specific training for public safety workers	Lead	Partners
Establish collaboration among the Alzheimer's Association, Indiana Department of Homeland Security and Indiana Law Enforcement Academy to offer statewide dementia-specific training (basic and continuing education) to first responders such as emergency medical services, firefighters, law enforcement officers, dispatchers, search and rescue, homeland security.	Dept of Homeland Security	Dept of Homeland Security, ILEA, Alz Assn

Priority 6 – Improve driving safety	Lead	Partners
Update Indiana Bureau of Motor Vehicles policy and process for restricting driving for people with dementia (include forms for referrals to BMV by physicians/practitioners and family members). Raise awareness of process.	BMV	Alz Assn, BMV, FSSA, ISDH
Priority 7 – Secure Adult Protective Services for cognitively impaired adults	Lead	Partners
Secure emergency placement facilities/services for cognitively impaired adults found in dangerous situations by Adult Protective Services.	FSSA	APS, Alz Assn, FSSA, LTC Facilities, Hospitals

Goal E: Enhance Research and Data About Alzheimer’s Disease

Priority 8 – Encourage participation in Alzheimer’s research	Lead	Partners
Engage physicians, practitioners and community partners to encourage referral to and participation in clinical trials and longitudinal studies by diverse populations in Indiana.	IADC	Alz Assn, IADC, Researchers, Professional Practitioner and Provider Associations
Priority 9 – Improve State Alzheimer’s data	Lead	Partners
Improve State Alzheimer’s data by adding the Caregiver Module and Cognitive Impairment Module to Indiana’s Behavioral Risk Factor Surveillance System. Secure funding to repeat these modules every 1-2 years. Produce report on findings and use the data for planning and program design.	ISDH	Alz Assn, ISDH

Goal F: Implement the Plan Effectively

Priority 10 – Implement the plan and develop a system for continuity	Lead	Partners
Create a voluntary council of the Indiana Commission on Aging per IC 12-10-2-7 to oversee implementation of this Plan.	Alz Assn	Alz Assn, FSSA, ISDH, NGOs, Task Force Members



Photo courtesy of the Alzheimer’s Association

Indiana Plan for Alzheimer’s Disease and Dementia

Vision for Indiana: A Dementia-Friendly State

Goals, Objectives, Outcomes and Action Plan

GOAL A Raise Awareness about Alzheimer’s Disease and What Individuals Can Do to Support Those with Alzheimer’s Disease

Background: Indiana has more than 120,000 diagnosed cases of Alzheimer’s disease and dementia. This figure is projected to increase by 20% by 2020. Many of these individuals and their families are not aware of services available to them through public and private sources. Nearly one-third of respondents to the task force survey were dissatisfied with access to public information. The lack of public awareness spans the disease and its progression, brain health, legal and financial issues, and assistance for unpaid caregivers.

Objective: To raise Hoosiers’ awareness about Alzheimer’s disease and dementia through increased availability of current, evidence-based information about Alzheimer’s disease, dementia, and available services.

Outcome: An increased awareness of Alzheimer’s disease and services as demonstrated by consumer satisfaction surveys and the Behavioral Risk Factor Surveillance System (BRFSS) Caregiver Module, leading to measurably increased use of available Alzheimer’s services.

Process Outcomes:

1. Completion of a plan to enhance strategies to reach diverse populations to make aware of available services.
2. Inclusion of the Cognitive Impairment Module and the Caregiver Module on the Behavioral Risk Factor Surveillance System (BRFSS) survey.

Action A1 Action Plan to Raise Public Awareness of Alzheimer’s Disease

Priority 1 – Raise public awareness of Alzheimer’s disease			
Priority Action	Activities	Lead	Partners
Improve public access to current information about Alzheimer’s disease, support services, and Alzheimer’s care.	Collaborate to ensure that current information is available about BRFSS survey findings, facts about Alzheimer’s disease, maps and lists of services available, including specialized dementia care, etc. Review and update content at least annually. Maintain the ISDH’s Alzheimer’s Disease and Dementia Resource Center on the ISDH website and enhance with electronic links to the Alzheimer’s Association, FSSA Division on Aging, Indiana Alzheimer Disease Center, U.S. Department of Health and Human Services, and others.	Alz Assn	Alz Assn, FSSA, ISDH IADC, NGOs

Raise Alzheimer's awareness by providing information of Alzheimer's disease and services

- Continue to provide hard copy and electronic information about Alzheimer's disease and the services available to support patients and families via key agencies: the Alzheimer's Association www.alz.org, Family and Social Services Administration Division on Aging www.in.gov/fssa/da/3453.htm, Indiana Alzheimer Disease Center iupui.edu/, State Department of Health www.state.in.us/jsdh/25190.htm, and U.S. Department of Health and Human Services www.alzheimers.gov.



Photo courtesy of the Alzheimer's Association

- Heighten public awareness of resources such as the 2-1-1 information line, Alzheimer's Association 24/7 helpline, Area Agencies on Aging/Aging and Disability Resource Centers, State Department of Health website, veterans' clinics, Indiana Alzheimer's Disease Center, HHS, and others.
- Promote the use of the latest communication technologies/tools (mobile apps, Facebook, Twitter, emerging technologies) by the Alzheimer's Association when disseminating public education campaign messages.
- Enhance the Indiana State Department of Health's online *Health Care Facility Consumer Reports* on long-term care to include items such as whether facilities have Alzheimer's specialists on staff and search features that enable comparison of dementia care services.

Increase utilization of available Alzheimer's services

- The Alzheimer's Association will lead efforts to develop a plan to enhance strategies to reach diverse populations (such as racial and ethnic minorities, people living in rural areas, high-risk and special populations) to improve utilization of available Alzheimer's services.
- The Alzheimer's Association will lead efforts to distribute information about support services and resources to the licensed health professionals who assess and diagnose Alzheimer's disease (e.g., physicians, physician assistants, nurse practitioners, nurses, social workers).

Action
A2

Action Plan to Maintain and Improve Brain Health

Promote activities that maintain and improve brain health

Heart and brain risk factors that may be controlled include blood pressure, blood sugar, body weight, and cholesterol. Healthy lifestyle choices include staying mentally and physically active, remaining socially involved, and adopting a brain-healthy diet.

Improve brain health surveillance

- Include the Cognitive Impairment Module on the Behavioral Risk Factor Surveillance System survey conducted by the Indiana State Department of Health.
- Use results from the BRFSS Cognitive Impairment Module by stakeholders to study brain health and cognitive impairment.

Promote disease prevention and brain health through a public health approach to Alzheimer's disease

- The Indiana State Department of Health and the Alzheimer's Association will lead efforts to coordinate campaigns with public and private organizations working to reduce Alzheimer's disease-related risk factors, such as those for heart disease, hypertension, and diabetes.
- The Alzheimer's Association will lead efforts to create and disseminate culturally competent public information to raise the level of public education about brain health and the warning signs of Alzheimer's and other dementias, some of which should specifically target populations with disproportionately higher rates of these diseases.
- Encourage a wellness agenda for public and private sectors that includes a brain-healthy lifestyle inclusive of exercise, nutrition, cognitive activity, and social engagement as key protective factors against Alzheimer's disease.

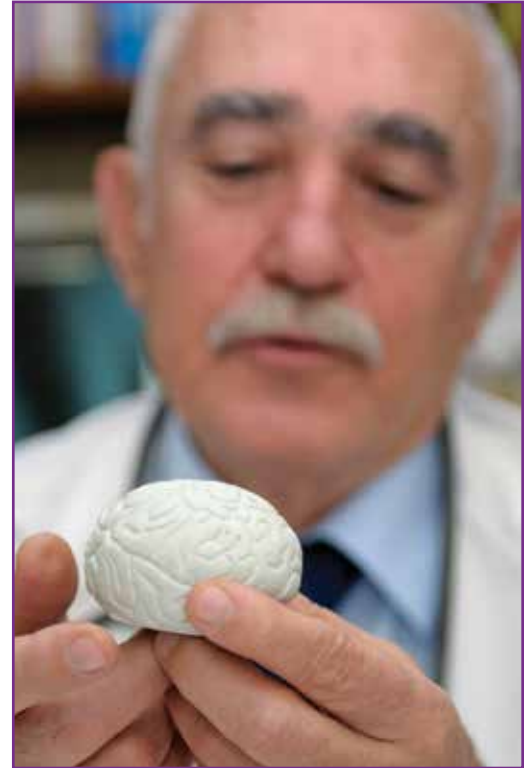


Photo courtesy of the Alzheimer's Association

Action A3

Action Plan to Improve Legal and Financial Planning

Address legal protections for and legal issues faced by individuals with Alzheimer's disease

Increase use of advance directives and financial planning

- The Alzheimer's Association will lead efforts to raise awareness/educate families about legal and financial issues facing people with Alzheimer's disease and encourage them to consult with professionals and plan early for financing options, advanced directives, last wills and testaments, financial and health care powers of attorney, trusts, guardianships, living wills, physicians orders for scope of treatment, end-of-life decisions, hospice, and other elder care issues.
- The Alzheimer's Association will lead efforts to use health care provider and community agency education to encourage widespread and early use of advanced health care directives.

Support guardianship and conservator policies

- Continue Alzheimer's representation on the Indiana Adult Guardianship Task Force. Support guardianship and conservator policies that align with national standards and other states' laws that respect the rights of people with dementia, and that minimize the burden on families and the legal system.

Action A4

Action Plan to Assist Unpaid Caregivers

Assist unpaid Alzheimer's caregivers

Provide training and support for caregivers

- The Alzheimer's Association will lead efforts to direct unpaid family caregivers to training resources such as the National Alzheimer's Association's low-cost online training program "EssentialALZ" (10 one-hour courses), and its free "Navigator" system at the Alzheimer's Association website www.alzheimersnavigator.org and caregiver support website www.alz.org/care/.



Photo courtesy of the Alzheimer's Association

- The Alzheimer's Association will lead efforts to educate and enlist the faith community as resources that can help support family caregivers.
- Indiana State Department of Health and the Alzheimer's Association will take the lead to disseminate information about caregiving as a health risk factor and encourage health professionals to recognize health risks associated with caregiving. Utilize information from the 2012 Caregiver Module of the Behavioral Risk Factor Surveillance System.
- The FSSA Division of Aging and Area Agencies on Aging/Aging and Disability Resource Centers will make available and promote training materials for family caregivers, especially in rural areas.

Encourage employers to include family caregiver support services as part of their benefit packages and policies

- Work through Chambers of Commerce and other employer organizations to encourage workplaces to offer within their benefit packages family caregiver support services such as flexible work hours, telecommuting, referrals services, onsite support and counseling through Employee Assistance Programs, and other employee incentives.

GOAL B

Connect Patients and Families to Services on a Timely Basis

Background: Knowledge of and access to early detection, diagnosis, and referral to care/case management is lacking in Indiana as raised during public input forums throughout Indiana.

Objective: To improve early detection and diagnosis of cognitive impairments and improved care coordination.

Outcome: Earlier care for those with Alzheimer's disease and dementia as evidenced by percent of medical histories of seniors that include a cognition assessment.

Process Outcomes:

1. Development and publishing of consensus Alzheimer's disease diagnostic and treatment protocols.
2. Completion of a plan for a statewide system of dementia care coordinators.

Action B1

Action Plan to Increase Early Detection and Diagnosis of AD

Encourage increased detection and diagnosis of Alzheimer's disease

In January 2011, a federal requirement became effective recognizing cognition as a vital sign.

Expert international workgroups convened by the Alzheimer's Association and the National Institute on Aging (NIA), an agency of the U.S. National Institutes of Health (NIH), have jointly issued four new criteria and guidelines to diagnose Alzheimer's disease. These new criteria update, refine and broaden previous widely used guidelines jointly issued by the Alzheimer's Association and the NIH over the past 30 years.

Improve detection of cognitive impairments

- The National Alzheimer's Association, in conjunction with the U.S. Department of Health and Human Services, will publicize the nationally developed "tool box" of promising practices for physicians/practitioners to use for detecting and diagnosing persons with Alzheimer's through Medicare annual wellness visit and post practices on websites. See, for example, http://www.alz.org/research/diagnostic_criteria/#use.
- The Alzheimer's Association will lead efforts to promote use of the Medicare Annual Wellness visit for the detection of cognitive impairment, recognizing cognition as a vital sign.
- Partners will post on their websites current, accurate, culturally aware information for health care professionals, including physicians, nurse practitioners, psychologists and social workers, to detect and diagnose dementia in its earliest stages.
- The Alzheimer's Association will promote the use of Alzheimer's diagnostic and treatment prompts/protocols in electronic medical records systems through the Indiana Health Information Exchange (IHIE) and IU Center for Aging Research.

Action Plan to Improve Care Coordination and Case Management

Improve the individual health care that those with Alzheimer’s disease receive

Priority 2 – Improve care and case management system			
Priority Action	Activities	Lead	Partners
Improve the statewide care coordination system for Alzheimer’s disease and dementia	<p>Explore developing a statewide system of dementia care coordinators (e.g., one coordinator per area agency on aging) to assist in care planning for people with Alzheimer’s disease, with short-term care planning and referral services.</p> <p>Explore systems for certifying care coordinators.</p> <p>Explore the feasibility of a system for ensuring that, upon diagnosis of Alzheimer’s disease, physicians, nurse practitioners, and physician’s assistants automatically refer patients and families to the Alzheimer’s Association or similar organization for information and family support.</p>	AAA/ ADRCs	AAA/ADRCs, Alz Assn, ACG, FSSA

Ensure reimbursement for care planning and care coordination

- The Alzheimer’s Association will lead efforts to ensure that care planning/care coordination is included as a reimbursable service for people with Alzheimer’s disease in programs such as Medicare, Medicaid, private insurance, employee benefit programs, etc. Partners may include the Alzheimer’s Association, Alzheimer’s Care Group, National Association of Professional Geriatric Care Managers (www.caremanager.org) and Case Management Society of America (www.cmsa.org).

Enhance care coordination for Alzheimer’s disease and dementia

- Encourage care providers to partner with special interest groups as they develop dementia- friendly services for rural, ethnically and culturally diverse clients and families of choice across the continuum of care, including adult day care, in-home respite, assisted living, long-term care, and specialized dementia care.
- Partners will lead efforts to increase coordination between regional medical centers and community hospitals to improve assessment, referral, and care coordination for people with dementia who are treated in emergency departments, ambulatory care, hospital, and community service settings.
- Partners will promote the use of Area Agencies on Aging/Aging and Disability Resource Centers and the Alzheimer’s Association as points of entry for information, referral, and resources for families and consumers.
- Promote the use of the Alzheimer’s Association regional resource guides (updated annually), the Alzheimer’s Association toll-free nationwide helpline, and other dementia-specific resource guides.

**GOAL
C**

Improve the Quality of Care for Individuals with Alzheimer’s Disease or Dementia

Background: Indiana has several quality care components in place through Indiana State Department of Health licensure and regulation. Additionally, several NGOs advocate for quality care. Nevertheless, the need for improved quality of care was mentioned throughout open-ended responses to the task force’s electronic survey.

Objective: To improve the quality of care provided for individuals with Alzheimer’s disease or dementia throughout the spectrum of health care: physicians, home and community-based services, long-term care, hospitals, end-of-life.

Outcome: Diagnosis and treatment of Alzheimer’s disease and dementia will include evidence-based standards of care as evidenced by compliance with state regulations and industry-driven protocols and procedures.

Process Outcomes:

1. Number of task forces or work groups that include a representative advocating for Alzheimer’s disease and dementia.
2. Implementation of emergency care and inter-facility transfer protocols for caring for individuals with Alzheimer’s disease and dementia.
3. Number of electronic learning modules made available to health care providers.
4. Number of providers accessing electronic learning modules.

**Action
C1**

Action Plan to Address Alzheimer’s and Dementia Care Issues in Health Facility Regulations

Improve the quality of the health care system in serving people with Alzheimer’s disease

Priority 3 – Address Alzheimer’s and dementia care issues in health care facility regulations			
Priority Action	Activities	Lead	Partners
Provide input on Alzheimer’s disease and dementia care issues in health care facilities when the State is updating regulations or developing quality improvement projects.	<p>Include an Alzheimer’s/dementia representative on the task force(s) assigned to write health care facility regulations when they expire in order to promote dementia-friendly regulations.</p> <p>Include an Alzheimer’s/dementia representative on the task forces assigned to write regulations about home and community-based services and promote dementia training for workers in these settings.</p> <p>Sustain or enhance Indiana’s special care unit disclosure laws and reporting system. Explore development of searchable online database for use by consumers.</p>	Alz Assn	Alz Assn, ISDH, FSSA, ACG, NGOs

Implement care protocols for emergency care and inter-facility transfers

- The Alzheimer’s Association will lead efforts to support implementation of protocols for emergency care of persons with dementia. See, for example, study by Indianapolis Discovery Network for Dementia (IDND) and IU Center for Aging Research.
- Support implementation of protocols for transfers of persons with dementia between long-term care and hospital facilities.
- The Indiana State Department of Health will continue educational programming on quality, such as the ISDH Conference on Quality.



Photo courtesy of the Alzheimer’s Association

Improve services provided in the home and community to delay and decrease the need for institutionalized care

- Continue and expand programs specifically directed to individuals in the early stages of Alzheimer’s disease that help them to continue as productive members of society.

Action C2

Action Plan to Expand Health Care System Capacity and Funding

Expand the capacity of the health care system to meet the growing number and needs of those with Alzheimer’s disease

Increase funding to meet the growing number of individuals diagnosed with Alzheimer’s

- The Alzheimer’s Association will lead efforts to ensure that “cognitive impairment” is used along with activities of daily living (ADLs) to determine eligibility for programs such as Medicare, Medicaid, and private insurance.
- The Alzheimer’s Association and FSSA will explore options to increase funding for individuals with Alzheimer’s and other dementias, including 1) eligibility for Medicaid and other state/federal programs for individuals with younger-onset Alzheimer’s; 2) the potential for supporting Alzheimer’s and dementia services with other Medicaid waivers; 3) services and options under private insurance.
- Partners will encourage eligible applicants to pursue federal funding for evidence-based projects including but not limited to U.S. Administration on Aging grants to states for development of “dementia capable” sustainable service delivery systems and other demonstration/innovation grants.

Action Plan to Improve Dementia Training and Supply of Health Care Professionals

Better equip health care professionals and others to care for individuals with Alzheimer’s

Increase the number of health care professionals prepared to treat the growing aging and Alzheimer’s population

Indiana currently requires several hours of dementia training for direct care staff and Alzheimer’s Unit directors in licensed health care facilities, but does not specify the content or quality of such training.

2012 Indiana State Department of Health Training Requirements: All nursing home staff with regular resident contact must receive six hours of dementia-specific training within six months of hire. Three hours of dementia-specific training is required annually thereafter. Personnel assigned to the Alzheimer’s/Dementia Special Care Unit must receive six hours of dementia-specific training within 30 days of the assignment. Three hours of dementia-specific training is required annually thereafter. In facilities with an Alzheimer’s/Dementia Special Care Unit, the designated unit director must have 12 hours of dementia-specific training within three months of employment and six hours annually thereafter.

ISDH, Ivy Tech and others such as the Alzheimer’s Care Group offer dementia-specific training and certifications for staff in a wide array of care settings. These programs have been designed for professionals in health care. Those who should consider attending include professionals in adult day services; long-term care; assisted living; hospice; home health care; acute care; and social services. In order to help meet this requirement, the Alzheimer’s Association and Ivy Tech Community College developed training courses and a dementia professional certification.

Dementia Professional Certification: The Alzheimer’s Association and Ivy Tech Community College have launched the Dementia Professional Certification (DPC). This certification is the first of its kind and recognizes healthcare professionals who have furthered their study in quality dementia care. This partnership allows the Alzheimer’s Association’s professional courses to be delivered throughout Ivy Tech’s statewide campus system. Courses were developed by experts throughout Indiana in response to training deficits. The courses provide realistic best practices to provide quality dementia care. To earn the DPC, health care professionals must have a total of 40 hours of course work from courses offered through this program.

The Task Force recommends as follows:

Priority 4 - Ensure availability of Alzheimer’s training for health care providers			
Priority Action	Activities	Lead	Partners
Provide free or low cost e-learning modules for health care providers on Alzheimer’s disease and dementia care.	<p>Make available e-learning modules that can be used to meet state requirements for training direct care providers, such as on the topics currently part of a voluntary 40-hour dementia care professional certification program offered by Ivy Tech.</p> <p>Broaden access to e-learning modules to train workers in other settings beyond licensed health care facilities, such as adult day care, assisted living, home health care, hospice, emergency rooms, adult protective services, area agencies on aging/ADRCs, etc.</p> <p>Explore development of a system to track student completion of e-learning modules, so that course completion is documented and portable.</p>	Alz Assn	Alz Assn, Ivy Tech, ISDH, ACG, NGOs

Improve professional medical education on Alzheimer's disease and dementia

- Promote the inclusion of best practices curriculum for early detection and diagnosis in medical, nurse practitioner, physician's assistant, and graduate clinical psychology schools, hospital education programs, and continuing medical and nursing education.
- The Alzheimer's Association will explore the formation of support groups for professional caregivers.
- Support national efforts to ensure that schools of medicine, nursing, psychology, social work, occupational therapy, physical therapy, and speech pathology incorporate dementia training in the education of professionals, including those who do not specialize in geriatrics/aging.

Improve training standards for health care providers for Alzheimer's disease and dementia

- The Alzheimer's Association will lead efforts to encourage dementia training not only for direct care workers but also for workers who interact with people with dementia, such as:
 - AAA/ADRC staff
 - Adult protective service workers
 - First responders/public safety workers
 - ISDH surveyors, state ombudsmen, and other state regulators
- The Alzheimer's Association will lead efforts to provide input on acute care and long-term care training regulations to promote dementia-friendly training regulations.
- The Alzheimer's Association will lead efforts to create and post online a list of dementia training curricula/programs for direct-care providers. Direct paid caregivers to training resources such as www.caresprogram.com.

Increase number of qualified health care professionals prepared to provide care for the growing aging and Alzheimer's population

- Work through the Indiana Intercollegiate Council on Aging to promote public, private, and employer-based incentives (tuition assistance, loan forgiveness, stipends) to increase the number of health care professionals who pursue education and training to specialize in gerontology, geriatrics, clinical psychology, and aging-related fields.
- Support dementia care certification for health care professionals and paid caregivers working with older adults and persons with Alzheimer's disease through their respective professional associations.
- Establish contacts and offer networking support to the newly established medical school at Marian University to enhance dementia- and aging-related education for their students.



Photo courtesy of the Alzheimer's Association

GOAL D

Increase Public Safety for People with Alzheimer’s Disease and Their Families

Increase safety for people with Alzheimer’s disease and their families

Background: Individuals with Alzheimer’s disease and dementia may behave in ways that can be misinterpreted. Safety concerns, such as driving safety and the need for training first responders, were raised in public input sessions and on the electronic survey.

Objective: To enhance recognition and response to Alzheimer’s disease and dementia by public safety officials and first responders, including fire, emergency medical service, police, and adult protective service workers.

Outcome: Improve safety for people with Alzheimer’s and dementia and the general public as evidenced by a reduction in injuries, abuse, neglect, and fraud resulting from the care of individuals with Alzheimer’s disease or dementia.



Process Outcomes:

1. Percent of emergency responders that have completed Alzheimer’s training.
2. Publication of driving restrictions for people with dementia.

Action D1

Action Plan to Ensure Availability of Dementia-Specific Training for Public Safety Workers

Improve public safety and address the safety-related needs of those with Alzheimer’s

Train first responders throughout Indiana how to recognize and respond to people with Alzheimer’s disease. In 2012, the national Alzheimer’s Association received a grant to put its public safety training online. The Indiana Department of Homeland Security has an e-learning platform.

Priority 5 – Ensure availability of dementia-specific training for public safety workers			
Priority Action	Activities	Lead	Partners
Establish collaboration among the Alzheimer’s Association, Indiana Department of Homeland Security, and Indiana Law Enforcement Academy to offer statewide dementia-specific training (basic and continuing education) to first responders such as emergency medical services, firefighters, law enforcement officers, dispatchers, search and rescue, homeland security.	Place curriculum and training modules on e-learning platforms. Monitor training of public safety workers and consider mandatory training/ certification if voluntary enrollment is insufficient.	Dept of Homeland Security	Alz Assn, Dept of Homeland Security, ILEA

**Action
D2**

Action Plan to Improve Driving Safety

Improve driving safety for people with Alzheimer’s disease and the general public

Priority 6 – Improve driving safety			
Priority Action	Activities	Lead	Partners
Update Indiana Bureau of Motor Vehicles policy and process for restricting driving for people with dementia (include forms for referrals to BMV by physicians/practitioners and family members). Raise awareness of process.	Post information prominently on BMV website and other key websites. Publicize and raise awareness of BMV policy and driving safety practices among family caregivers.	BMV	Alz Assn, BMV, FSSA, ISDH

Improve safety of individuals through ensuring transportation needs

- Encourage physicians/practitioners to incorporate driving restrictions and safety within patient treatment plans and encourage independent driving assessments.
- Address the unique transportation needs of persons in the early stage of Alzheimer’s disease and other dementias, including driving cessation policies and independent driving assessments. Promote resources such as the Alzheimer’s Association Dementia and Driving Resource Center at www.alz.org/care/alzheimers-dementia-and-driving.asp and the National Center on Senior Transportation at www.seniortransportation.easterseals.com.



**Action
D3**

Action Plan to Protect Cognitively Impaired Adults from Fraud, Abuse, and Neglect

Secure emergency placement or services for cognitively impaired adults in dangerous situations

Priority 7 – Secure Adult Protective Services for cognitively impaired adults			
Priority Action	Activities	Lead	Partners
Secure emergency placement facilities/ services for cognitively impaired adults found in dangerous situations by APS.	Review caseloads for Adult Protective Services (APS), currently provided by FSSA and local prosecutors.	FSSA	APS, Alz Assn, FSSA, LTC Facilities, Hospitals

Decrease fraud, abuse, neglect, and self-neglect of persons with Alzheimer’s disease or dementia

- The Alzheimer’s Association will lead efforts to support Adult Protective Services and other public safety officials on detecting, addressing, and preventing fraud, abuse, neglect, and self-neglect of persons with dementia, in the community or in institutions of care.

GOAL E

Enhance Research Efforts and Data About Alzheimer’s Disease

Background: Alzheimer’s disease is the sixth leading cause of death in Indiana and the United States. Additionally, it is the only disease that has no cure or a way to slow the progression, and is the only disease category to have an increased mortality rate over the past 10 years. Individuals with Alzheimer’s disease/dementia plus another diagnosis (such as heart disease, kidney disease, pulmonary disease, stroke, or cancer) have higher health care use and cost than do people with these medical conditions but without co-existing dementia. The way to slow disease progression and/or find a cure is through data collection and research.

Objective: To slow the progression of and/or finding a cure for Alzheimer’s disease and dementia and improve knowledge about the impact of the disease in Indiana.

Outcome: Improve knowledge about Alzheimer’s disease through participation in clinical trials.

Process Outcomes:

1. The continued presence of an active Alzheimer’s disease research center in Indiana.
2. Inclusion of the Cognitive Impairment Module and the Caregiver Module on the Behavioral Risk Factor Surveillance System survey.

ACTION PLAN FOR GOAL E:

Action E1

Action Plan to Increase Research

Increase available studies related to Alzheimer’s disease and increase clinical trial participation in the State of Indiana

Priority 8 – Encourage participation in Alzheimer’s research			
Priority Action	Activities	Lead	Partners
Engage physicians, practitioners and community partners to encourage referral to and participation in clinical trials and longitudinal studies by diverse populations in Indiana.	Promote programs such as the national Alzheimer’s Association Trial Match at www.alz.org/trialmatch as a way to match individuals with clinical research studies, including those underway at the nation’s 29 Alzheimer’s Disease Research Centers.	IADC	Alz Assn, IADC, Researchers, Professional Practitioner and Provider Associations

Support Indiana's commitment to Alzheimer's research

- Support the pursuit of federal and private funding, including grants, for Alzheimer's disease research by Indiana institutions and businesses. Explore existing information clearinghouses.
- Support and strengthen Indiana's commitment to research and best practices via groups such as the Alzheimer's Association Medical and Scientific Advisory Board. This Board should take a lead role in building collaboration among BioCrossroads, Health Industry Forum, Indiana Alzheimer Disease Center, and others to maintain Indiana's commitment to research and development by private and public entities in Indiana. This may include peer-to-peer education, graduate medical education/residencies, promotion of clinical trials, and other strategies.
- Encourage networking of public and private researchers to include institutions active in aging and dementia research, such as Indiana University, Purdue University, Indiana University-Purdue University at Indianapolis, Ball State University, University of Indianapolis, Indiana State University, Notre Dame, and others. This type of networking is encouraged in Central Indiana by the Indianapolis Discovery Network for Dementia (IDND)(www.indydiscoverynetwork.org).
- Support federal investment in research and aging services. Provide input on federal legislation that improves research, care, and treatment for people with Alzheimer's and their families. In 2012, this included the Health Outcomes Planning and Education for Alzheimer's Act (HOPE; H.R. 1386) and Alzheimer's Breakthrough Act (H.R. 1897).

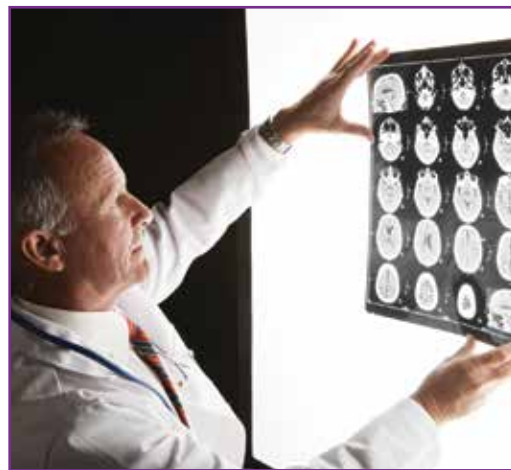


Photo courtesy of the Alzheimer's Association

Sustain an Alzheimer's disease research center

- Sustain the Indiana Alzheimer Disease Center based at the Indiana University School of Medicine in Indianapolis, one of 29 federally funded Alzheimer disease research centers in the United States.
- Continue, if funding permits, the IADC's annual NIH-funded Alzheimer conference. Include schools of speech pathology, pharmacy, medicine, nursing, geriatrics, psychology, and occupational and physical therapy.

Action E2

Action Plan to Improve Data Collection

Create a better system of data collection regarding Alzheimer's disease and its public health burden

The Indiana State Department of Health implements Indiana's participation in the U.S. Centers for Disease Control's annual Behavioral Risk Factor Surveillance System survey to track health behaviors and conditions, then generate information about rates of smoking, obesity, etc. The BRFSS survey contains a combination of mandated and optional questions. Questions about caregiving and cognitive impairment are available as options. Based on Task Force recommendations, these questions were incorporated within the 2012 survey; findings are expected by spring 2013.

Priority 9 – Improve State Alzheimer’s data			
Priority Action	Activities	Lead	Partners
Improve State Alzheimer’s data by adding the Caregiver Module and Cognitive Impairment Module to Indiana’s Behavioral Risk Factor Surveillance System.	Secure funding to repeat these modules every 1-2 years. Produce reports on findings. Use the data for planning and program design.	ISDH	Alz Assn, ISDH

Improve data collection on Alzheimer’s disease and its public health burden

- Enhance the State’s role in creating and compiling data on Alzheimer’s disease and dementia incidence (as a new diagnosis), hospital admissions (acute care hospitals and long-term placements), and mortality. Increase tracking by aggregating data and making it accessible from sources such as:
 - Adult protective services calls and cases
 - Death certificate data via health departments
 - Medicare cognitive assessment data
 - Minimum data set (MDS) cognitive impairment data in nursing homes
 - Hospital records on cognitive impairment/dementia as a diagnosis



**GOAL
F**

Implement the Plan Effectively

Background: Currently, more than 120,000 Hoosiers are diagnosed with Alzheimer’s and dementia. This figure is expected to triple by 2050. Unless a cure or a way to delay onset or slow the progression of the disease is found, there will be a significant impact on Indiana’s health care system, caregivers, case managers, safety and law enforcement personnel, and Medicaid/insurance programs. Implementation of the recommendations contained in this report through our public and private sectors will address the significant impact of Alzheimer’s disease and dementia now and in the future.

Objective: To improve State oversight of Alzheimer’s disease care through a cohesive and integrated system.

Outcome: An ongoing statewide effort to address Alzheimer’s and dementia care issues and delivery of services.

Process Outcomes:

1. A reauthorized task force or commission to oversee implementation of this Plan.
2. Implementation progress tracked, as evidenced by regular meetings.
3. An updated State Plan within five years.
4. Integration of dementia goals within other Indiana plans.

**Action
F1**

Action Plan to Improve State Infrastructure for Implementing the AD Plan

Strengthen how government, non-profit and for-profit sectors evaluate and adopt policies to help people with Alzheimer’s disease and their families

Priority 10 - Implement the plan and develop a system for continuity			
Priority Action	Activities	Lead	Partners
Create a voluntary council of the Indiana Commission on Aging per IC 12-10-2-7 to oversee implementation of this Plan.	Create a council to oversee implementation of this Plan.	Alz Assn	Alz Assn, FSSA, ISDH, NGOs, Task Force Members

Pursue funding in support of this Plan, track implementation progress, and collaborate with partners to integrate dementia-specific goals into related plans

- Encourage eligible applicants to pursue federal and private grant opportunities that support this plan and/or can be used to improve awareness, diagnosis and treatment of AD, and services to families.
- Convene a task force or similar group on a regular basis to track and guide implementation of the Plan.
- Convene a task force or similar group to create an updated Indiana Plan within five years.

- Integrate dementia-specific goals and ideas within related plans including but not limited to:
 - Indiana State Plan on Aging (FSSA)
 - Area Agency on Aging Plans (AAA/ADRC)
 - Indiana State Health Improvement Plan (ISDH)
- Work to have an Alzheimer's/dementia representative review and offer input on draft state plans such as those listed above.
- FSSA and ISDH will designate staff as points of contact responsible for Alzheimer's and dementia issues.
- The ISDH will augment FSSA Division on Aging's work with a public health approach to confront Indiana's significant projected growth in Alzheimer's disease.

Action F2

Action Plan to Coordinate the Indiana AD Plan with Related Plans

Coordinate Indiana's AD Plan with national plans for Alzheimer's disease

Coordinate Indiana's participation in the *National Plan to Address Alzheimer's Disease*, first adopted in May 2012. The National Plan establishes five goals to prevent future cases of Alzheimer's disease and to better meet the needs of the millions of American families facing this disease:

- Goal 1. Prevent and Effectively Treat Alzheimer's Disease by 2025
- Goal 2. Optimize Care Quality and Efficiency
- Goal 3. Expand Supports for People with Alzheimer's Disease and Their Families
- Goal 4. Enhance Public Awareness and Engagement
- Goal 5. Track Progress and Drive Improvement

Here are links to the National Plan and new National Alzheimer's website:

National Plan to Address Alzheimer's Disease

Full HTML Version <http://aspe.hhs.gov/daltcp/napa/NatPlan.shtml>

Full PDF Version <http://aspe.hhs.gov/daltcp/napa/NatPlan.pdf> (69 PDF pages)

National Alzheimer's Website

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

Here is a link to other state's Alzheimer's plans and a comparison of the plans: http://www.alz.org/join_the_cause_state_plans.asp

The **five goals of the National Plan** are outlined below, along with some of the ways that Indiana can be involved in the objectives and strategies outlined therein:

Goal 1. Prevent and Effectively Treat Alzheimer's Disease by 2025

- Participate in Alzheimer's disease research summits planned by National Institute on Aging, Health and Human Services and others.
- Provide input regarding the nation's AD research agenda and National Plan updates.
- Apply for research grants and participate in clinical trials for promising pharmaceuticals and lifestyle interventions.
- Help increase enrollment of racial and ethnic minorities in AD studies.
- Help maximize collaboration among federal agencies and the private sector in Indiana.
- Help coordinate research among public and private entities in Indiana.
- Help translate research findings into community medical practice and public health programs.

Goal 2. Optimize Care Quality and Efficiency

- Participate in expanded training of health care providers. This may include opportunities to support geriatric training for physicians, nurses, and other health workers, including the need for information on how to implement the "detection of any cognitive impairment" requirement in the Medicare Annual Wellness Visit included in the Affordable Care Act. Participate in enhanced specialist training to prepare practitioners for unique challenges faced by people with AD. HHS will undertake comprehensive provider education targeting physicians/practitioners, nurses, direct care workers, and other professionals via HRSA's Geriatric Education Centers and will focus on AD.
- Participate in national efforts to encourage providers to pursue careers in geriatric specialties.
- Use new HHS clearinghouse of dementia curricula and practice recommendations.
- Utilize new training tools to strengthen nursing home direct-care staff.
- Participate in efforts to strengthen state aging workforces. AoA will ask states to specify strategies to improve the AD capability of the workforce in their State Aging Plans. These may include enhancing AD competencies among aging network staff, developing AD-capable health and long-term care Options Counseling in Aging and Disability Resource Centers, and linking State Long Term Care Ombudsmen programs to AD-specific training and resources.
- Improve efforts to ensure timely and accurate diagnosis, including for early-onset. NIH's Alzheimer's Disease Education and Referral Center (ADEAR) will continue to educate the public and providers about the latest evidence on signs, symptoms, and current methods of diagnosing the disease. AoA's National Alzheimer's Call Center will help connect families and people with symptoms of AD with resources, including diagnostic services, through NIH-funded Alzheimer's Disease Centers.
- Use new assessment tools to support Affordable Care Act's Medicare Annual Wellness Visit requirement to detect cognitive impairment.
- Support federal efforts to educate health care providers and the aging network to meet the needs of people with AD and their families.
- Support federal efforts to develop high-quality dementia care guidelines across myriad care settings.
- Participate in federal efforts to explore new models of care via CMS Center for Medicare and Medicaid Innovation, such as the Medical Home model and Independence at Home demonstration.
- Support federal efforts to ensure that people with AD experience safe and effective transitions between care settings and system, such as Partnership for Patients (safety in emergency room visits and hospitalizations), and ADRC Evidence Based Care Transitions Program.

- Use the proposed free toolkit on care transitions for people with AD.
- Improve care for populations disproportionately affected by AD and facing care challenges, such as racial and ethnic minorities, people with intellectual disabilities, and people with younger-onset AD.

Goal 3. Expand Supports for People with Alzheimer’s Disease and Their Families

- Utilize materials to be developed and distributed via aging networks and health departments with culturally sensitive training and education information for caregivers.
- Utilize informatics/health information technology to reach and assist caregivers and people with AD.
- Utilize federal findings analyzing surveys and datasets to identify unmet service needs.
- Utilize best-practice information disseminated by federal partners about caregiver assessment and referral, interventions by community-based organizations, and other interventions to support people with AD and their caregivers.
- Participate in federal efforts to develop more AD-capable long-term care services and support systems, including respite care.
- Utilize lessons learned through the VA system, such as the Caregiver Support Program, REACH-VA, and Home-Based Primary Care.
- Utilize federal support for crisis and emergency situations via the National Alzheimer’s Call Center and Alzheimer’s Disease Education and Referral Center (ADEAR); participate in a federal webinar to learn more about these services.
- Use federal resources to help families plan for future care needs.
- Support federal efforts to maintain the dignity, safety, and rights of people with AD via AoA Long Term Care Ombudsmen, education of legal service professionals about AD via AoA’s National Legal Resource Center, monitoring and reducing inappropriate use of anti-psychotics, and addressing the housing needs of people with AD via affordable housing models to be explored by HUD and HHS.

Goal 4. Enhance Public Awareness and Engagement

- Participate in HHS effort to collaborate with states and NGOs on a multifaceted public awareness, outreach, and education initiative.
- Collaborate with other states and local governments to improve coordination and identify model initiatives to advance AD awareness and readiness.
- Participate in federal effort to convene leaders from state and local governments to identify steps for increasing AD awareness and readiness, and in creating an agency for partnering in the National Plan.

Goal 5. Track Progress and Drive Improvement

- Help identify additional data needs and research topics.
- Use federal data such as the National Health and Agency Trends Study and Medicare Current Beneficiary Survey to assess progress. Use new data tracking AD care that is incorporated for the first time into Healthy People 2020.



Indiana State Department of Health

2 North Meridian Street
Indianapolis, IN 46204
www.in.gov/isdh

317-233-1325

Family and Social Services Administration

402 West Washington Street
P.O. Box 7083
Indianapolis, IN 47207-7083
www.in.gov/fssa

317-233-4454

Division of Aging

800-232-7020

Adult Protective Services Hotline

800-992-6978

Long Term Care Ombudsman

800-622-4484

Area Agency on Aging

800-986-3505

Alzheimer's Association Greater Indiana Chapter

50 East 91st Street, Suite 100
Indianapolis, IN 46240
www.alz.org/indiana

800-272-3900