



Living Well with Dementia

**HCBS Conference
September 16, 2014**

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AARP Policy, Strategy, and International Affairs**



3 Things You Know, But Need to Remember

- 1. Our Population is Aging.**
- 2. Risk of Dementia greatly increases
With Age**
- 3. We CAN take steps to help people
living with dementia and their
caregivers have much better lives.**

We're entering a time of
profound and permanent change
to the demographic composition of the United States



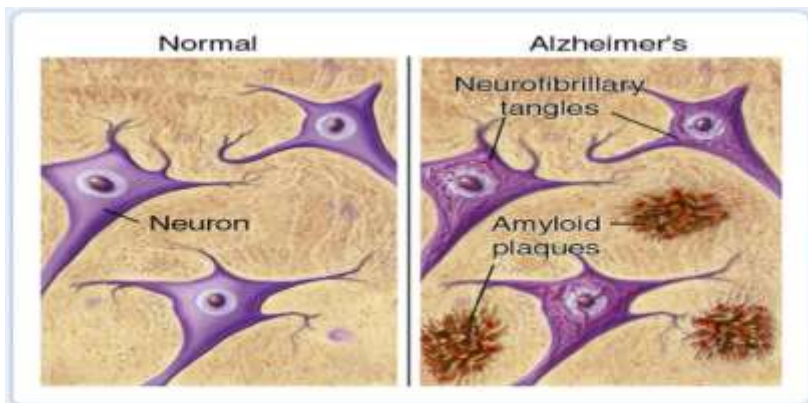
Every **day**, 10,000
boomers turn 65



By 2030 the U.S. will have **twice as many people over the age of 65** as we have today

Dementia Overview

- **Dementia is an umbrella term used to describe a collection of general symptoms**
 - Decline in memory, thinking skills, and ability to perform everyday tasks
- **3 common Types of Dementia**
 - Alzheimer's Disease, Vascular Dementia, Dementia w/ Lewy Body



Greatest Risk Factor for Dementia

- increasing age, followed by family history**
- incidence of AD approximately doubles every 5 years after the age of 65**
- Approximately 50% of individuals 85+ have some form of dementia**

Because we expect our 65 plus population to double by 2050, so to will the incidence of people living with dementia.

Estimates of Dementia Prevalence

- **An estimated 5.2 Million older adults in the United States will have dementia**
- **Total national annual cost of caring for people with dementia will reach \$214 billion in 2014**
- **Projected to reach \$1.2 trillion in 2050.**

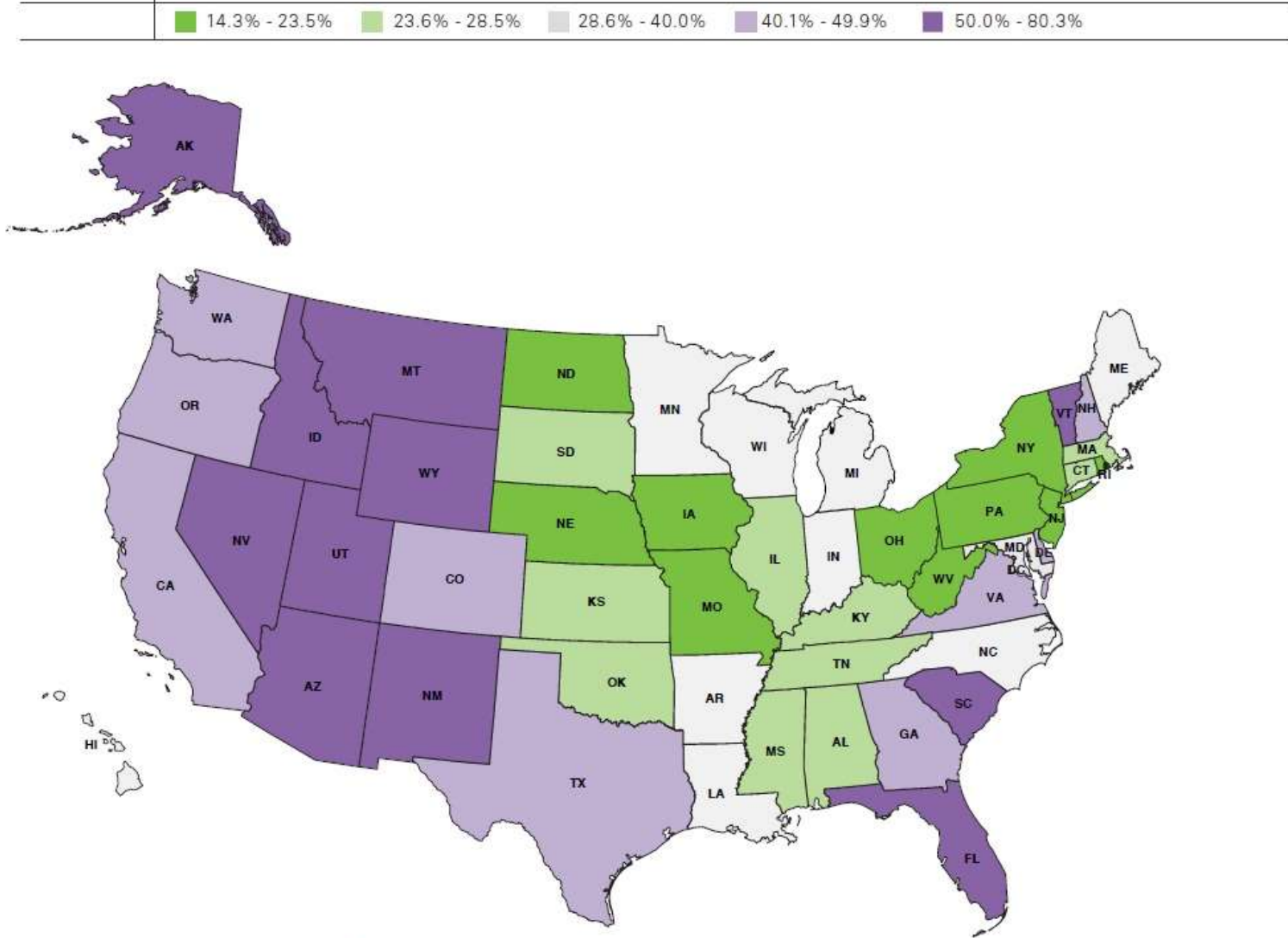
- ❑ **1 in 9 older Americans has Alzheimer's disease.**
- ❑ **African-Americans are about *twice* as likely as whites to have dementia**
- ❑ **Hispanics are *1.5* times as likely**
- ❑ **In 2013, Americans provided 17.7 billion hours of unpaid care to people living with dementia.**

Urgency to Act

- **1990: 4%**
- **2014: 13%**
- **2030: 20%**

figure 4

Projected Changes Between 2014 and 2025 in Alzheimer's Disease Prevalence by State



Change from 2014 to 2025 for Washington, D.C.: -2.2%

Created from unpublished data provided to the Alzheimer's Association by Hebert et al.^{A10}

Action to make Living Well with Dementia more Possible

- Federal
- State
- International



National Plan to Address Alzheimer's Disease


Dementia Capability: the Basics

Jane Tilly, DrPH
September, 2014





Overview

- Impact of dementia, including Alzheimer's Disease (AD)
 - National Plan to Address Alzheimer's Disease
 - Dementia-capability
 - ACL and Other Resources
- 

Dementia in the community

- 15% of older adults in community with one daily activity limitation have cognitive disability
- 24% of people who receive Medicare or Medicaid home health have moderate to severe cognitive disability
- People with dementia use 3 times as many health services and more intense LTSS
- 17% of those with severe dementia live alone
- 59% of National Family Caregiver Support Program participants care for someone with Alzheimer's disease, dementia, or other memory-related illness

National Alzheimer's Project Act of 2011

Requires the Secretary of HHS to develop and maintain a National Alzheimer's Plan designed to

1. Prevent and effectively treat Alzheimer's disease by 2025
2. Optimize care quality and efficiency
3. Expand supports for people with Alzheimer's disease and their families
4. Enhance public awareness and engagement
5. Track progress and drive improvement

Model dementia-capable systems are able to help those with dementia by:

- Educating the public about brain health and participating in research
- Identifying people with possible dementia and referring for diagnosis
- Ensuring that program eligibility and resource allocation account for cognitive disabilities
- Ensuring services are person and family-centered and culturally appropriate
- Educating workers to identify possible dementia, understand its symptoms, and provide appropriate services
- Implementing quality assurance systems that measure dementia service impact
- Encouraging development of dementia-friendly communities

Educate the public

- Risk factors associated with developing dementia - http://www.acl.gov/Get_Help/BrainHealth/Index.aspx
- First signs of cognitive problems- <http://www.nia.nih.gov/alzheimers> and National Alzheimer's Call Center at 1-800-272-3900
- Evidence-based management of symptoms - http://aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx.
- Opportunities to participate in research - <http://www.nia.nih.gov/alzheimers/clinical-trials> or www.alz.org/trialmatch.

Identify people with possible dementia

- Use assessment and staff training to identify possible impairment
- Explore the ACL-sponsored assessment of cognitive screening tools that non-medical staff can use at http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=33535
- Recommend that those with impairment get a diagnosis and rule out reversible causes of dementia or conditions that resemble it

Ensure appropriate eligibility and resource allocation

- Recognize prompting and supervision in eligibility criteria for LTSS programs
- Recognize that people with dementia use more and different services
- Service preference may vary and involve respite for caregivers

Provide person/family-centered services

- Identify person's abilities, preferences, needs and desired outcomes
- Staff and family caregivers help the person with dementia manage services
- Offer self-direction opportunities
- Recognize role of family caregivers – education and training, respite
- Cultural appropriateness – *Serving Diverse Communities: A Self-Assessment of Alzheimer's Disease Services Provided by the Aging Network and Its Partners* at www.adrc-tae.acl.gov/tiki-download_file.php?fileId=33539
- Secretary of HHS' guidance on person-centered planning and self-direction: <http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf>

Educate workers


- Identify possible dementia
- Understand symptoms of dementia
- Deliver appropriate services
- Toolkit with links to trainings, knowledge tests, staff competencies, and information on state dementia training policies at:
http://aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/docs/Staff-Training-Toolkit_September_2013.pdf

Assure quality

- Assess dementia-capability of the system
- Measure the experience of people with dementia
- CQI with feedback
- ACL grantees can track their progress in improving dementia-capability -
[http://aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/docs/Learning Collaborative Quality Assurance Tool-FINAL.pdf](http://aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/docs/Learning_Collaborative_Quality_Assurance_Tool-FINAL.pdf)

Dementia-friendly communities

- These communities learn about dementia and interact effectively with people with dementia and their caregivers as they go about their daily lives:
 - Understand dementia
 - Improve customer service
 - Encourage participation in spiritual life and faith communities
 - Accommodate their needs in transportation and emergency services
- The leading organization promoting dementia-friendly communities is Minnesota's *ACT on Alzheimer's*. www.ACTonALZ.org has tools that help explore building dementia-friendly communities



What is your first step toward dementia-capable health and LTSS or dementia-friendly communities?

Can you commit to implementing this step when you get home?

Contact: jane.tilly@acl.hhs.gov



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

Olivia Mastry, Executive Lead

<http://www.ACTonALZ.org>

What is ACT on Alzheimer's?



statewide

60+
ORGANIZATIONS

500+
INDIVIDUALS

volunteer driven

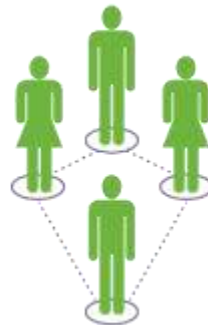
collaborative

IMPACTS OF ALZHEIMER'S

BUDGETARY



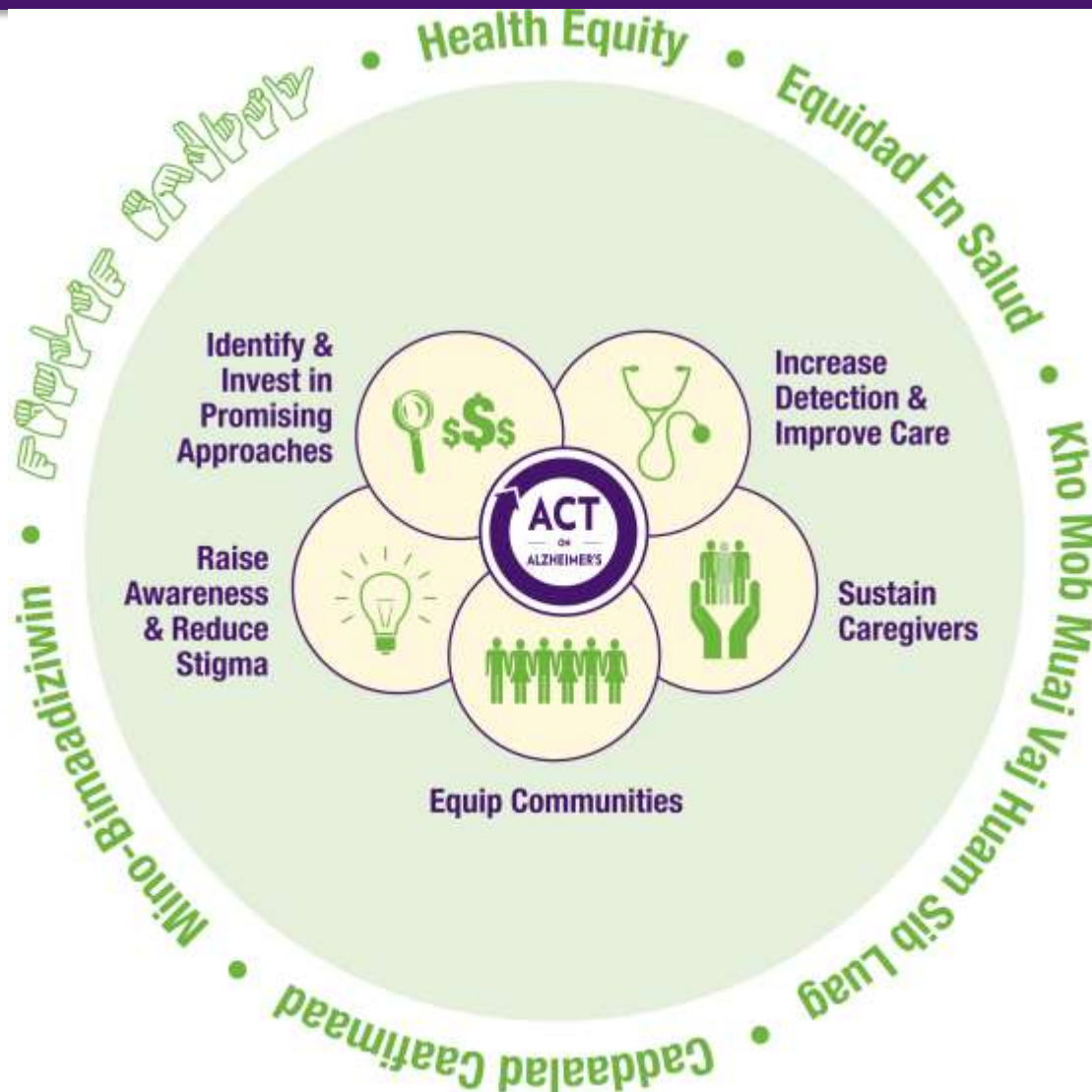
SOCIAL



PERSONAL



Collaborative Goals/Common Agenda



5 shared goals with a Health Equity perspective

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



Early diagnosis and quality care and support

Specialized memory loss services

Dementia-aware and responsive client services

Welcoming and supportive spiritual environment

Dementia-aware and responsive customer service

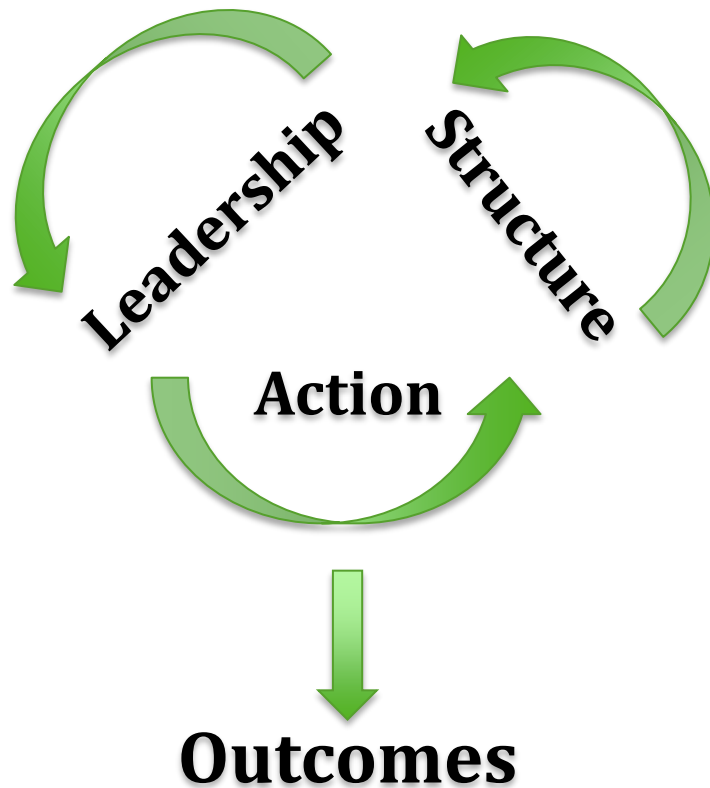
Suitable transportation and public spaces

Emergency preparedness and response

Independent living and quality of life support

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

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



Assess Phase: Actions Needed



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

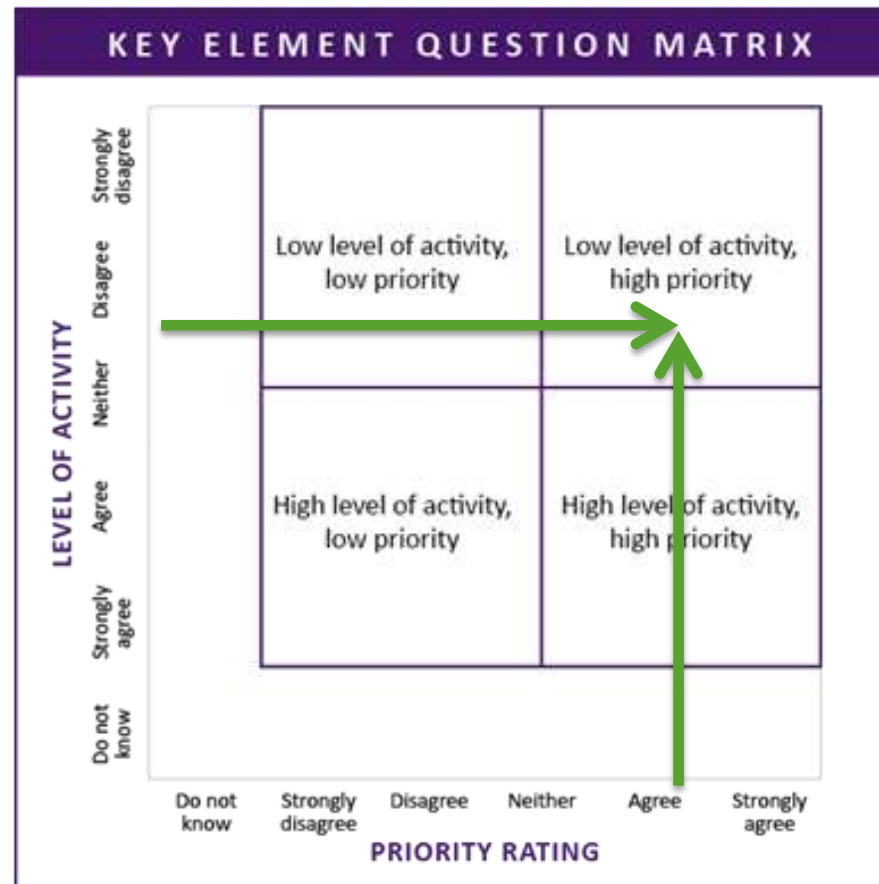
Sectors:

- 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



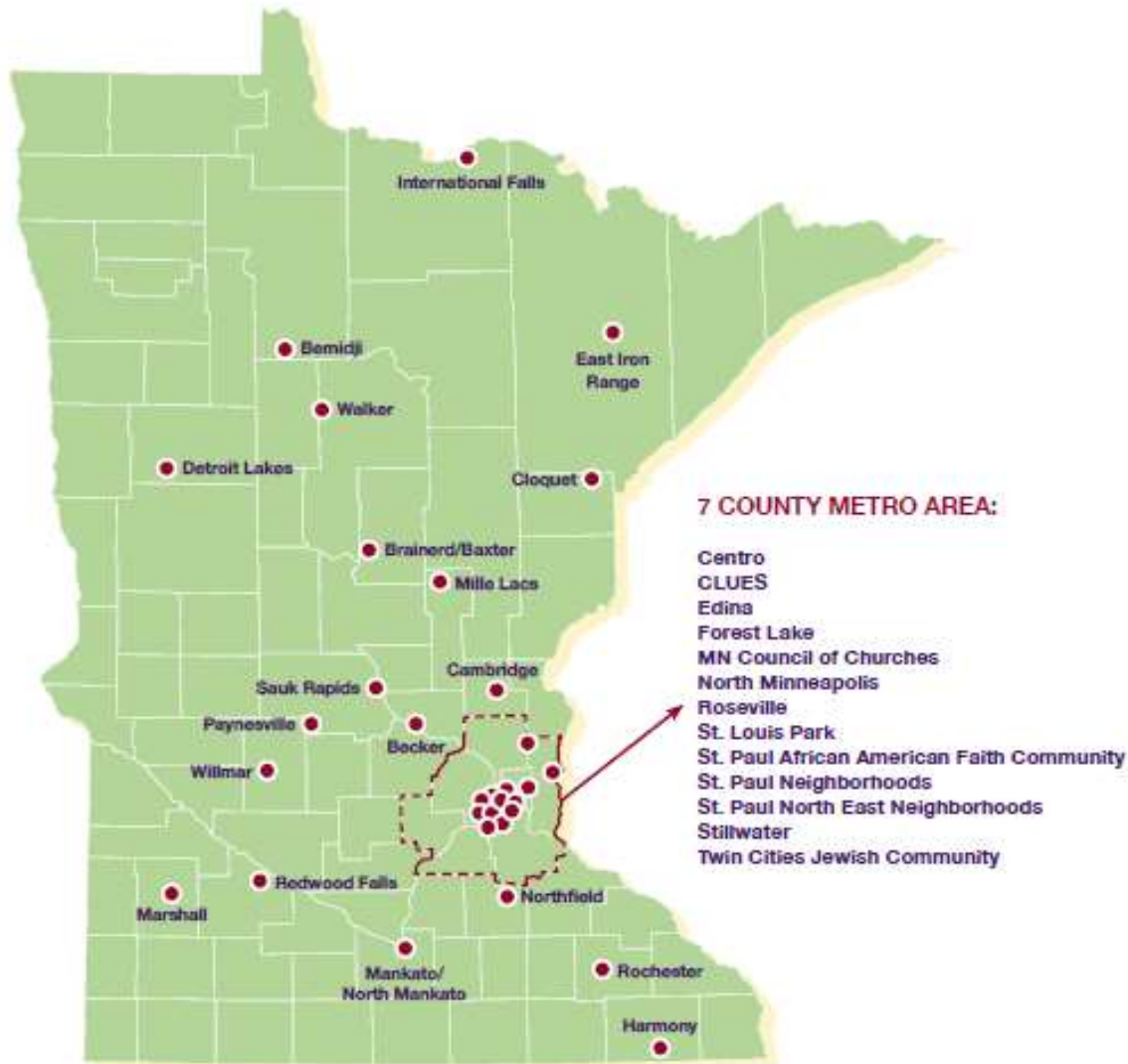
ACT Together Phase: Prioritize, Plan and Implement



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



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
- 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 <http://www.ACTonALZ.org>

Questions? Email info@ACTonALZ.org



Increase Detection Of Alzheimer's Disease And Improve Ongoing Care And Support

September 16, 2014

Donna Walberg, Dementia Capability Project Mgr

ACL Integrated Systems Grant



- Three year grant from the U.S. Administration for Community Living (ACL)
- Two components to the grant:
 - Integrated Systems Development
 - Partnerships with Health Care Homes (medical homes)
 - Dementia Service Capability Development
- Engagement with ACT on Alzheimer's Collaborative

Creating a Dementia Capable State



Senior LinkAge Line[®] and MinnesotaHelp.info[®]

- Enhancements to MinnesotaHelp.info[®]
- Dementia capable Senior LinkAge Line[®] staff
 - 5 hour online training series
 - 5 infomercial refreshers
- Results
 - Increased identification of caregivers and people with memory issues.
 - Increased connections to Alzheimer's Association and Dementia Capable Caregiver Consultants

Creating a Dementia Capable State



Dementia Capable Caregiver Consultation

- 104 Dementia Capable Caregiver Consultants
- Certificate Training Program
 - 2 day – 14 hours – in person
 - Core components: diagnostic guidelines, screening/assessment, co-morbidities, family issues, role play and practice sessions
 - Quarterly 90 minute Deep Dive Dementia Refreshers
- Revation Link Live – 3 way live connections
- Increase in knowledge, skills and confidence

Minnesota Health Care Reform



- 2008 Health Care Reform
 - State Certification for Health Care Homes
 - Quality, Cost and Payment Reform
- 2011 CMS Multi-Payer Advanced Primary Care Practice Demonstration
- 2012 State legislation
 - requiring certified health care homes & hospitals to refer at risk older adults to the Senior LinkAge Line[®]
 - requiring Alzheimer’s Learning Collaborative
- 2013 Minnesota awarded 1 of 6 State Innovation Model ‘testing’ grants of \$45 million

Educational Sessions to Health Care Homes Statewide to Foster the Adoption of the ACT on Alzheimer's Practice Tools

Objectives

- Identify barriers to dementia screening and diagnosis in primary care
- Explain rationale for timely detection and diagnosis of dementia in aging patients
- Examine easy and efficient screening/diagnostic tools and practice techniques to simplify patient care
- Analyze intervention and referral strategies to maximize patient/family support
- Discuss the cognitive screening requirement for Medicare Wellness exams and how to establish a complete 'turn-key' approach to better serve the needs of the community regarding cognitive issues and dementia

Cultural Awareness in Dementia Care



ACT on Alzheimer's seeks to reduce health disparities and the impact of Alzheimer's disease and to practice inclusiveness and equity in engaging communities to build supportive, dementia-friendly environments.

ACT on Alzheimer's work across all goals and participant groups is evolving to include a health disparity/health equity focus related to dementia care and beyond.

The Minnesota Board on Aging is deepening its work to build dementia capable health care systems by offering a series of statewide educational sessions:

Tools for Your Practice When Working with American Indians

To provide information on characteristics and concepts in American Indian culture that affect the assessment, diagnosis, treatment, and support of dementia.

Objectives

- Identify aspects of tribal culture that are unique in the context of dementia
- Define tools to help guide productive conversations with patients and families
- Demonstrate ways to cope with difficult issues in the management and treatment of dementia

Sessions and Audience

- Sanford Clinic, Bemidji, Physicians, Nurses, Care Coord
- Leech Lake Reservation Elder Service Providers
- Cass Lake Indian Health Services, Physicians
- Minneapolis American Indian Center, Elder Service Providers
- Hennepin County Medical Center, Mpls, Physicians, Nurses and Care Coordinators (webinair)
- MN Dept of Human Services, St Paul, DHS staff statewide
- Minneapolis VA Medical Center, VISN 23 webinair, physicians, advanced practice professionals

Dementia Capable Health Care Home



The Minnesota Department of Human Services is funding the development of Dementia Capable Health Care Home's

- Dementia is the organizing principle of care
- Required to implement the ACT on Alzheimer's Provider Practice Tools
- Essentia Health System is completing first year
- Lakewood Health System has just been funded

Essentia Health System

Dementia Capable Health Care Home



Standardize early dementia diagnosis and care to reduce cost and improve outcomes for individuals with dementia and their families.

- Lead by Director of Primary Care
- Workgroup of stakeholders from primary and specialty care and community
- Two pilot clinics: Ely and West Duluth
- Embedded ACT on Alzheimer's Electronic Medical Records Decision Support Tools into their EMR system
<http://actonalz.org/provider-practice-tools>

Essentia Health System

Dementia Capable Health Care Home



- Mini Cog screening of all patients 65 and older
- Patients who fail are assessed using the Montreal Cognitive Assessment (MoCA) and further evaluated (dementia diagnostic work-up)
- Care Coordination including behavioral health, other specialties, medication management programs, Senior LinkAge Line[®] and the Alzheimer's Association
- Caregiver is identified and supported
- Communication feedback loop

Essentia Health System

Dementia Capable Health Care Home



Evaluation

- Business process mapping used to create training, staffing, and workflow models
- An outside evaluator will examine effectiveness of the models, clinical/patient outcomes and community connections
- The cost effectiveness of engaging community providers in joint care coordination will be a key finding
- Upon pilot completion Essentia will implement system wide

- MN Board on Aging Memory Care
 - http://www.mnlivewellathome.org/Know-the-Risks/Memory_Concerns.aspx
- ACT on Alzheimer's
 - <http://www.actonalz.org/>
 - Professionals – Practice Tools



Living Well with Dementia: Georgia Initiatives

Presenter: Cliff Burt, MPA
Caregiver Specialist
Georgia Division of Aging Services

Date: September 16, 2014
NASUAD Conference



Georgia Department of Human Services

Vision, Mission and Core Values

Vision

Stronger Families for a Stronger Georgia.

Mission

Strengthen Georgia by providing Individuals and Families access to services that promote self-sufficiency, independence, and protect Georgia's vulnerable children and adults.

Core Values

- **Provide access to resources that offer support and empower Georgians and their families.**
- **Deliver services professionally and treat all clients with dignity and respect. Manage business operations effectively and efficiently by aligning resources across the agency.**
- **Promote accountability, transparency and quality in all services we deliver and programs we administer.**
- **Develop our employees at all levels of the agency.**



Cartoon: Thomas Brothers/P. Kleyman

"I think we can get the votes if we call it 'The Faith-Based Family Caregivers Mental Health Initiative for Homeland Security Act.'"

Training for Health Care Professionals with Rosalynn Carter Institute for Caregiving (RCI)

- RCI implemented a dementia capable training program for health care professionals
 - First conducted a statewide assessment of training needs
 - There were 357 respondents
 - 52 from AAAs (15%)
 - 77 from AAA Providers (22%)
 - 55 from Behavior Health (15%)
 - 22 from Developmental Disabilities (6%)
 - 132 from Division of Aging Services, including Adult Protective Services (36%)
 - 19 from Independent Living/Skilled Nursing Facilities (5%)

Training for Health Care Professionals with Rosalynn Carter Institute for Caregiving

- Topics covered during the Program included but were not limited to:
 - Alzheimer's 101
 - Alzheimer's 102
 - Identifying & responding to mental health issues during assessment and care management
 - Strategies for managing problem behaviors
 - Saint Louis Univ. Mental Survey Exam (SLUMS)
 - Distinguishing between Depression & Dementia
 - Financial Capacity related to Dementia and Disabilities

Training for Health Care Professionals with Rosalynn Carter Institute for Caregiving

- Attendance was tracked by number of computers, individuals, and agencies
- For years 2 and 3:
 - Average pre test score was 87.5
 - Post-test score was 100
- All webinars were archived, and links sent to attendees
- To view all 23 webinars, go to
 - http://www.rosalynncarter.org/gdas_trainings/

Steps to Creating an Inclusive Network: Include LGTB Cultural Competency Training

Provide the LGBT Awareness to State agencies and Aging service providers throughout the State

- Georgia Division of Aging Services Leadership Team
- Georgia Department of Human Services – Human Resources Staff
- Georgia Cares
- Nonprofit Service Providers within the State Aging Network

Conduct Cultural Competency Training throughout the State's Aging Network

- Georgia Division of Aging Services Staff
- Georgia Adult Protective Services Staff
- Georgia Medicare/Medicaid Surveyors Conference
- Georgia Ombudsman Statewide Conference
- Georgia Gerontology Society Conference
- SE Association of Area Agencies on Aging Conference



Identify LGBT inclusive service providers within the State's Aging Network

- Convened a statewide LGBT Work Group
- Established criteria to determine LGBT inclusive service providers
- Developed a self-assessment tool for providers to gauge their inclusiveness
- Provider technical assistance and training to Aging service providers

TRAINING FOR CAREGIVERS: POWERFUL TOOLS FOR CAREGIVERS (PTC)

- PTC is an evidence-based six week education/training program for family caregivers
- PTC is based on the highly successful Chronic Disease Self Management program developed by Dr. Kate Lorig & colleagues at Stanford University
- Georgia Division of Aging Services (GDAS) contracted with all 12 Georgia AAAs to implement PTC with funding through the Systems Integration Grant (SIG)
- Implementation occurred over the three year period of the Systems Integration (SIG) Part B grant:
 - Three AAAs in Year One
 - Five AAAs in Year Two
 - Four AAAs in Year Three
- Contracted with Health Policy Center at Georgia State University to evaluate the program

TRAINING FOR CAREGIVERS: POWERFUL TOOLS FOR CAREGIVERS

- Results were based on paired sample t-tests to test for statistical significance between the pre and post surveys
- Inclusion in the analysis required that participants attend the first class, as well as a minimum of four of the six classes
- 158 participants from eight AAA regions met this criteria
- Caregiver stats:
 - 88 % female
 - 60% White/Caucasian; 38% non-white; (four did not indicate their race)
 - 29.7% live in rural areas; 56.3% in cities over 5,000; 11.4% in towns under 5,000\
 - 28.3% caring for mother; 17.2% other female; 16.7% male spouse; 13.3% father; 6.1% other male; 18.3% other
 - 20% (27 caregivers) were caring for two persons
 - Length of time providing care ranged from 3 months to 45 years; average 7.4 years

TRAINING FOR CAREGIVERS: POWERFUL TOOLS FOR CAREGIVERS

- On all 12 measures, the mean score gain was statistically significant for each of the statements.
- The program is successful in improving participant's perception of their ability to manage the four primary goals of improving: 1) self-care behaviors 2) management of emotions 3) self-efficacy, and 4) awareness of community resources
- There were two statements that had particularly high levels of disagreement reported prior to taking the PTC classes:
 - "Currently, I assert myself with other to get my needs met."
36.2 % of the participants either strongly disagreed or disagreed with. After the program, the percentage changed to 11%.
 - "Currently, I take time for myself without feeling guilty". Prior to the program 61 participants either strongly disagreed or disagreed, whereas after the program six were in disagreement and the remaining 152 were in agreement.

Training for Health Care Professionals: AT-RISK ADULT CRIME TACTICS (ACT) Training

- Forensic Special Investigations unit with Division of Aging Services comprised of persons with background in Medicaid fraud, criminal justice, law enforcement.
- Focus of ACT is to equip primary & secondary responders with knowledge and skills to address the needs of at-risk adult crime victims in Georgia.
- Frequently, victims of abuse, neglect and exploitation (ANE) crimes have AD or related dementia.



Training for Health Care Professionals: AT-RISK ADULT CRIME TACTICS (ACT) Training

- ACT Training:
 - covers at-risk adult abuse, neglect, and exploitation as it relates to Georgia law
 - describes the types of abuse(physical, sexual, emotional, neglect, and exploitation
 - Explains the role of Georgia social service agencies (Adult Protective Services, Healthcare Facilities regulation, Long-term Care Ombudsman Program, and Department of Behavior Health and Developmental Disability
 - Explains Alzheimer’s Disease and the basics of investigating (evidence, red flags, and tips for interviewing at-risk adults
- For more information about ACT Training in Georgia:
 - Website: <http://aging.dhs.georgia.gov/forensic-special-investigations-unit-fsiu>
 - Contact at the Division: Amanda Carter, amcarter@dhr.state.ga.us

Safety: Abuse, Neglect, and Exploitation App

- **Problem:**

Law enforcement and Adult Protective Services staff frequently encounter situations where someone appears to have been abused, neglected, or exploited.

Health care professionals could benefit from quick access to information, screening, and services for these and other situations that often occur in the middle of the night.



“Marie, are you still driving?”

Safety: Abuse, Neglect, and Exploitation (ANE) App

Background:

- Adult Protective Services, Alzheimer's Association, and other Division of Aging Services staff have worked together on a number of ANE initiatives.
- Through this collaboration, it was determined that an ANE App could prove useful for law enforcement, APS, and other health care professionals, as well as the general public.



Safety: Abuse, Neglect, and Exploitation App: Features available to General Public and Health Care Professionals

- Contact information for various agencies
- Information on laws related to abuse, neglect, and exploitation



Safety: Abuse, Neglect, and Exploitation App: Features available to Professionals via an Activation Code

- Screening questions with algorithms:
 - Cognitive functioning
 - Abuse, neglect, & exploitation
 - Financial Capacity (pending)
- Placement places, by zip code, and nearest location to your location (pending)
- Mattie's Call
- Push Notifications of latest scams



Safety: Abuse, Neglect, and Exploitation App

- Next Steps:
 - Solicit and select persons to do Beta testing
 - App Completed
 - Web-X Training to those testing
 - Finalize survey for those testing
 - Send survey to testers
 - compile results from survey
 - Conduct focus group with testers
- Make enhancements/tweak App
- Develop video for training
- Make the video available through the App Store and Division You tube channel



Questions?

- Contact Information:
 - Cliff Burt
 - Georgia Division of Aging Services
 - gcburt@dhr.state.ga.us
 - Phone: 404-657-5336