FROM PLAN TO PRACTICE:
Implementing the National Alzheimer’s Plan in Your State

Hosted by:

National Alliance for Caregiving
ALZHEIMER'S FOUNDATION OF AMERICA
n4a
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About the Alliance

- Nonprofit coalition of over 40 national organizations focused on family caregiving issues
- Established in 1996 to support family caregivers and the professionals who work with them
- NAC Activities:
  - Conduct research and policy analysis;
  - Develop national programs;
  - Strengthen state and local coalitions;
  - Increase public awareness;
  - International work and awareness.
Join Our Network!

Join by taking our survey at:
https://www.surveymonkey.com/s/carecoalitions
Role of AAAs in State Alzheimer’s Plans

• AAAs = Advocacy, Planning, Coordination across systems
• Get involved in your state’s plan (if not already)
• If you need to start or re-boot efforts in your state, pull together a coalition of stakeholders to push for development

www.n4a.org
Who Is AFA?

• A national nonprofit organization that unites more than 1,700 member organizations (including 169 AAAs) with the goal of providing optimal care and services to individuals with Alzheimer’s disease or related dementias, and to their caregivers and families.

• 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.

• AAA’s that join AFA get their dues waived!
Alzheimer’s Disease Is at Crisis Proportions

• Sixth (or third?) leading cause of death in the U.S.
• Only disease in the top 10 to be a growth category:
  • Over 5 million individuals in the U.S.
  • Projected to almost triple to 14 million by 2050
• Only disease state in CDC’s top 10 with no cure or effective treatment
Cost of Alzheimer's Disease

- 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
  - Costs are projected to soar to $1.1 trillion (in today’s dollars) by 2050
Federal Response

• National Alzheimer’s Project Act (NAPA)
  • Enacted January 2011
  • Establishes the Advisory Council on Alzheimer’s Research, Care, and Services (Advisory Council)
  • Requires HHS, in collaboration with the Advisory Council, to create a national plan to overcome Alzheimer’s disease
• In May 2012, HHS unveiled the first ever “National Plan to Address Alzheimer’s Disease”
  • Has been updated annually
  • NAPA Website: http://aspe.hhs.gov/daltcp/napa/
Five Main Goals of Federal NAPA Plan

- Research: Prevent or Effectively Treat Alzheimer’s Disease by 2025
- Clinical Care: Enhance Care Quality and Efficiency
- Long Term Services and Supports: Expand Supports for People with Alzheimer’s Disease and Their Families
- Awareness: Enhance Public Awareness and Engagement
- Measures: Improve Data to Track Progress
Implementing Alzheimer’s Plans at the State Level

• First efforts to adopt plans to confront Alzheimer’s disease at the state level were in the 1980’s and early 1990’s
  • early efforts, with few exceptions, were mostly written, shelved and forgotten
  • spurred by new research and alarming studies that projected the prevalence of Alzheimer’s disease, a new wave of state plans started to be developed and efforts accelerated after passage of NAPA

• Currently, 43 states and the District of Columbia have, or are in the process of finalizing, state Alzheimer’s plans
  • States with no plans are: NH, MS, SD, NE, KS, WY and MT. PR also has no plan
All politics is local....
Thomas (Tip) O'Neill, former Speaker of the House

“a state may, if its citizens choose, serve as a laboratory; and try novel social and economic experiments without risk to the rest of the country.”
Louis Brandeis, U.S. Supreme Court Justice
Why Need for State Action?

• States offer a unique perspective, differing demographics and needs; marshal different resources and control a majority of the 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.
Six Takeaways for State Plans

• 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.

• Assess the ability of the state Alzheimer’s disease community to support diagnosed individuals and their families.

• Develop a state plan for Alzheimer’s disease that includes goals specific to the state population, and outlines measures to track progress.
Six Takeaways for State Plans (cont.)

• Keep stakeholders engaged in the design, implementation and evaluation of the plan.
• Recognize that state plans are “living documents,” and modify them as appropriate over time.
• Learn from the successes and challenges of other states and the National Alzheimer’s Plan.
Thank you!

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ACT on Alzheimer’s

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http://www.ACTonALZ.org
What is ACT on Alzheimer’s?

Statewide

60+ Organizations

400+ Individuals

Collaborative

Volunteer driven

Impacts of Alzheimer’s

Budgetary

Social

Personal
Collaborative Goals/Common Agenda

5 shared goals with a Health Equity perspective
Identify and Invest in Promising Approaches

- Economic model to identify care approaches that slow costs
- Initially use model to estimate savings for in-person caregiver support
- Results reflected in *Health Affairs* and subsequent Net Savings analysis

Identify/Invest

[www.actonalz.org/economic-impact](http://www.actonalz.org/economic-impact)
Increase Detection and Improve Care

- Develop and disseminate Practice Tools that support providers in detecting, treating and managing dementia
- Develop interdisciplinary dementia curriculum that embeds tools

www.actonalz.org/improve-care
Provider Practice Tools
Provider Tools

DEMENTIA CURRICULUM

People living with Alzheimer’s disease and related dementias, along with their caregivers, turn to trusted professionals to understand the condition and the challenges they may face. Get prepared for these conversations by exploring the Dementia Curriculum offered by ACT on Alzheimer’s.

Developed by leading experts in Minnesota, the 10-module curriculum can stand on its own or be integrated into complementary education offerings. Educators, practicing professionals, and students across multiple disciplines will benefit from advancing their knowledge of dementia.

The Dementia Curriculum is available free of charge at: www.ACTonALZ.org

Topics of the 10 modules and their learning objectives follow.

Disease Description
- Gain understanding of normal aging and cognitive functioning.
- List potential causes of dementia and memory loss.
- Identify the impact that Alzheimer’s disease and other dementias have on the human brain and its function.
- Demonstrate knowledge of Alzheimer’s disease, including stages and categories, symptoms, diagnosis, risk factors and disease duration.

Demographics
- Identify the demographics of people affected by Alzheimer’s disease.
- Gain insight of the anticipated increase and impact of Alzheimer’s disease in the future.

Societal Impact
- Identify challenges that families and caregivers experience when caring for someone who has dementia.
- Gain insight into the costs, risks and stressors that affect families and caregivers.

Effective Interactions
- Understand the principle of person-centered care and the importance of recognizing a person as a unique individual.
- Articulate verbal and non-verbal communication that people with cognitive impairment may display.
- Reframe what is traditionally defined as behavior to expressions of needs, distress and distress, and understand how these expressions are manifested in specific behaviors.

Cognitive Assessment and Early Detection
- Identify tips for detecting cognitive impairment and using observation as an assessment tool.
- List and describe a variety of cognitive tools for conducting assessments and demonstrate an understanding of the recommended course of action when cognitive impairment is identified.

COMMUNITY BASED ORGANIZATIONS

Supporting Clients with Memory Concerns

When client has diagnosis:
- Other care consultation or refer to the Alzheimer’s Association Minnesota North Dakota or Senior LinkLine Live® for care consultation.
- Provide education about diagnosis and disease process.

When client has memory concerns, but no diagnostic:
- Conduct screening (see Flow Chart).
- Encourage client to make appointment with primary care physicians for memory loss work up.

Identify client’s needs using organization’s assessment tool.

Provide or arrange services based on client’s needs, diagnosis and stage of disease (if known).

Counselling and Support
- Individual and family counseling.
- Support groups for person with disease.

Medication Therapy and Management
- Refer to health care provider to create a medication management plan.
- Refer to pharmacist for medication review and to simplify medication regimen.
- Educate client and care partner on medication management side effects (allergies, dispersions, alarms).

Care Partner Education and Support (if client has a care partner)
- Support groups, respite care, caregiver education and training programs, and caregiver coaching services.
- Provide information on maintaining health and well-being (visit www.alz.org/care).
- Provide education on behaviors and stigmas (visit www.alz.org/care).

Health, Wellness and Engagement
- Engagement programs (Call Alzheimer’s Association Minnesota North Dakota 24/7 Helpline 1-800-272-3900).
- Adult day care and Exercise and healthy eating programs.

Home and Personal Safety
- Referral to an occupational therapist and/or physical therapist to address fall risk, sensory/mobility aids and home modifications.
- Refer to occupational therapy for driving evaluation (http://www.mn.gov/driver_education/default.aspx).

Legal Planning
- Refer to an estate law attorney.
- Encourage client to assign durable power of attorney and healthcare power of attorney.

Advance Care Planning
- Link to an expert by calling Senior LinkLine Live®, A One Stop Shop for Minnesota Seniors at 1-800-333-2483 or visit www.Minnesotasafetyline.org to locate and arrange for support, such as indoor and outdoor alarm services, home-delivered meals, transportation and assistance with paying for prescription drugs.

Determine timeframe for follow-up and plan for communication.
Audiences for Provider Practice Tools

- Primary care providers
- Care coordinators
- Community-based organizations
- Persons with AD; care partners
- Direct care service staff trainers
- Mid-Late stage providers
- Professional school faculty
- Electronic record providers

www.actonalz.org/provider-practice-tools
• Dementia-capable Senior LinkAge Line® staff and caregiver coaches
• After a Diagnosis Tool
Equip Communities and Raise Awareness

- Develop a Community Toolkit to foster dementia-friendly communities
- Support community implementation of the toolkit

www.actonalz.org/toolkit
Dementia-Friendly Community

All sectors are informed, safe and respectful and foster quality of life.
Foundation for Community Toolkit

Informed by research regarding stages of community readiness and engagement

- Initiate mobilization
- Establish organizational structure
- Build capacity for action
- Plan for action
- Implement
- Refine
- Institutionalize
1. **Convene** key community leaders and members to form an Action Team.
2. **Assess** current strengths and gaps within the community.
3. **Analyze** findings to understand your community’s needs and develop a plan to take action.
4. **ACT Together** to pursue priority goals that foster community readiness for dementia.
Convene Phase: Build Action Team

- People with Dementia
- Action Team
- Family Caregivers
- Employers/Human Resources
- Community Members
- Caregiver Support Providers
- Social Service Agencies
- Transportation Providers
- Legal & Financial Planning
- Health Care Community
- Local Government
- Residential Settings
- Adult Day Programs

Diverse & underserved populations
- Local businesses and retail
- Faith communities
- Educational institutions
- Service clubs
- Youth groups

Wellness programs (nutrition, physical activity)
Engagement activities (creative arts, group programs)
Community-based services (chores, meal delivery, home safety)
Assess Phase: Actions Needed

- Define your community
- Determine who to survey and who will survey
- Target sectors
- Include diverse populations

Sectors:
- Adult day
- Caregiver support providers
- Employers/businesses
- Health providers
- Legal and financial planners
- Local government
- Residential settings
- Social service agencies
- Transportation
- Faith communities
Analyze Phase: Planning for Action

Look for High Priority, Low Activity areas of need
ACT Together Phase: Prioritize, Plan and Implement

Action communities are:

- Creating dementia-friendly businesses
- Training Dementia Friends
- Training health care providers on ACT tools
- Training local emergency responders
- Creating memory cafés
- Developing Rabbi training
- Hosting a caregiver conference
- Training teens in a faith community
- Training government staff on how to identify individuals with dementia and communicate effectively
Communities ACTing on Alzheimer’s

32 Action Communities

7 COUNTY METRO AREA:

Centro
CLUES
Edina
Forest Lake
MN Council of Churches
North Minneapolis
Roseville
St. Louis Park
St. Paul African American Faith Community
St. Paul Neighborhoods
St. Paul North East Neighborhoods
Stillwater Area
Twin Cities Jewish Community
Collaborative Learnings

• No one owner
• Consistent project support, coordination and communications
• Collective impact structure
• Transparency and inclusiveness
• Diverse participants and funders
• Reporting progress to foster engagement
Contact Us

Learn more at [www.ACTonALZ.org](http://www.ACTonALZ.org)

Questions? Email [info@ACTonALZ.org](mailto:info@ACTonALZ.org)
For more information, visit:

www.caregiving.org/advocacy/napaplan

www.alzfdn.org

www.n4a.org

www.actonalz.org