



FROM PLAN TO PRACTICE:

Implementing
the National
Alzheimer's Plan
in Your State

July 2014

A Joint White Paper by



National Alliance for Caregiving



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ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

Established in 1996, the National Alliance for Caregiving, is a non-profit coalition of national organizations focused on advancing family caregiving through research, innovation and advocacy. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, government agencies, and corporations. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.

Recognizing that family caregivers make essential social and financial contributions toward maintaining the well-being of the people they care for, the Alliance is dedicated to improving quality of life for families and their care recipients through research, innovation and advocacy.

For more information about the Alliance, please call 301-718-8444, visit www.caregiving.org, or follow us on Twitter, Facebook, or LinkedIn.

ABOUT THE ALZHEIMER'S FOUNDATION OF AMERICA

The Alzheimer's Foundation of America, based in New York, is a national nonprofit organization that unites more than 1,700 member organizations nationwide with the goal of providing optimal care and services to individuals with Alzheimer's disease or related dementias, and to their caregivers and families. Its services include a toll-free hotline staffed by licensed social workers, educational materials, a free quarterly magazine for caregivers, and professional training. For more information about AFA, please call toll-free 866-232-8484, visit www.alzfdn.org, follow us on Twitter, or connect with us on Facebook.

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Moving the Needle on Alzheimer's Disease

There are few greater threats to our global society than Alzheimer's disease. As the world's population ages, societies including our own will be faced with the task of providing quality and support and services for the growing number of individuals affected by Alzheimer's disease and related dementias. What can be done to support the estimated 5 million Americans currently living with Alzheimer's disease and the more than 14 million Americans who will be living with Alzheimer's disease by 2050?

Because there is no known cure or prevention for the brain disorder, family caregivers serve as the backbone for individuals with the disease. In particular, caregivers are overwhelmed with daily responsibilities such as helping their loved ones with Activities of Daily Living (ADLs), including bathing and dressing, and Instrumental Activities of Daily Living (IADLs), such as managing finances. Caregivers also provide assistance with medical tasks, such as managing medication or coordinating their loved one's care.

States also play a vital role in addressing the needs of families struggling with Alzheimer's disease and related dementias. Many have adopted and begun implementing state plans, building on the work of the federal government's "National Plan to Address Alzheimer's Disease." Other states with plans in place are still identifying how to reach goals. Some have not yet crafted plans.

The National Alliance for Caregiving and the Alzheimer's Foundation of America were pleased to offer a half-day conference in December 2013, titled *From Plan to Practice: Implementing NAPA in Your State*. Over 250 webinar participants from more than 39 states and the District of Columbia heard from federal and state policy makers involved in developing comprehensive plans to provide supports and services to people with Alzheimer's disease and their family caregivers. Federal and state experts also provided best caregiver practices, tools and strategies on how best to implement these action steps in states and localities.

This White Paper is the next step in moving the vital conversation forward. It is our hope that state and local policymakers and advocates will find it useful in understanding the Alzheimer's disease crisis facing the U.S., and the best practices that states are using to confront the challenges facing individuals with the disease, caregivers, healthcare professionals, policy makers and society as a whole.

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Executive Summary

Alzheimer's disease is already at crisis proportions in the U.S. As our nation ages, the number of people with Alzheimer's disease is expected to triple in the next 40 years. To address this threat, the U.S. joined in a global effort to confront the disease through the enactment of the National Alzheimer's Project Act (NAPA). NAPA resulted in the creation of the federal "National Plan to Address Alzheimer's Disease" which laid the groundwork for increasing collaboration within the federal government and between the public and private sectors.

Following the lead of the federal government, 42 states and the District of Columbia have developed state Alzheimer's plans to support individuals and their family caregivers who are facing Alzheimer's disease and related dementias. Still, other states have yet to develop plans. In states where plans are in place, there is a need to continually act on the plan's implementation to ensure that gaps in services are adequately addressed.

This report offers six key recommendations, applicable to both new and existing state plans:

- 1. Establish and maintain a task force (formal or informal) of Alzheimer's disease stakeholders, including government officials, community groups, individuals with dementia, and family caregivers.**
- 2. Assess the ability of the state Alzheimer's disease community to support diagnosed individuals and their families.**
- 3. Develop a state plan for Alzheimer's disease that includes goals specific to the state population, and outlines measures to track progress.**
- 4. Keep stakeholders engaged in the design, implementation, and evaluation of the plan.**
- 5. Recognize that state plans are "living documents," and modify them as appropriate over time.**
- 6. Learn from the successes and challenges of other states and the National Alzheimer's Plan.**

Executive Summary

To provide an illustration of successful state plans, this report offers three case studies from states at various stages of developing their state plans. Minnesota's ACT on Alzheimer's initiative began in 2011, and has been successful in uniting the local Alzheimer's disease community. Indiana's plan, released in 2013, began as a community effort later supported by the state legislature and policy makers. Rhode Island, which also implemented a plan in 2013, is experiencing a transition in executive leadership and seeking new champions among policy makers to continue the plan's successes.

Ultimately, it falls on local activists, care providers, family caregivers, and persons living with Alzheimer's disease or a related dementia to monitor the implementation of the plan in their states and hold public officials accountable for their progress. In order for state plans to move forward and affect change, localities need to come together and make confronting this brain disorder a priority in their community.

Addressing the Crisis of Alzheimer's Disease & Related Dementias

THE SCOPE OF THE CRISIS

Alzheimer's disease, which is the most common cause of dementia, is not part of the normal aging process. It is a fatal, irreversible, progressive brain disorder that destroys memory and intellectual function. Common symptoms include memory loss, confusion, spatial disorientation, lack of judgment, and inability to communicate.¹ Over a period of years, the disease leads to the complete loss of cognitive function, a long period of dependency and, ultimately, death.

Alzheimer's disease is already at crisis proportions in the U.S. As our nation ages, the number of people with Alzheimer's disease is expected to triple in the next 40 years. **Researchers project that the total number of people with Alzheimer's disease in the U.S. in 2050 will be 13.8 million, up from 4.7 million in 2010.**² About 7 million Americans with the disease will be 85 or older.³ Currently, Alzheimer's disease is the sixth leading cause of death in the U.S.⁴

ROLE OF CAREGIVERS

Caring for a loved one with Alzheimer's disease or a related dementia poses enormous and life-changing challenges for families and caregivers. Family caregivers, often called the "invisible second patients," are critical to the quality of life of individuals with dementia. The effects of being a family caregiver, though sometimes positive in terms of building character and strength, are generally negative; caregivers face high rates of burden and psychological morbidity as well as social isolation, physical ill-health, financial hardship, and premature death.⁵

Caregivers of individuals with Alzheimer's disease report experiencing negative health issues as a result of providing care.⁶ A 2011 report reveals that family caregivers for a loved one with Alzheimer's disease had a 25 percent increase in the use of all types of health services, with the median cost of healthcare averaging \$4,766 more per year than non-caregivers.⁷

NATIONAL ALZHEIMER'S DISEASE PROJECT ACT

In May 2012, the U.S. Department of Health and Human Services (HHS) unveiled the first ever "National Plan to Address Alzheimer's Disease" (National Alzheimer's Plan),⁸ which was mandated by passage of the National Alzheimer's Project Act (NAPA).⁹ **The National Alzheimer's Plan addresses the major challenges presented by Alzheimer's disease and outlines various action steps and goals—from advancing scientific collaboration to improving care of diagnosed individuals.** HHS is tracking activities now being undertaken with increasing collaboration within the federal government and between the public and private sectors.

**BY 2050, NEARLY
14 MILLION
AMERICANS WILL
HAVE ALZHEIMER'S
DISEASE.**

1 National Institute on Aging, Alzheimer's Disease Fact Sheet (www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet).

2 Alzheimer's disease in the United States (2010–2050) estimated using the 2010 census, www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract.

3 Ibid.

4 Centers for Disease Control, September is World Alzheimer's Month (www.cdc.gov/features/worldalzheimersday/).

5 Family caregivers of people with dementia, *Dialogues in Clinical Neuroscience*, Volume 11(2); June 2009 (www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/).

6 CAREGIVING COSTS: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient, *National Alliance for Caregiving*, Nov. 2011 (www.caregiving.org/pdf/research/Alzheimers_Caregiving_Costs_Study_FINAL.pdf).

7 Ibid.

8 See, <http://aspe.hhs.gov/daltcp/napa/natplan.shtml>.

9 P.L. 111-375 (January 4, 2011).

Addressing the Crisis of Alzheimer's Disease & Related Dementias

IN 2012 ALONE,
ALZHEIMER'S
DISEASE AND
RELATED
DEMENTIAS
COST
AMERICAN
SOCIETY \$200
BILLION.

The National Alzheimer's Plan's five overarching goals are:

1. Prevent or Effectively Treat Alzheimer's Disease by 2025
2. Enhance Care Quality and Efficiency
3. Expand Supports for People with Alzheimer's Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Improve Data to Track Progress.¹⁰

CAREGIVING PROVISIONS IN THE NATIONAL ALZHEIMER'S PLAN

The recommendations, action steps and strategies contained in the National Alzheimer's Plan recognize that supports for individuals affected by Alzheimer's disease and related dementias should extend beyond the care provided in formal settings such as doctors' offices, hospitals or nursing homes. Families and other informal caregivers play a central role. **In particular, families and caregivers need tools to plan for future needs, and to ensure that the person with Alzheimer's disease or a related dementia is cared for safely and with dignity.**

Caregiver-specific strategies in the National Alzheimer's Plan include:

- educating and supporting people with Alzheimer's disease and their families upon diagnosis;
- exploring the effectiveness of new models of care for people with Alzheimer's disease;
- advancing coordinated and integrated health and long-term services and supports (LTSS) for individuals living with Alzheimer's disease;
- ensuring receipt of culturally-sensitive education, training, and support materials;
- enabling family caregivers to continue to provide care while maintaining their own health and well-being;
- assisting families in planning for future care needs; and
- maintaining the dignity, safety and rights of people with Alzheimer's disease.

¹⁰ Ibid.

THE COSTS OF ALZHEIMER'S DISEASE

As the incidence of Alzheimer's disease grows, costs are skyrocketing. In 2012, the direct costs of caring for people with Alzheimer's disease or related dementias to American society totaled an estimated \$200 billion, including \$140 billion in costs to Medicare and Medicaid.¹¹ These costs will soar to a projected \$1.1 trillion (in today's dollars) by 2050.¹²

Complicating this, people with Alzheimer's disease tend to have multiple co-existing medical conditions, such as coronary artery disease, diabetes, congestive heart failure, and chronic obstructive pulmonary disease. Thus, they tend to have higher rates of healthcare use than others without the disease. For example, hospital stays are more frequent among people with Alzheimer's disease than among those without this brain disorder.¹³ In addition, avoidable hospitalizations are more common among Medicare beneficiaries with Alzheimer's disease than for beneficiaries with diabetes (short-term and long-term complications of diabetes), hypertension, COPD or asthma, and heart failure.¹⁴

11 Ibid.

12 Ibid.

13 Zhanlian Feng, PhD, et al., Hospital and Emergency Department Use by People with Alzheimer's Disease and Related Disorders: Final Report (August 2013) (<http://aspe.hhs.gov/daltcp/reports/2013/ADRDhed.shtml#execsum>).

14 Ibid.

Addressing the Crisis of Alzheimer's Disease & Related Dementias

THE NEED FOR STATE ACTION

Many states have already put together strategies to coordinate resources and marshal services related to this brain disorder. Yet development of a plan is just the beginning of ensuring that local responses and strategies are executed and gaps in coverage strategies are adequately addressed.

Successful state plans need consistent efforts to be effective, including keeping stakeholders engaged and oversight to ensure implementation of plan recommendations and action steps. In addition, state plans need to be frequently revisited to measure progress and consider new recommendations that identify gaps in plans.

All plans, including those already in motion, should articulate performance metrics to ensure actions steps are fulfilled and the plan is progressing. If the plan is not effective, states should determine how to modify the implementation, or even the plan if need be. **In short, state plans must be living documents where progress is constantly being measured and recommendations are continually updated.**

WHY STATE PLANS MATTER

For states that have not yet implemented plans, even simple plans, such as coordinating state and local resources and targeting services, can have a profound positive impact on the community. For example, dementia training for first responders will ensure greater degrees of community safety during emergencies or national disasters that could require evacuations of vulnerable populations in nursing homes, assisted living residences or hospitals.

Adoption of a state plan will galvanize stakeholders and allow them to hold state and local officials accountable for implementation of recommendations and achieving certain benchmarks. Advocates for family caregivers and direct care providers can use the state plan to motivate state and local policy makers to effectuate legislation and regulation that enhance access to care services while removing barriers to implementation of innovative care models.

State plans calling for the adoption of innovative care delivery models and enhanced care supports, like those articulated in the National Alzheimer's Plan, can also help extend limited care resources in the state.

In a recent report,¹⁵ AFA examined specific care-focused goals in the National Alzheimer's Plan, including coordinated care delivery models,

15 Alzheimer's Foundation of America, "Cost of Care: Quantifying Care-Centered Provisions of the National Plan to Address Alzheimer's Disease," (April 2014) (<http://www.alzfdn.org/documents/Quantifying-Care-Centered-Provisions-of-the-National-Plan-to-Address-Alzheimers-Disease.pdf>).

Addressing the Crisis of Alzheimer’s Disease & Related Dementias

transitional care programs, and expanded caregiver supports. The report also modeled the economic impact of their implementation. **The evaluation indicated that adoption of such programs will provide a cost savings to the federal government of more than \$110 billion during a 10-year period, while promoting better health outcomes for diagnosed individuals and improving quality of life for their caregivers.**

These strategies are already bearing fruit. As the Minnesota case study in this White Paper reports, adoption of “best practices in dementia care models” has the potential savings of nearly \$1 billion over 15 years for its state.

IMPLEMENTING ALZHEIMER’S PLANS AT THE STATE LEVEL

Spurred by new research and alarming studies that projected the increasing prevalence of Alzheimer’s disease in the future, a new wave of state plans started to be developed in 2006 and accelerated after passage of NAPA and the formation of a National Alzheimer’s Plan. Currently, 42 states and the District of Columbia have or are in the process of finalizing state Alzheimer’s disease plans.¹⁶

States offer a unique perspective, based largely on state demographics and needs; they also marshal different economic resources and control a majority of funding for caregiver services and programs. Specifically, states:

- provide services and benefits, such as through Medicaid, not controlled by federal health programs;
- have the authority to license and certify certain care workers and facilities;
- administer U.S. Administration on Aging programs (e.g., respite care, adult day services, Meals on Wheels);
- can influence workforce development curriculum;
- oversee law enforcement and first responders at both the state and local level; and
- have jurisdiction over elder care cases and other legal issues.¹⁷

16 Ibid. States without Alzheimer’s plans are: New Hampshire, Tennessee, Mississippi, South Dakota, Nebraska, Kansas, Wyoming and Montana. Puerto Rico also lacks a local strategy.

17 Ibid.

Addressing the Crisis of Alzheimer’s Disease & Related Dementias

BEST PRACTICES FOR IMPLEMENTATION

As the following case studies illuminate, state plans are locally-oriented roadmaps developed by Alzheimer’s disease stakeholders and other interested parties. **Although plans vary from state to state, the strategies to implement plans share some common elements, which include:**

- obtaining buy-in from the state executive and legislative bodies;
- assembling a highly skilled, committed task force that represents a cross section of stakeholders;
- keeping recommendations local in nature;
- ensuring broad input from the whole community;
- making the plan culturally sensitive; and
- continually updating the plan and its recommendations, including charting progress of implementation.

Although states have limited or no access to resources to fund clinical research on Alzheimer’s disease, state plans often include recommendations to foster Alzheimer’s disease drug development through clinical trial recruitment education and outreach, as well as holding symposiums and conferences on research development.¹⁸

State plans are also being used to help eliminate the institutional bias under the Medicaid program to care for persons with dementia. Such plans will also facilitate the ability of people with Alzheimer’s disease to remain in the community in fulfillment of the *Olmstead* decision,¹⁹ which requires individuals to obtain care in the “less restrictive setting possible.”²⁰ In order for states to receive federal Medicaid funds for home- and community-based services (HCBS), including person-centered care coordination programs, states need to apply for a federal waiver. Elimination of these barriers will allow persons with Alzheimer’s disease or related dementias to “age in place” and delay institutionalization for as long as possible.

18 Ibid.

19 *Olmstead v. L.C.*, 527 U.S. 581 (1999).
<http://www.supremecourt.gov/opinions/boundvolumes/527bv.pdf>.

20 See, *ibid.* “the State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated...”

Addressing the Crisis of Alzheimer’s Disease & Related Dementias

RECOMMENDATIONS

This report offers six key recommendations, applicable to both new and existing state plans:

- 1. Establish and maintain a task force (formal or informal) of Alzheimer’s disease stakeholders, including government officials, community groups, individuals with dementia, and family caregivers.** Leaders should work with state leadership (legislative and executive), Alzheimer’s-specific community organizations, caregiver coalitions and other key stakeholders to establish a task force to examine the need for support within the state.
- 2. Assess the ability of the state Alzheimer’s disease community to support diagnosed individuals and their families.** State leaders should understand the Alzheimer’s disease population, including challenges facing people with Alzheimer’s disease, availability of long-term care services and supports, presence of community organizations, supports (or lack of) for family caregivers, and how state demographics may impact the plan.
- 3. Develop a state plan for Alzheimer’s disease that includes goals specific to the state population, and outlines measures to track progress.** All plans, including those already implemented, should articulate performance metrics to ensure actions steps are fulfilled and the plan is progressing. If the plan is not effective, states should determine how to modify the implementation or even the plan if need be.
- 4. Keep stakeholders engaged in the design, implementation and evaluation of the plan.** Successful state plans need consistent efforts to be effective, including keeping stakeholders engaged and oversight to ensure execution of plan recommendations and action steps.
- 5. Recognize that state plans are “living documents,” and modify them as appropriate over time.** Progress should be constantly measured and recommendations should be continually updated.
- 6. Learn from the successes and challenges of other states and the National Alzheimer’s Plan.** States that have successfully implemented state plans have learned from others that have established plans and from federal programs to support families managing Alzheimer’s disease.

Addressing the Crisis of Alzheimer's Disease & Related Dementias

CONCLUSION

Alzheimer's disease has infiltrated all aspects of life. It does not discriminate and is felt by both rich and poor, urban and rural, red states and blue states. It is beyond a federal problem since a majority of its impact, both social and economic, falls on the community.

If communities are to effectively combat the growing healthcare crisis that is Alzheimer's disease, states and stakeholders must be fully engaged in this movement. Having plans in place can empower states and localities to provide quality services in the most efficient manner. States should also communicate and learn from each other's successes and failures, using these lessons to inform their own state plans.

Ultimately, it falls on local activists, care providers, family caregivers, and persons with Alzheimer's disease to monitor the implementation of the plan in their states and hold public officials accountable for their progress. As former Speaker of the House Tip O'Neill was fond of saying, "All politics is local."²¹ In order for state plans to move forward and affect change, localities need to come together and make confronting this brain disorder a priority in their community.

²¹ See, BrainyQuote.com at:
<http://www.brainyquote.com/quotes/quotes/t/thomaspo212119.html>

Case Study: The Indiana Plan for Alzheimer's Disease and Related Dementias, 2013-2017

Michael Sullivan, Chair, Governor's Task Force on Alzheimer's Disease, Indiana

FAST FACTS

- 2013 state population: 6,570,901 ²²
- Number of people living with Alzheimer's disease: 120,000 (approximately 2 percent of the total population)
- Percentage of population over 65 with Alzheimer's disease: 11 percent
- Approximately 325,000 Indiana caregivers provide 371 million hours of care.
- Just under 2,000 residents die from Alzheimer's disease each year.
- Indiana's Alzheimer's disease plan was released in 2013.



DEVELOPING A PLAN FOR INDIANA

Step 1: Learn From the Success of Other States

Indiana reached out to Kentucky and Iowa, the two states that first developed state Alzheimer's plans. In particular, Alzheimer's disease advocates wanted to assess their process and review the content of their plans. The community wanted to ensure that the state plan was an *Indiana* plan, unique to the needs of the state.

120,000 PEOPLE IN THE STATE OF INDIANA HAVE ALZHEIMER'S DISEASE.

Step 2: Meet With Aging and Disability Leaders in Your Home State

In the summer of 2008, aging and disability leaders met with the Assistant Commissioner of the State Department of Health and the Director of the Division of Aging to assess their interest and support. At the same time, a presentation about the concept of a state plan was presented to Indiana's Commission on Aging.

At the Commission on Aging's meeting in November 2008, the following statement was approved and forwarded to the governor:

"The Commission on Aging has reviewed the impact of Alzheimer's disease and related dementia disorders on the lives of Indiana residents. Therefore, the Commission on Aging supports and endorses the Alzheimer's Association's plan to develop a strategy to mobilize a state response to the Indiana Dementia Health Crisis. We applaud the Indiana Division of Aging's willingness to facilitate and administer the Alzheimer's Disease and Related Dementia Disorders Task Force with assistance from the Indiana State Department of Health."

Step 3: Win Support From State Alzheimer's Disease Advocates

The Indiana legislature created the Alzheimer's Disease and Related Senile Dementia Task Force in 1992, with the primary responsibility to administer Administration on Aging dementia grants. However, the grants ended in

22 U.S. Census Quickfacts (<http://quickfacts.census.gov/qfd/states/18000.html>).

Case Study: The Indiana Plan for Alzheimer's Disease and Related Dementias, 2013-2017

Michael Sullivan, Chair, Governor's Task Force on Alzheimer's Disease, Indiana

2002, and the task force stopped meeting in 2004. Thus, the work began to convince then Governor Mitch Daniels to reappoint the task force and charge it with the development of a state plan.

Step 4: Convene the Task Force to Support a State Plan

In January 2011, Gov. Daniels re-commissioned the task force, charged it with creating an Alzheimer's Disease State Plan, and recommended potential task force members. The first meeting of the Governor's Task Force took place in March 2011.

The 17-member task force included legislators, physicians, healthcare providers, attorneys, state representatives from the Division of Aging, State Department of Health and Division of Mental Health, and others with expertise in Alzheimer's disease. The task force met monthly for 20 consecutive months.

Step 5: Gather Information From the Broader Community

The task force also realized the need for input from other stakeholders, beyond its own members, to obtain essential information for inclusion in the plan. To garner these perspectives, the task force invited speakers representing law enforcement, nursing homes, Adult Protective Services, Area Agencies on Aging, Bureau of Motor Vehicles, home and community-based services, and other sectors to present at meetings.

To hear from the general public, the task force held three input sessions in different parts of the state. More than 150 participants weighed in on various services, training needs, research, care coordination, cost of care and other financial issues, early diagnosis, workforce issues, health system coordination, and the needs of individuals with young-onset Alzheimer's disease.

Providing another avenue for public input, the task force posted an Internet survey during the summer and fall of 2011. Nearly 950 responses, representing 84 of Indiana's 92 counties, were received and considered in the development of the plan. Respondents included persons with Alzheimer's disease (1 percent), family caregivers (62 percent), non-family caregivers (2 percent), professional caregivers/providers (33 percent) and public employees/officials (2 percent).

Step 6: Develop the Plan

To ensure an organized and comprehensive plan, the task force hired a contractor to draft the plan. In addition, the task force utilized the services of a nursing administration doctoral candidate for survey analysis, gap analysis and an implementation metric tool.

Case Study: The Indiana Plan for Alzheimer's Disease and Related Dementias, 2013-2017

Michael Sullivan, Chair, Governor's Task Force on Alzheimer's Disease, Indiana

Step 7: Seek State Approval and Implementation

The task force approved the state plan on October 23, 2012, and a report was printed and available in March 2013. In the interim, Indiana had elected a new governor, Mike Pence. The task force sought a continued commitment from the new administration, resulting in the governor's authorship of a supportive cover letter for the state plan.

Other outreach included sending Indiana's 150 legislators a printed copy of the plan and the cover letter. Task force members were also instrumental in the distribution of the electronic version to various organizations, such as Area Agencies on Aging, Commission on Aging, AARP, Indiana University Health, Indiana Minority Health Coalition, Indiana Senior Law Project, Indiana Senior Bar Group, Healthcare Excel and appropriate professional and trade associations.

NEXT STEPS: TRANSITION TO A VOLUNTARY COUNCIL

With the task force facing a sunset date of December 31, 2013, its members and other stakeholders wanted to ensure that the implementation of the state plan's recommendations would continue. With assistance from the Division on Aging and the Indiana State Department, the task force approached the Commission on Aging – the same commission where these efforts began in the summer of 2008. The law establishing the Commission on Aging allows the Commission to: “promote the organization of and officially recognize voluntary councils for the study and discussion of problems of the aging and the aged.”

At its June 2013 meeting, the Commission on Aging agreed to appoint a 13-member voluntary council to oversee the implementation of the state plan. Among the members, six had served on the task force that developed the state plan. This subcommittee has met five times as of May 2014 and continues to track the implementation of the state plan.

Case Study: The Indiana Plan for Alzheimer's Disease and Related Dementias, 2013-2017

Michael Sullivan, Chair, Governor's Task Force on Alzheimer's Disease, Indiana

SUCSESSES

The success of Indiana's state plan relied on a couple of factors:

- 1. Strong support from the Indiana government:** The state administration (specifically the Commission on Aging, the State Department of Health, and the Division of Aging) and the Governor's office were supportive.
- 2. High-skilled, committed task force members:** The task force was comprised of skilled and committed individuals.
- 3. Available funding to support the work of the task force:** The Alzheimer's disease community had additional funding for consultant fees, enabling the task force to use the skill set brought by the nursing administration doctoral candidate.
- 4. Robust input from state and community stakeholders:** The task force received and incorporated valuable statewide input, information, and support from statewide outside experts and organizations.

RESOURCES

Indiana State Plan:

http://www.in.gov/fssa/files/Indiana_Alzheimers_State_Plan_2013-2017.pdf

Indiana Alzheimer's Disease & Dementia Resource Center:

<http://www.state.in.us/isdh/25190.htm>

Case Study: Minnesota ACT on Alzheimer's

Donna Walberg, MBA, Dementia Capable Integrated Systems, Minnesota Board on Aging

FAST FACTS

- 2013 state population: 5,420,380 ²³
- Number of people with Alzheimer's disease or related dementias: 100,000
- In 2011, 70 percent of people with Alzheimer's disease and other dementias lived at home with help from family members.
- Caregivers provide more than 280 million hours of unpaid care, valued at \$3.5 billion annually.
- Caregivers for persons with Alzheimer's disease spend an average of \$175,000 out-of-pocket over the course of the disease.
- Minnesota's Alzheimer's disease plan was released in 2011.



BACKGROUND

The genesis of ACT on Alzheimer's was in 2009, when the Minnesota Legislature called on the Minnesota Board on Aging to establish the Alzheimer's Disease Working Group (ADWG) to study and make recommendations to the legislature for needed policy changes related to Alzheimer's disease. The ADWG delivered recommendations to the Minnesota Legislature in January 2011. After the recommendations were delivered, a subgroup of the ADWG participants committed to ensuring that the recommendations were implemented beginning in June 2011.

The vision of ACT on Alzheimer's is for a Minnesota that is prepared for the personal, social and budgetary impacts of Alzheimer's disease through building community capacity and resources to support people with the disease and their caregivers.

ACT on Alzheimer's is focused on five interconnected goals:

1. identifying and investing in promising approaches that reduce costs and improve care;
2. increasing detection of Alzheimer's disease and improve ongoing care and support;
3. sustaining caregivers by offering them information, resources, and in-person support;
4. equipping communities to be "dementia capable" to support residents who are touched by Alzheimer's disease; and

23 U.S. Census Quickfacts (<http://quickfacts.census.gov/qfd/states/27000.html>).

Case Study: Minnesota ACT on Alzheimer's

Donna Walberg, MBA, Dementia Capable Integrated Systems, Minnesota Board on Aging

THE PHYSICAL AND EMOTIONAL IMPACT OF CARING FOR A PERSON WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS RESULTS IN AN ESTIMATED \$162 MILLION IN ANNUAL HEALTHCARE COSTS.

5. raising awareness and reducing stigma by engaging communities in planning for and integrating Alzheimer's disease resources that foster early detection, quality care and support, and community readiness.

COST OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

There were over 100,000 Minnesotans over age 65 who were estimated to have Alzheimer's disease or a related dementia in 2012 (88,000 of them had Alzheimer's disease).²⁴ In 2011, 70 percent of people with Alzheimer's disease and other related dementias lived at home with help from family members. Nearly 250,000 Minnesotans care for family members with Alzheimer's disease. These caregivers provide more than 280 million hours of unpaid care, valued at \$3.5 billion yearly.

The physical and emotional impact of caring for a person with Alzheimer's disease and other dementias is estimated to result in nearly \$162 million in healthcare costs for Minnesota caregivers. One in seven people with Alzheimer's disease lives alone and is at greater personal risk of jeopardized health, missed or delayed diagnosis, self-neglect, untreated medical conditions, wandering behavior, and accidental death. Caregivers of individuals with Alzheimer's disease spend an average of \$175,000 of their own money over the course of the disease.

ALZHEIMER'S ADVOCATES

ACT on Alzheimer's currently unites more than 300 individuals and 60 nonprofit, private and governmental entities involved in the collaborative. Individuals and organizations support one or more of the five goal areas above. The coalition's role is to coordinate and leverage the collective work of all participants and align their work with a common, transformational agenda. (A complete roster reflecting the entities and individuals involved in ACT on Alzheimer's can be found at <http://actonalz.org/our-partners>.)

No one organization owns or controls ACT on Alzheimer's; it is organized under a unique collaboration structure entitled "collective impact,"²⁵ which is designed to foster accountability and measurable results.

²⁴ Over 90 percent of individuals with dementia are over the age of 65, thus the intrinsic focus of ACT is designed to support older adults with dementia and their family caregivers.

²⁵ Channeling Change: Making Collective Impact Work: SSIR, 1/26/2012, John Kania and Mark Kramer.

Case Study: Minnesota ACT on Alzheimer's

Donna Walberg, MBA, Dementia Capable Integrated Systems, Minnesota Board on Aging

The ACT on Alzheimer's organizing structure consists of:

- **A Leadership Council** comprised of 45 leaders from the healthcare, long-term care, academic, community, government, business, faith, funding and other nonprofit sectors. Council members develop strategy and serve as ambassadors for the ACT on Alzheimer's initiative.
- **A Management Steering Team** comprised of approximately 10 individuals from organizations actively involved and invested in the day-to-day work of the initiative (including the Minnesota Board on Aging, the Alzheimer's Association Minnesota/North Dakota Chapter, Care Providers of Minnesota, care partners of people with Alzheimer's disease and others). The team is responsible for operational guidance and oversight.
- **Six Leadership Groups**, of stakeholders and experts in the five goal areas, including one focused on health equity for underserved and highly impacted, diverse communities. The groups set and implement strategy in their focus areas.
- **Action Communities** throughout Minnesota, which is applying a grassroots approach to become dementia friendly, supported by resources like the ACT on Alzheimer's Dementia Capable Communities Toolkit.

LESSONS LEARNED

ACT on Alzheimer's is deep in the formative evaluation process and has not yet compiled a list of lessons learned, but anecdotal observations include:

- Conducting work in a neutral forum with no one organization owning or controlling the process is of value.
- Having consistent support, providing project management, facilitation, process development, and communications, is critical to success.
- Using a collective impact structure with a shared common agenda, accountability, and mutually reinforcing activities are keys to affect change.
- Being transparent and open to everyone's input aids success.
- Having diverse participants and funders strengthens the outcomes.
- Continually reporting progress across the initiative keeps people engaged.
- Including personal, systemic and community-level perspectives has allowed multi-dimensional success.

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GOALS OF ACT ON ALZHEIMER'S

1. Identify and Invest in Promising Approaches

This goal is focused on helping Minnesota better understand the potential cost savings of best-practice dementia care interventions using a unique economic model. The model has been used to estimate potential costs to Minnesota families and taxpayers if caregivers of people with dementia had access to coordinated and effective caregiver support resources. The results of that analysis reflect a potential savings of nearly \$1 billion over 15 years if such innovative care delivery models were fully implemented in the state. The results appeared in *Health Affairs* in April 2014. The article and the model can be found at: <http://actonalz.org/economic-impact>.

2. Increase Detection and Improve Ongoing Care and Support

This goal is focused on developing and disseminating educational curricula and best practice tools and resources to increase dementia competency for primary and specialty healthcare providers, as well as community-based organizations that serve persons with dementia and their caregivers.

To date, ACT on Alzheimer's has developed:

- A Clinical Provider Practice Tool for identifying and managing cognitive impairment and making referrals to specialty care and critical community-based services, helping both individuals with the disease and their caregivers.
See <http://actonalz.org/provider-practice-tools>.
- Electronic Medical Record Decision Support Tool and a Guide to Implementation, a template to assist health systems in embedding the Clinical Provider Practice Tool into the electronic health record and a guide with tips, steps, and case studies.
See <http://actonalz.org/provider-practice-tools>.
- A recommended Care Coordination in Health Care Settings Tool using dementia as the organizing principle.
See <http://actonalz.org/provider-practice-tools>.
- A Community Based Service Provider Practice Tool as a guide for supporting persons with dementia and their caregivers.
See <http://actonalz.org/provider-practice-tools>.
- Online, interdisciplinary, dementia educational modules for incorporation into undergraduate and graduate level courses throughout the Minnesota University System. These educational offerings can help ensure that health professionals are prepared to recognize and respond to Alzheimer's disease.
See <http://actonalz.org/dementia-curriculum>.

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- In partnership with the State of Minnesota, articulation of dementia standards for Alzheimer's disease health care home demonstrations and Alzheimer's disease learning collaboratives.

3. Sustain Caregivers

This goal is focused on supporting caregivers with information, resources, and person-to-person support. Work to date includes:

- Developing *After a Diagnosis*, tips and resources for caregivers and persons with Alzheimer's disease as a guide when a diagnosis is made; the information aligns with the Provider Practice Tools.
- Enhancing state information resources by providing expert input into dementia capability trainings for Senior LinkAge Line® staff and caregiver consultants.
- Including caregiver support information in resources for community action teams to help build awareness in key community sectors, such as business and faith.

4-5. Equip and Engage Communities and Raise Awareness

This goal is focused on helping communities become dementia friendly. The Equipping Communities Leadership Group, in partnership with Stratis Health, developed the Dementia Capable Communities Toolkit to help community leaders and influencers assess and enhance dementia readiness. The community toolkit guides communities through the process of developing action teams; assessing dementia capability within the community; synthesizing the assessment results; and planning and implementing needed changes. Communities receive technical assistance throughout the process from ACT on Alzheimer's staff as well as staff of Area Agencies on Aging and the Alzheimer's Association. The toolkit design and technical assistance are based on research regarding effective community engagement that fosters meaningful, long-lasting change.²⁶

The community toolkit was initially piloted in 19 communities in Minnesota. Ten additional communities were added in June 2014.

²⁶ The toolkit development process was supported by research from the University of Minnesota's Civic Engagement Model and The University of Colorado's Tri-Ethnic Center, which fosters locally initiated change driven by community defined goals with links to external resources. Specific studies considered include: Chazdon, S. 2010. Ready for Engagement: Using Key Informant Interviews to Measure Community Social Capacity. *Community Development* 41(2):156-175. Theodori. 2009. Community Leadership and Community Theory: A Practical Synthesis. *Journal of the Community Development Society* 39(2): 196-212. Edwards, R. Community Readiness: Research to Practice (2000). *Journal of Community Psychology*. Vol. 26, No. 3, 291-307. Florin, P., et al Identifying training and technical assistance needs in community coalitions: a developmental approach (1993); Goodman, R. et.al. A construct for Building the Capacity of Community-Based Initiatives in Racial and Ethnic Communities: (2008).

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FUTURE WORK/NEXT STEPS

- 1. Identify and invest in promising approaches.** This work aims to: 1) embed standardized provider tools into primary care, community-based care, and the care coordination process so that persons with dementia and their caregivers receive optimal care and support; and 2) embed dementia curriculum into professional education programs to ensure providers are prepared to detect, treat and manage dementia.
- 2. Increase detection and improve ongoing care and support.** This work shares the same goals as the above, to embed standardized provider tools in the patient's healthcare pathways and to embed dementia curriculum into professional education programs.
- 3. Sustain caregivers.** This work aims to ensure that caregiver support statewide includes dementia-specific components and that caregivers can access resources to navigate the care journey.
- 4. Equip and engage communities and raise awareness.** This work aims to impact communities across Minnesota in setting and implementing goals that foster supportive environments for persons with Alzheimer's disease and their caregivers.

RESOURCES

All ACT on Alzheimer's resources and tools are located at www.ACTonAlz.org.

Case Study: The Rhode Island State Plan on Alzheimer's Disease and Related Disorders

Catherine Taylor, Director, Division of Elderly Affairs, Department of Human Services, State of Rhode Island and Providence Plantations

FAST FACTS

- 2013 state population: 1,051,511 ²⁷
- More than 24,000 Rhode Islanders are living with Alzheimer's disease.
- More than 100,000 family caregivers support loved ones with Alzheimer's disease.
- Approximately 10 percent of Rhode Islanders are directly affected by the disease.
- Rhode Island's Alzheimer's disease plan was released in 2013.



DEVELOPING A PLAN FOR RHODE ISLAND

In February 2012, the Rhode Island Division of Elderly Affairs (DEA) was approached by concerned advocates regarding the need to write a Rhode Island plan on Alzheimer's disease. DEA immediately recognized the opportunity to create a plan and use it as a comprehensive framework to address numerous, seemingly unrelated issues that the State Unit on Aging was confronting at the time. Some of these issues included:

- a disconnect between clinical and social service supports for individuals with dementia;
- the inappropriate use of 911, rescue, and hospital emergency departments to respond to disruptive elders in the community;
- the inadequacy of the state's Volunteer Guardianship Program to respond to the issue of individuals with diminished capacity "stranded" as long-term stay hospital patients;
- the role of assisted living facilities in the state's continuum of long-term services and supports;
- problems with transportation to adult day health centers; and
- policy discussions about whether there should be a separate rate paid to nursing homes for the care of individuals with dementia, versus other residents without dementia.

²⁷ U.S. Census Quickfacts (<http://quickfacts.census.gov/qfd/states/44000.html>).

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STEP 1: FIND BROAD SUPPORT FOR A STATE ALZHEIMER’S DISEASE PLAN

Rhode Island Lieutenant Governor Elizabeth Roberts, who was serving as chair of the legislatively-mandated, all-volunteer Long Term Care Coordinating Council (LTCCC), enthusiastically agreed with the need to write the plan and with the appropriateness of the LTCCC as the basis for the task force to take on the project. The LTCCC was already charged by Rhode Island’s General Assembly to do similar work. Most of the readily-identified stakeholders were already part of the LTCCC and were energized to take on an active role in policy development.

Knowing that a state plan would only be successful if written and implemented with the broadest possible support, the Lt. Governor and DEA jointly approached members of the General Assembly. In May 2012, simultaneous to the release of the National Alzheimer’s Plan, the Rhode Island’s Legislature unanimously approved a joint resolution directing the LTCCC to write a “State Plan on Alzheimer’s and Related Disorders,” with the Lt. Governor and the Director of the DEA as co-chairs. The plan was due to the Governor and the General Assembly within a year.

STEP 2: CONVENE AN EXPERT WORKING GROUP TO DEVELOP THE STATE PLAN

While the membership of the LTCCC formed the core of the working group, a broad and always expanding group of experts and stakeholders that represented the Rhode Island Alzheimer’s disease community provided input. Members included the Alzheimer’s Association; family caregivers; individuals living with Alzheimer’s disease; state legislators, policy makers; and program administrators; medical professionals, including physicians, nurses, hospital administrators, and brain researchers; social services professionals, including social workers, case managers, and Adult Protective Service Workers; the Aging and Disability Resource Center (known as THE POINT); long-term care facility administrators, senior center directors, and direct care workers; legal professionals, including advocates, the State Long Term Care Ombudsman, lawyers, guardians, probate judges, and law enforcement; and performing and visual artists.

Over the course of the next year, the full group met periodically to receive reports related to the federal government’s development of the National Alzheimer’s Plan and from Rhode Island’s leading Alzheimer’s disease resources, including the Rhode Island Geriatric Education Center (RIGEC) at the University of Rhode Island; the Brown University Center for Gerontology and Health Care Research; the Brain Bank at Brown University; the Norman Prince Neurosciences Institute; the Alzheimer’s Prevention Registry at Rhode Island Hospital; and the Rhode Island chapter of the Alzheimer’s Association.

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STEP 3: ESTABLISH FOCUSED WORKING GROUPS AND COMMUNITY LISTENING SESSIONS

The work of developing recommendations to make Rhode Island a truly dementia-capable state was divided among six subgroups, which met monthly, to focus on:

- caregivers;
- access (availability of resources, especially to hard-to-serve, minority, or disabled individuals, as well as adequacy of transportation);
- legal services;
- workforce (both adequacy of the direct-care workforce and impact of Alzheimer's disease on the workforce at large);
- long-term care (residential and community-based supports); and
- research and clinical care.

The group held external stakeholder meetings with long-term care trade association members; the Citizens Commission on the Safety and Care of the Elderly (made up of municipal police and fire department senior advocates); and the Probate Judges Association, including offering a Continuing Legal Education (CLE) workshop on the development of the state plan.

To ensure there was robust input from families living with Alzheimer's disease, DEA conducted listening sessions across the state, in English and Spanish, at public libraries, YMCAs and community centers. Families were invited to send their stories via email or post them on the Internet throughout the process.

The Lt. Governor's health policy staff took the lead in developing the draft of the plan in concert with the chairs of the six subgroups and with robust feedback from subgroup participants. The full work group reviewed the draft at a public meeting and then asked for public comment online. The final, revised plan was transmitted to the Governor and legislative leaders on June 24, 2013.

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ALZHEIMER’S DISEASE ADVOCATES

The initial champions of the plan were the Executive Director and volunteer leadership of the Rhode Island Alzheimer’s Association; the Director of the Division of Elderly Affairs; the Lt. Governor and staff; and Dr. Peter Snyder, Sr. Vice President and Chief Research Officer, Lifespan Hospital System, and Professor of Neurology at the Warren Alpert Medical School of Brown University.

The General Assembly unanimously supported the writing of the plan. It was well received on the whole, and received a warm written response from the Senate’s President, with a commitment to support the recommendations with legislation. Members of the full commission continue to be strong champions of implementing the recommendations.

LESSONS LEARNED

The listening sessions with families were most illuminating – and each one revealed something new to consider. Dealing with Alzheimer’s disease was like the tale of the seven blind men touching the elephant. Depending on one’s perspective – family caregiver, doctor, researcher, policymaker, direct care worker, judge – each stakeholder experienced the effects of Alzheimer’s disease as a completely different and seemingly unrelated set of challenges, but these challenges are all part of the same animal.

SUCCESSSES

The work to establish guiding principles for the development of Rhode Island’s state plan was guided by the following principles throughout the process:

- Build on – don’t replicate – national recommendations.
- Tackle Rhode Island-specific problems.
- Lead an inclusive process with the broadest possible involvement and support.
- Look at the effects of Alzheimer’s disease within the state from every possible angle.
- Focus on what families need *now* until a cure is discovered.
- Start with a state-wide inventory of:
 - what is excellent in Rhode Island;
 - what is in place but could be improved or better coordinated; and
 - what needs to be revised or discontinued.
- Assume that significant new funding is not imminent.
- Create a living, breathing, dynamic document.
- Don’t wait until the plan is written to start acting on emerging recommendations.

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IMPLEMENTATION AND NEXT STEPS

Immediate opportunities presented themselves to begin to accomplish the plan's goals, and the DEA began to seize them right away:

- July 2013 state promulgation of Nursing Home Greenhouse Regulations
- State procurement for non-emergency Medicaid transportation (NEMT) broker
- Dementia-capability training for the Department of Corrections, Police, and Fire Senior Advocates
- Department of Health EMS Innovations group – development of training for first responders with the Rhode Island Geriatric Education Center
- The University of Rhode Island's Living Rite program (\$14 million CMS innovations grant) to serve developmentally-disabled people with Alzheimer's disease or other chronic diseases
- Approval from CMS under Rhode Island's §1115 waiver renewal application to expand cost-not-otherwise-matched (CNOM) services to individuals under age 60 with a diagnosis of dementia, living at up to 250 percent of the federal poverty level (FPL)
- Donation of \$15 million to the University of Rhode Island for the new George and Anne Ryan Institute on Neurodegenerative Diseases (GARIN)
- Appointment of Director of Elderly Affairs to the Legislative Commission to Study the Feasibility of Modernizing Probate Law

The working group reconvened on October 30, 2013, to prioritize the recommendations in the state plan. New, targeted task forces were created to implement specific recommendations on:

1. developing a neutral, comprehensive, Rhode Island-specific online resource (which the University of Rhode Island recently committed to fund and host at GARIN);
2. establishing an annual conference for clinicians and researchers, the next to occur in March 2015 in conjunction with the Rhode Island Alzheimer's Association Caregiving Journey Conference;
3. developing and imparting cultural competency; and
4. developing and disseminating dementia-capability training to caregivers and across all professional sectors.

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Legal recommendations were taken up by the Probate Commission, safe driving recommendations by the Citizens Commission on the Safety and Care of the Elderly, and transportation recommendations were incorporated into the contract with the NEMT and elderly transportation broker. Great progress is being made on all fronts. Going forward, the DEA quickly learned that tying policy and funding proposals to the recommendations in the state plan has been extremely helpful and effective.

The working group continues to meet periodically to monitor and motivate these initiatives, and is open to new members at all times. There is, however, a sense of urgency on the part of leadership to accomplish or establish sustainable accountability for the goals of the Rhode Island State Plan, as the terms for the Lt. Governor and the Director of the DEA have now ended.

RESOURCES

The Rhode Island State Plan on Alzheimer's Disease and Related Dementias (and all supporting materials) can be viewed at:
<http://www.ltgov.state.ri.us/alz/>.

