Equipping and Engaging Communities to Address the Impacts of Alzheimer's

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What is ACT on Alzheimer's?

statewide

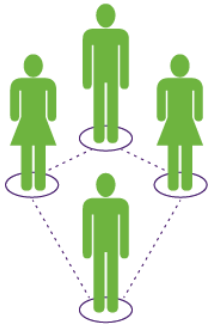
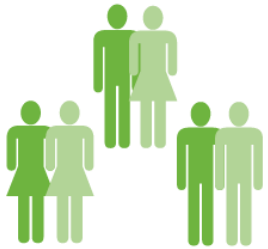
60+
ORGANIZATIONS

500+
INDIVIDUALS

volunteer driven

collaborative

IMPACTS OF ALZHEIMER'S

BUDGETARY	SOCIAL	PERSONAL
		

Genesis of ACT on Alzheimer's

- 2009 Legislative Mandate for Alzheimer's Disease Working Group (ADWG)
- Legislative Report Filed in January 2011
- ACT on Alzheimer's is second generation of work focusing on implementation

Collaborative Structure

45+ LEADERSHIP COUNCIL

Advisors • Strategists • Champions

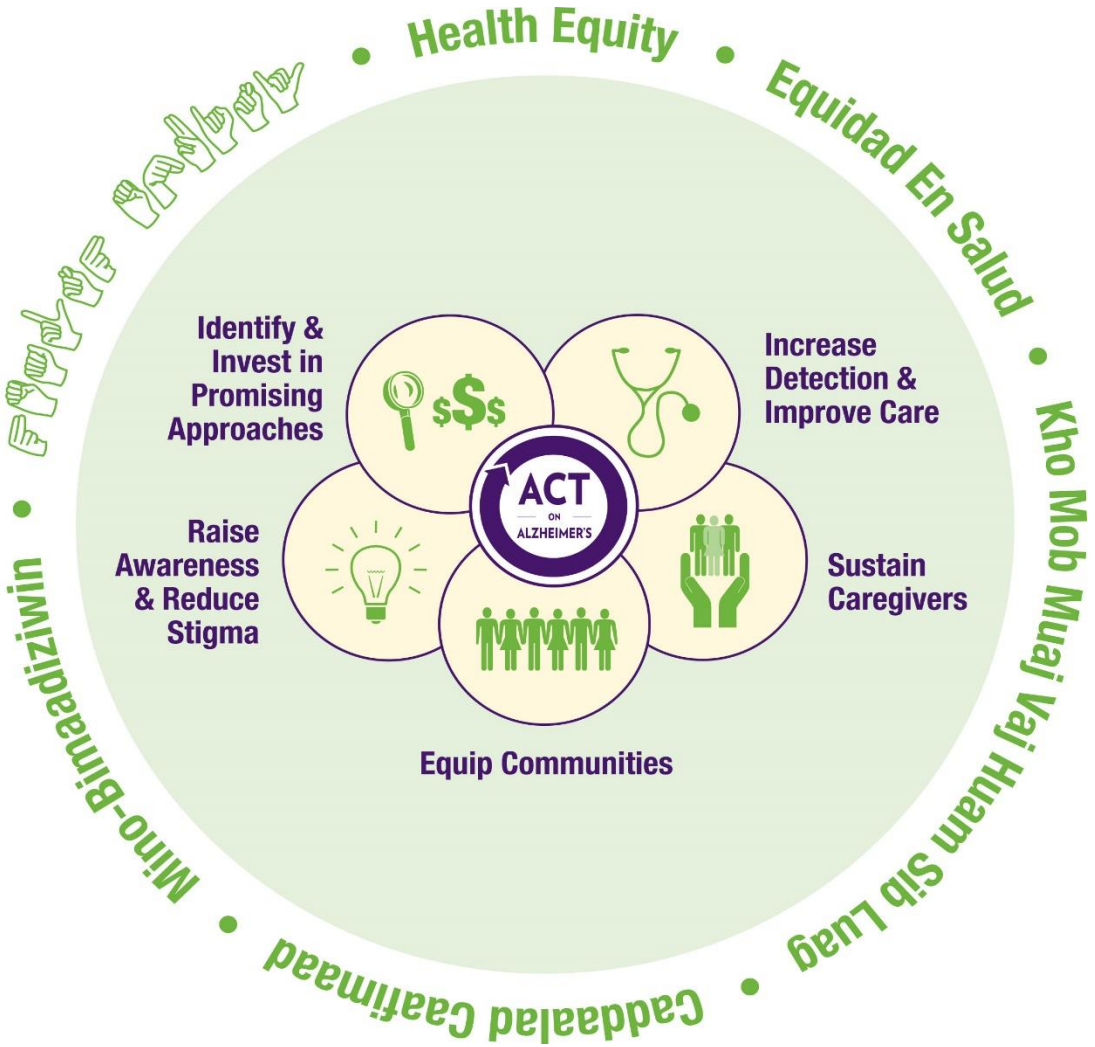
10+ MANAGEMENT STEERING COMMITTEE

Organizations actively involved in day-to-day operations

500+ OPERATIONS

- *Executive Lead*
- *Project Director*
- *Project Manager*
- *Five Leadership Groups*
- *Fiscal Sponsor*
- *Action Teams*

Collaborative Goals/Common Agenda



5 shared goals with a Health Equity perspective

Identify and Invest in Promising Approaches

Identify/Invest

- 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

http://www.actonalz.org/economic-impact

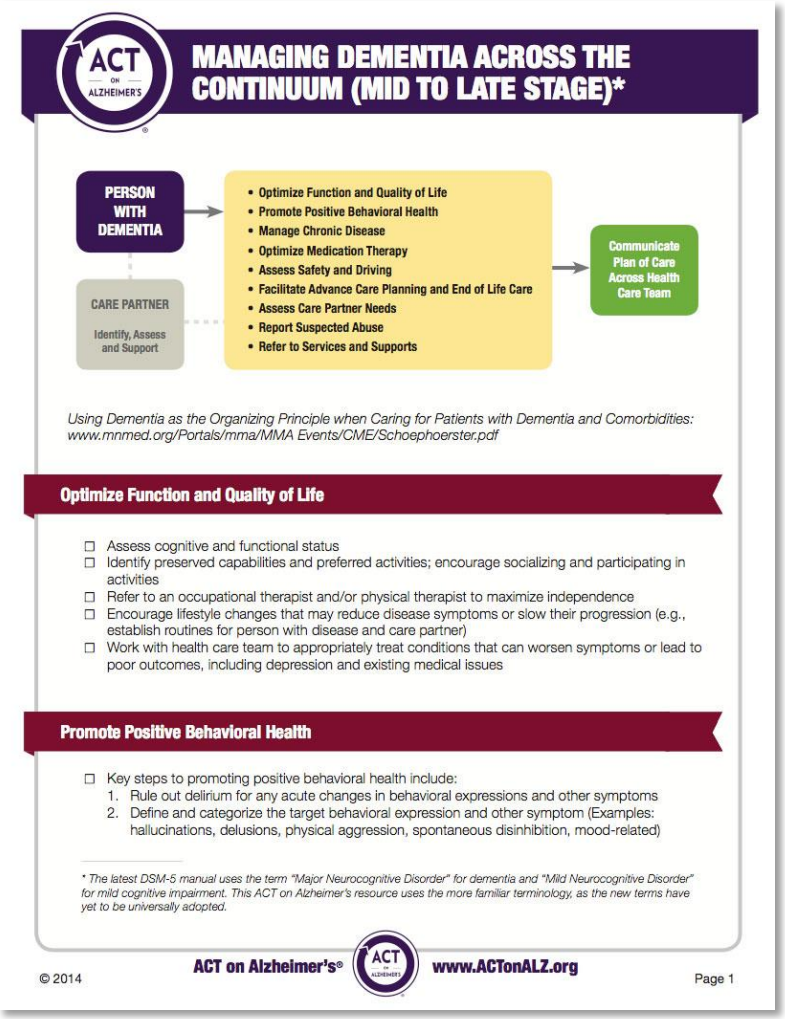
Increase Detection and Improve Care

Detection/Care

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

http://www.actonalz.org/improve-care

Provider Practice Tools



MANAGING DEMENTIA ACROSS THE CONTINUUM (MID TO LATE STAGE)*

PERSON WITH DEMENTIA

- Optimize Function and Quality of Life
- Promote Positive Behavioral Health
- Manage Chronic Disease
- Optimize Medication Therapy
- Assess Safety and Driving
- Facilitate Advance Care Planning and End of Life Care
- Assess Care Partner Needs
- Report Suspected Abuse
- Refer to Services and Supports

CARE PARTNER

Identify, Assess and Support

Communicate Plan of Care Across Health Care Team

Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities: www.mnmed.org/Portals/mma/MMA Events/CME/Schoephoerster.pdf

Optimize Function and Quality of Life

- ☐ Assess cognitive and functional status
- ☐ Identify preserved capabilities and preferred activities; encourage socializing and participating in activities
- ☐ Refer to an occupational therapist and/or physical therapist to maximize independence
- ☐ Encourage lifestyle changes that may reduce disease symptoms or slow their progression (e.g., establish routines for person with disease and care partner)
- ☐ Work with health care team to appropriately treat conditions that can worsen symptoms or lead to poor outcomes, including depression and existing medical issues

Promote Positive Behavioral Health

- ☐ Key steps to promoting positive behavioral health include:
  1. Rule out delirium for any acute changes in behavioral expressions and other symptoms
  2. Define and categorize the target behavioral expression and other symptom (Examples: hallucinations, delusions, physical aggression, spontaneous disinhibition, mood-related)

** The latest DSM-5 manual uses the term "Major Neurocognitive Disorder" for dementia and "Mild Neurocognitive Disorder" for mild cognitive impairment. This ACT on Alzheimer's resource uses the more familiar terminology, as the new terms have yet to be universally adopted.*

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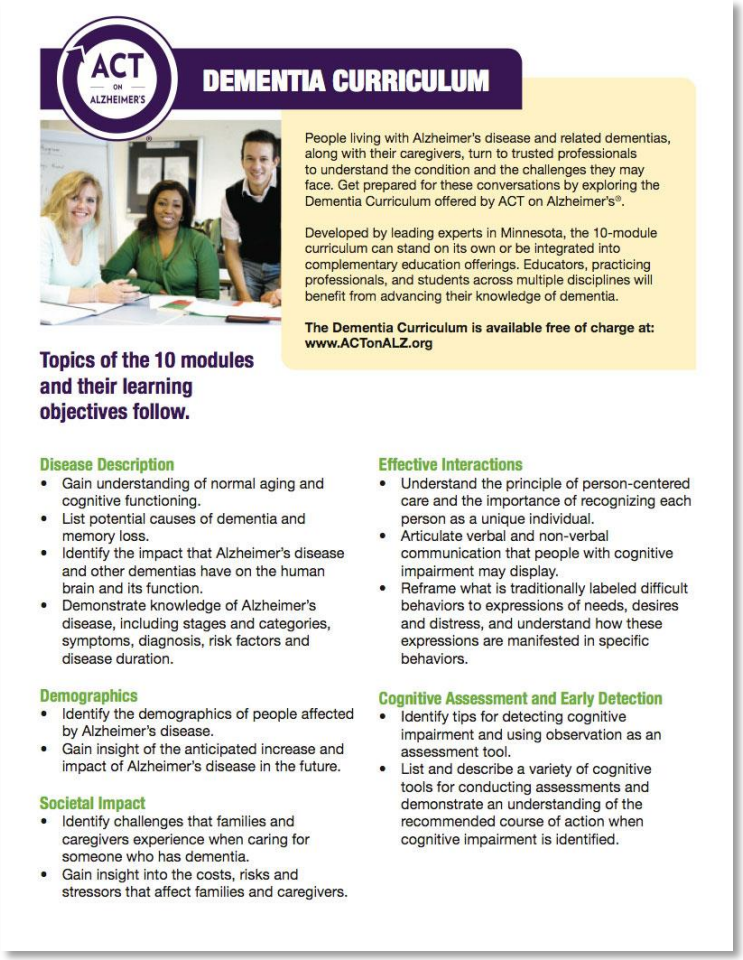
Tools for multiple audiences , including:

- Primary care
- Care coordination
- Community based organizations
- Full disease spectrum
- EMR decision support

http://www.actonalz.org/provider-practice-tools

Dementia Curriculum



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 each person as a unique individual.
- Articulate verbal and non-verbal communication that people with cognitive impairment may display.
- Reframe what is traditionally labeled difficult behaviors to expressions of needs, desires 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.

- Interdisciplinary dementia curriculum that embeds practice tools
- Curriculum is the foundation of national uniform dementia curriculum

Sustain Caregivers

Sustain Caregivers

- Enhancements to website, http://MinnesotaHelp.info®
- Dementia-capable Senior LinkAge Line® staff and caregiver coaches
- *After a Diagnosis* Tool

Equip Communities and Raise Awareness

Equip Communities

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

http://www.actonalz.org/toolkit

Dementia-Friendly Community

All sectors are informed, safe and respectful and foster quality of life

Sector-Specific Support Resources

DEMENTIA-FRIENDLY FAITH COMMUNITY

Faith communities play a vital role in offering safe, supportive, and welcoming environments for people with dementia, including opportunities for meaningful engagement and spirituality.

Congregants or visitors with Alzheimer's or other dementias should be welcomed and acknowledged, gently supported when experiencing difficulties, invited to spiritual activities and programs, and offered a volunteer companion when extra support is needed.

Establish dementia-friendly goals for ordained and lay clergy and staff

- Get training/education on recognizing the signs of dementia
- Learn and use dementia-friendly communication skills
- Know the local services available to help people with dementia and their caregivers

Support and empower the person with Alzheimer's

- Offer short devotions or inspirational stories that last no longer than five minutes
- Be attuned and flexible to the way the person talks about his or her spirituality
- Plan short, frequent home visits rather than lengthy ones
- Encourage the person to take part in services and social events appropriate to his or her abilities
- Help provide worship services at the family's home or bring them an audio or videotape when attending in person becomes difficult

Support and empower the person's caregiver

- Recognize the signs of caregiver stress; direct the caregiver/family to appropriate resources
- Help provide worship services or rituals in the caregiver's home or provide tapes, DVDs, and links to service on-line when the caregiver role affects attending in person
- Prompt the caregiver to use respite care for a break from daily responsibilities
- Form a caregiver support group

Create a dementia-friendly environment

- Provide a quiet room where the family or caregiver can take a person who may get anxious during the service
- Have a safe and accessible facility for the person with Alzheimer's by taking measures such as:
  - Well-lit hallways
  - Pictures and signs that easily identify restrooms

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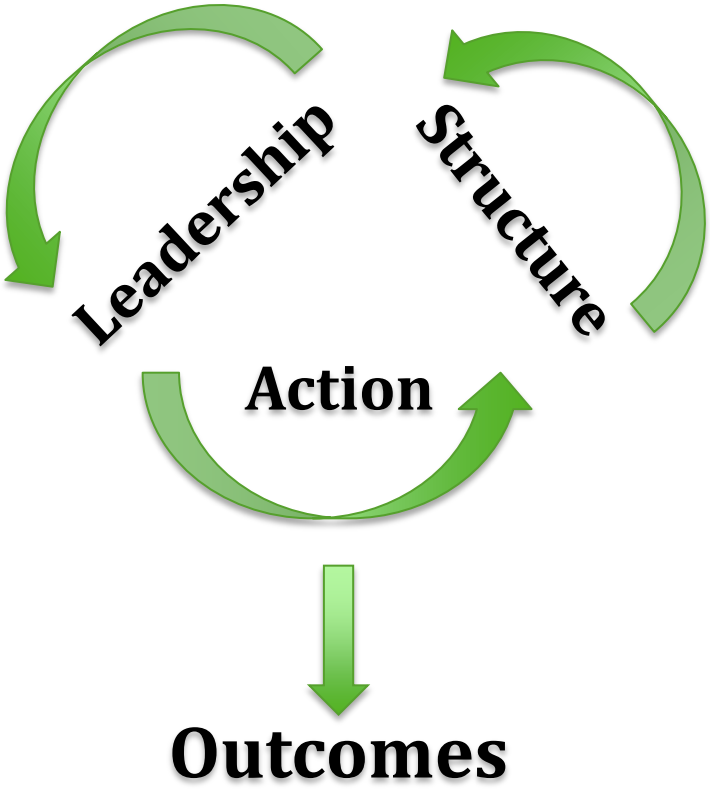
ACT on Alzheimer's® www.ACTonALZ.org

Dementia-friendly action steps for:

- Businesses
- Community-based supports
- Faith communities
- Health care community
- Legal and financial services
- Local government
- Residential settings

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

Four-Phase Toolkit Process

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

- 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

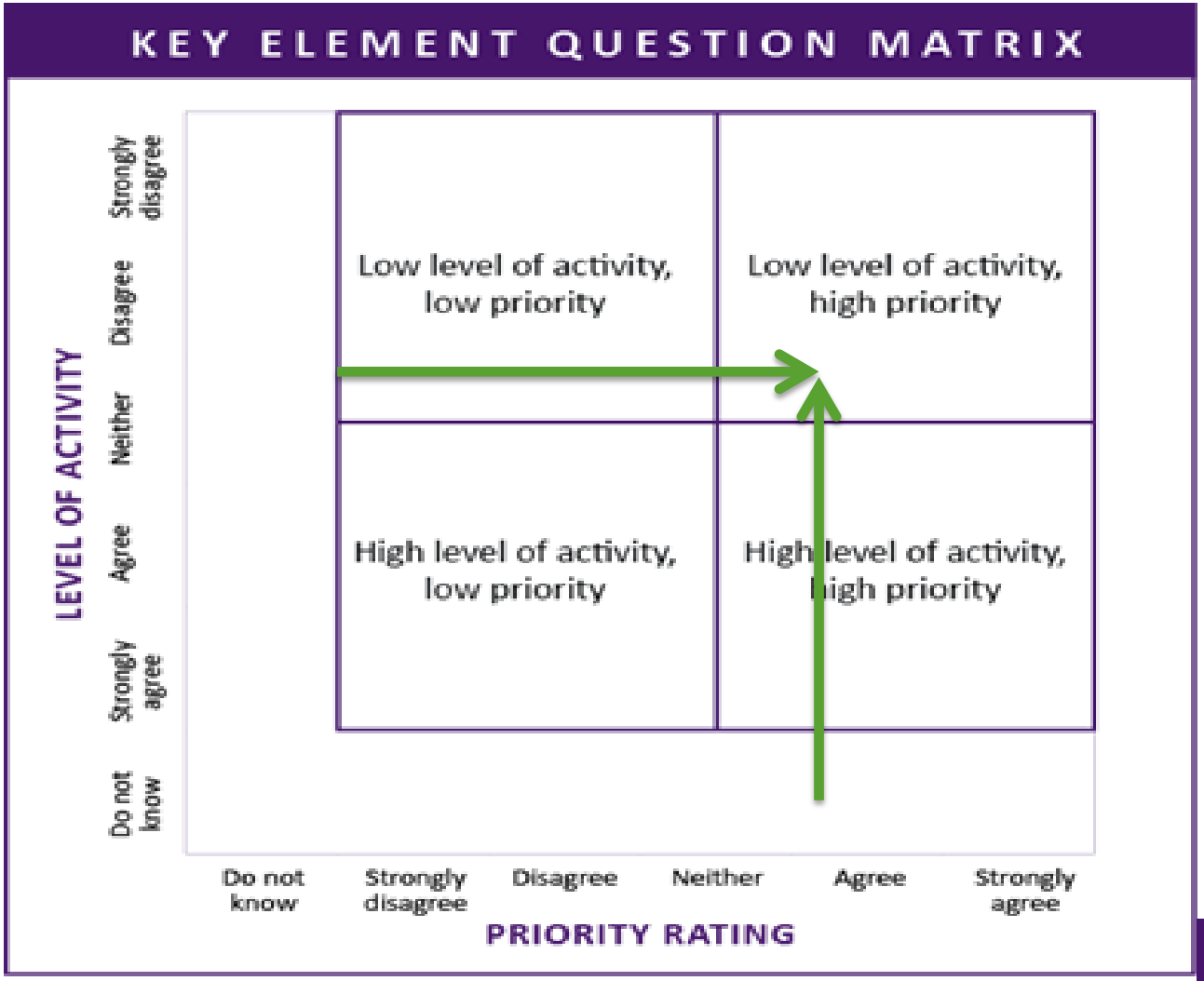
Sectors:

- 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

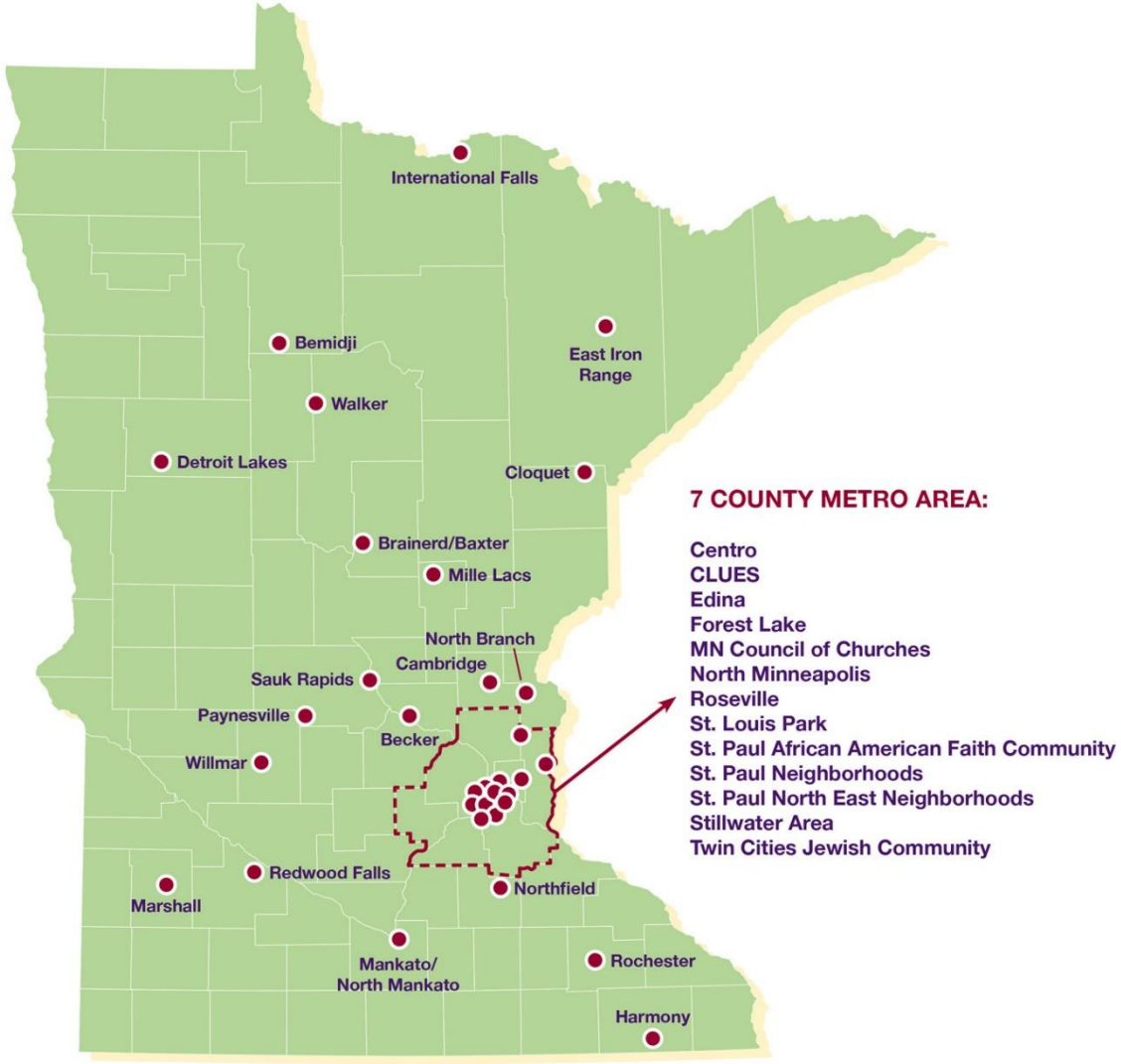


ACT Together Phase: Prioritize, Plan and Implement

Action communities are:

- Creating dementia-friendly businesses
- Training Dementia Friends
- Training health care providers on ACT tools
- Training local emergency responders
- Creating memory cafés
- Increasing awareness
- Developing Rabbi training
- Hosting a caregiver conference
- Training teens within the Jewish community
- Training government on planning and response

Communities ACTing on Alzheimer's



33 Action Communities

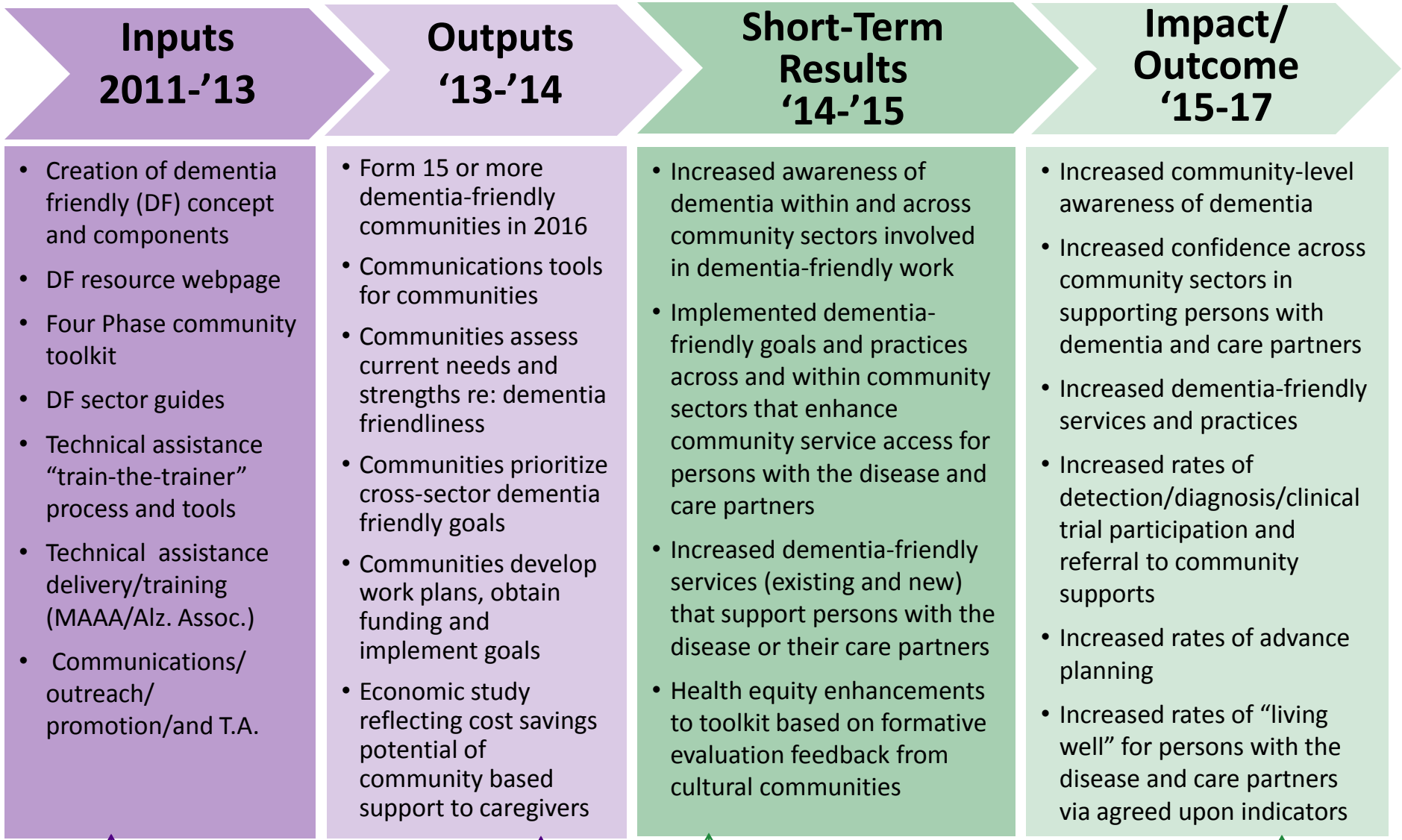
Technical Assistance

- Area Agencies on Aging
- Alzheimer's Association

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.

IMPACT MODEL: DEMENTIA CAPABILITY-COMMUNITIES



Source: Paone and Associates // Adapted from: Mary Davis, DrPH, MSPH, The North Carolina Institute for Public Health, University of North Carolina, Chapel Hill

IMPACT MODEL: DEMENTIA CAPABILITY-PROVIDERS

Inputs 2011-'13

- Convene community expert team re: dementia care
- Synthesize best practice and evidence-based dementia care
- Develop evidence and consensus-based community standard of care for dementia detection, diagnosis and care/support
- Articulate standards in dementia care algorithm (road map)
- Convene inter-professional peer review team to develop curriculum

Outputs '13-'14

- Provider tools reflecting dementia care best practices
- Electronic Medical Record Decision support tool for embedding tools in EMRs
- Inter-professional curriculum reflecting theory and tools (now foundation for national curriculum)
- Training program, videos and speakers bureau to disseminate tools
- Economic study reflecting cost savings of community based caregiver support

Short-Term Results '14-'15

- Enhancement of tools to include cultural competency resources
- Health leadership summit to foster statewide tool dissemination
- Training sessions delivering tools
- Adoption of and training on tools in health systems, clinics, HCHs, including training on support of care partners
- Baselines set for use of optimal dementia practices before training
- Initial adoption and practice changes based on early training on tools

Impact/ Outcome '15-17

- Increased use of optimal dementia practices by health systems and clinics in MN in comparison with baseline, including support of care partners
- Increased detection rates for providers using tools/including in cultural communities
- Reduction in medical crises, unnecessary admissions and re-admissions of PwDs of providers using optimal practices
- Improved satisfaction of PwDs receiving optimal care, including care partners

Process/Implementation

Outcome/Effectiveness

Source: Paone and Associates // Adapted from: Mary Davis, DrPH, MSPH, The North Carolina Institute for Public Health, University of North Carolina, Chapel Hill

Contact Us

Learn more at http:/www.ACTonALZ.org

Questions? Email info@ACTonALZ.org