

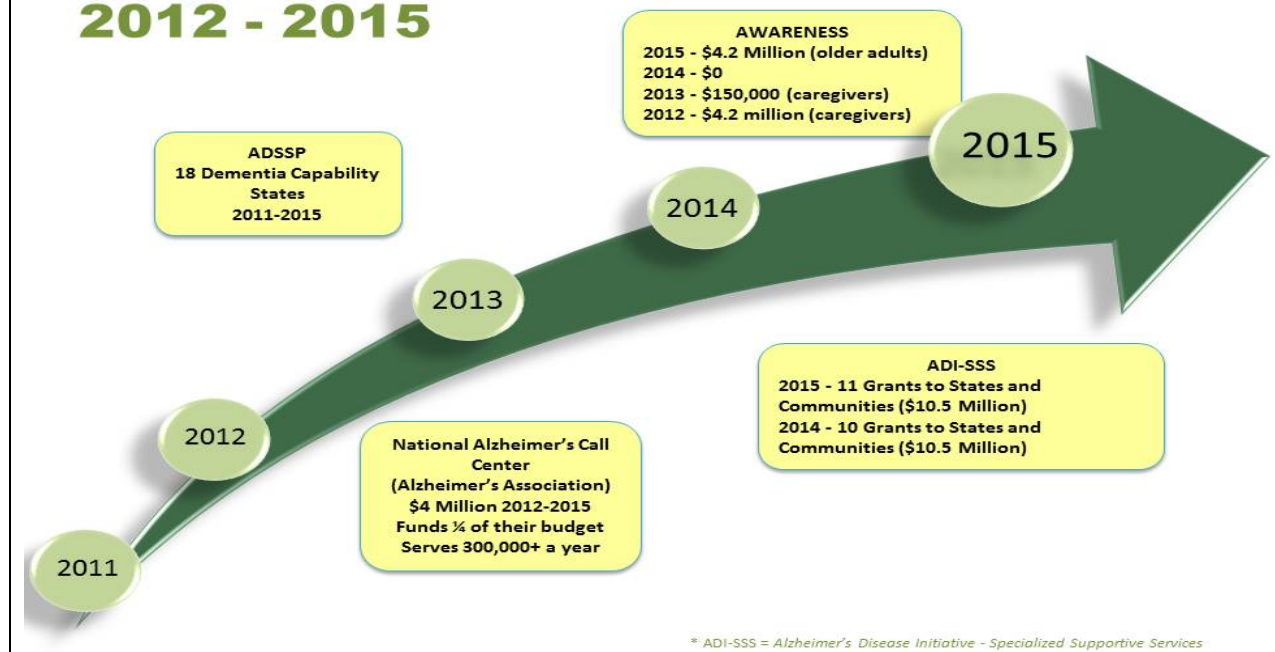
Long-term Services and Supports Federal Update October 2015

**ACL-Jane Tilly/Erin Long; ASPE-Rohini
Khillan; CDC-Lisa McGuire; CMS-Shari
Ling; HRSA-Joan Weiss; IHS-Bruce Finke;
NIA-Richard Hodes; VA-Richard
Allman/Susan Cooley**

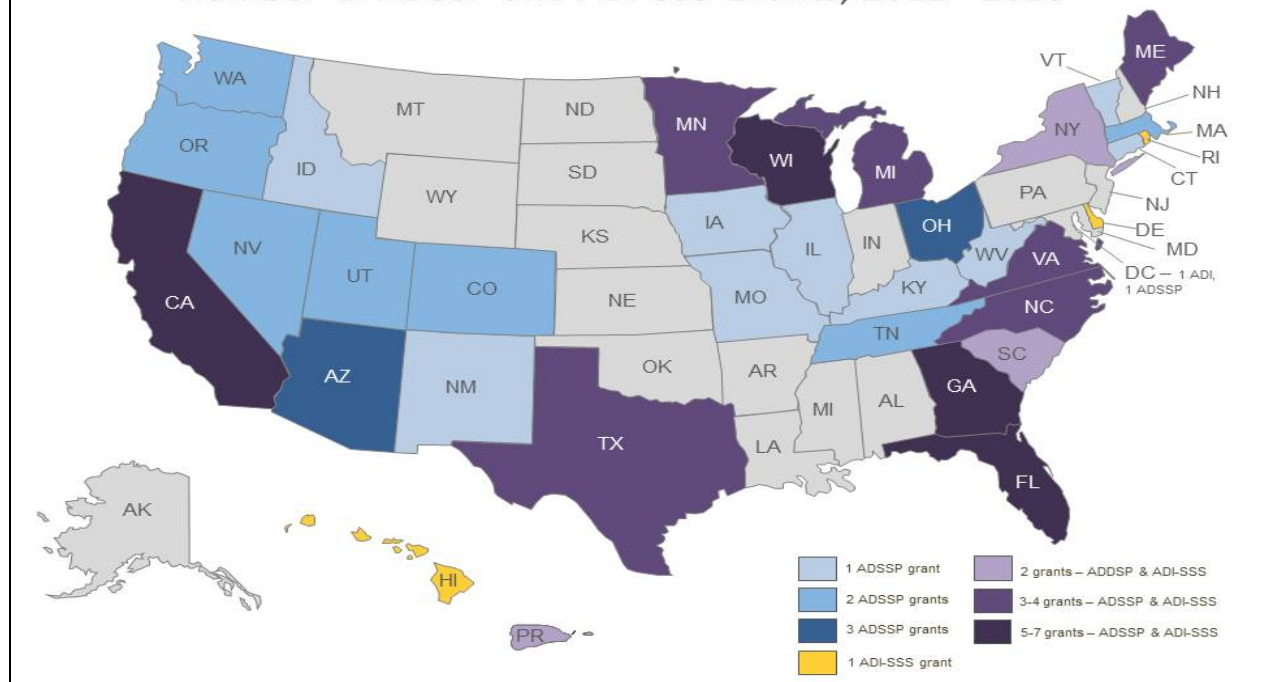
Overview

- Federal agencies work together to address National Plan goals & non-federal recommendations, within legislative, regulatory, and budgetary constraints
- Work involves partnerships with Indian Country, states, localities, & private partners to provide quality dementia services, caregiver supports & raise awareness
- Goals 2 & 3: enhance care quality and efficiency and expand supports through
 - Training and advocacy for those with dementia and their caregivers
 - Training for LTSS staff, agencies, & facilities, LTC ombudsmen, and VA staff
 - Investments in research, translation of interventions, & innovations
 - Dementia capable systems' change with lead state agencies
 - Dementia capable/friendly activities in communities across the country
 - Quality measures & evaluation
- Goal 4: enhance awareness
 - Awareness campaigns
 - Agency communication, education and training vehicles
- Results:
 - About 40 states engaging in surveillance and other public health activities
 - Dementia objectives accepted as part of Healthy People 2020
 - Thousands of providers and caregivers trained
 - 18 state systems becoming dementia capable
 - 10 evidence-based interventions translated and most sustained in states and communities
 - New caregiver intervention in Indian Country, where none previously existed
 - Thousands with dementia and their caregivers served
 - 25% reduction in use of anti-psychotics for long-stay nursing home residents

ACL Dementia Program Investments 2012 - 2015



ACL Number of ADSSP and ADI-SSS Grants, 2012 - 2015



ACL

ADSSP & ADI-SSS Grants Selected Private Partners 2012 – 2015

- AARP – 2 grants (PR, WI)
- **Alzheimer’s Association - in 53 Grants (42 Chapters in 27 States)***
- **Benjamin Rose Institute – in 6 grants (AZ, DC, GA, OH -2, TN)***
- Cleveland Clinic Lou Ruvo Center for Brain Health – 2 grants (NV)
- Coalition of Limited English Speaking Elderly (IL)
- Easter Seals – 2 grants (FL, TX)
- Home Care Partners (DC)
- Hospice organizations– 3 grants (HI, MN, UT)
- Jewish Family and Children’s Services – 3 grants (FL – 2, NY)
- Kaiser Permanente – 2 grants (CA)
- **National Task Group on Intellectual Disabilities and Dementia Practices – 4 grants (FL, HI, ME, RI)***
- Pastors United, Inc. (WI)
- Rosalynn Carter Institute – 3 grants (GA – 2, SC)
- **United Way – 5 grants (FL – 2, PR, TX, WI)***

*Largest private partnerships

ACL’s ADSSP & ADI-SSS Grants Selected Dementia Capable/Friendly Community Activities http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx

Dementia Capable Services

- Dementia care training for health professionals in diagnosis protocols (FL, HI, ME, OR)
- Dementia capability in the IDD community (HI, MI, MN, RI, TX, WI)
- Dementia capable care coordination training (VA)
- Awareness training for community service workers (NY)
- Training of hospital system care coordination staff (TX)

Early Diagnosis

- Education of the community and professionals about cultural values and norms to increase early diagnosis, and care coordination for African-American, Hispanics and limited English speaking populations (MN)
- Development of screening for early identification of dementia and their family caregivers (NV)
- Increase in access to evidence-informed early stage memory loss programs and behavioral support (WA)

Engagement of Faith-Based Community

- Outreach and training for clergy and faith-based communities. (DC, FL, NY, ME, MN, PR, WI)

Dementia Capable Communities

- Pilot “Dementia Capable Community” grant programs in 16 communities (WV)
- “Dementia Friendly Business” campaign for businesses, customer and employee support (NC)
- Training of community gatekeepers (bank tellers, shopkeepers, mail carriers, etc.) to identify possible cognitive impairment. (FL)

Independent Living

- Expansion of Share the Care networks of informal supports for people with dementia living alone (WI)
- Implementation of “Connections” intervention to match individuals’ functional levels with activities to sustain meaningful engagement in life (VA)
- Launching of a money management program to assist those with ADRD with finances (DC)
- Implementation of community gatekeeper program. (OR, FL, NY)

Emergency Preparedness

- In-person and online dementia training to first responders. (ME, MN, NY, VA, CA)

ACL – Ombudsman w/ CMS

Office of Long-Term Care Ombudsman Programs provides training, technical assistance, and federal regulations that help meet needs of people with dementia, who represent about half of people living in long-term care facilities, selected activities:

- **2015 training for ombudsmen** addresses the needs of those with dementia
 - advance care planning <http://ltcombudsman.org/library/advance-care-planning-for-residents-role-and-responsibilities-of-long-term>
 - person-centered complaint process
 - emergency-preparedness
- **2012 – 2014 trainings:**
 - Financial issues - <http://theconsumervoice.org/issues/other-issues-and-resources/financial-exploitation> & <http://www.consumerfinance.gov/blog/managing-someone-elses-money>
 - "Hand in Hand" training for ombudsman, in partnership with CMS, w/ evaluation planned <http://ltcombudsman.org/uploads/files/issues/hand-in-hand-tips-for-ombudsmen.pdf> & <http://ltcombudsman.org/issues/dementia-care>
 - Legal strategies to address transfer, discharge and eviction from long-term care facilities, which often occurs due to behaviors <http://www.ltcombudsman.org/issues/transfer-discharge>
 - Misuse of Antipsychotic Medications <http://ltcombudsman.org/issues/misuse-of-antipsychotic-drugs>
 - Person-Centered Care
- **New federal regulations** provide person-centered guidance on complaint processing, including when a resident, due to dementia or other condition, cannot communicate informed consent, and has no representative
- **Ombudsman Evaluation** completion in 2017

ACL Awareness Campaigns w/ NIA

- **2012 Caregiver Campaign:**
 - Target was making caregivers aware of the resources available in their communities
 - www.Alzheimers.gov
 - Television and radio public service announcements
- **2014 Advisory Council focus on cognitive awareness:**
 - Reduce stigma associated with dementia
 - Encourage older adults to begin conversations with their family and their doctors about memory loss or overall brain health
- **2015 *What is Brain Health?* Campaign:**
 - Brain changes as we age
 - Social content that models conversations about brain health
 - Message to talk with your doctor about any concerns
 - www.brainhealth.gov illustrates how brain changes, fact/fiction quiz, features PSAs by Marcia Gay Harden
 - Robust FaceBook, Twitter and YouTube channels
 - Paid media for this campaign focused on Las Vegas and St. Louis
- **Future:**
 - Paid media and PSA exposure for the general campaign
 - Development of similar cognitive awareness campaign with redesign for Hispanics
 - Hispanic campaign launched in following year

Selected ASPE-funded Dementia Studies

- **Compendium of Residential Care and Assisted Living Regulations and Policy: 2015 Edition** - Summarizes and compares states' residential care setting regulations, including provisions related to dementia and behavioral issues. URL: <http://aspe.hhs.gov/basic-report/compendium-residential-care-and-assisted-living-regulations-and-policy-2015-edition>
- **Institute of Medicine (IOM) Expert Panel on Advanced Dementia** (2015) - Panel invited experts to discuss: research, innovative models, and recommendations and made their own policy recommendations to the National Alzheimer's Advisory Council.
- **Identify Unmet Service Needs** (2014) - In spring 2014, ASPE released analyses from the National Health and Aging Trends Study (NHATS) and the National Survey of Caregiving. The reports included data on care needs of those with dementia and the experiences of their unpaid caregivers. People with probable dementia account for about 1/3 of older persons residing in the community who receive help and about 1/3 of unpaid caregivers assist older people with dementia. Caregivers to people with dementia report more negative effects of caregiving. [<http://aspe.hhs.gov/daltcp/reports/2014/NHATS.cfm>]
- **Review of evidence on care coordination models for people with Alzheimer's disease** (2014) - Review found that although some programs are promising, evidence is still equivocal. [<http://aspe.hhs.gov/daltcp/reports/2013/alzcc.shtml>]
- **Effect of Dementia on Hospitalization and Emergency Department Use in Residential Care Facilities** (2014)- Report on the experiences of individuals living in residential care facilities (including assisted living) who have dementia, based on analysis from the National Center for Health Statistics (NCHS)-ASPE National Survey of Residential Care Facilities (NSRCF). The analysis finds that: ½ of facility residents aged 65+ have severe cognitive impairment & ¼ of residents have at least one hospitalization and more than 1/3 have at least one emergency department visit in the past 12 months. [<http://aspe.hhs.gov/daltcp/reports/2014/RCFdementia.cfm>]
- **Long-Term Care Awareness Survey** (forthcoming) - ASPE is working to better understand why middle-aged adults do or do not plan for long-term care needs. ASPE conducted a national survey to examine attitudes toward long-term care. The survey had two distinct components – general survey items and policy options for long-term care financing. Survey of nationally representative sample of non-institutionalized adults between 40-70 years old residing in the United States.

CDC w/Alz Assoc, NACDD, ASTHO, & Researchers

- **Roadmap:** CDC & Alzheimer's Association produced [*The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*](#) outlining actions for public health community
- **Monitoring & Surveillance:**
 - [issue briefs](#) and [pod casts](#) reporting on BRFSS results from [21 states](#)
 - 46 states in 2015 & 2016 to complete CI module & 35 states the Caregiving module
 - CDC & NIA co-chair the Healthy People 2020 dementia workgroup, resulting in adoption of [2 objectives](#) for the nation's health
- **Forecasting Economic Cost of Dementia:** University of Washington conducting a literature review & estimating dementia-related costs to individuals, caregivers, and health and LTSS systems
- **Understanding Dementia and Co-occurring Chronic Conditions:** Series of projects examining impact of dementia and other chronic conditions on outcomes such as daily functioning, quality of life, and survival
- **Preventing Hospitalizations:** review of interventions related to dementia and reducing preventable hospitalizations.
- **Selected Partnerships:**
 - ASTHO to promote policies and programs related to cognitive health and impairment with a series of [6 Healthy Aging Webinars](#) and developed and disseminated a series of 7 public health and aging Issue Briefs and Case Studies
 - [Healthy Brain Research Network](#) conducting research to understand attitudes and perceived changes in cognitive functioning; develop evidence base for communication and improvement or maintenance of cognitive function; & translate the evidence into public health practice
 - National Association of Chronic Disease Directors one-year opportunity grants to [5 states in 2014](#) and [6 in 2015](#), plus Puerto Rico to promote cognitive health
 - Wt, Alzheimer's Association, and AARP incorporated lessons learned from local dementia-friendly community projects into a [tool kit](#)

CMS Quality Strategy



Better Care

Healthier People

Smarter Spending

Foundational Principles

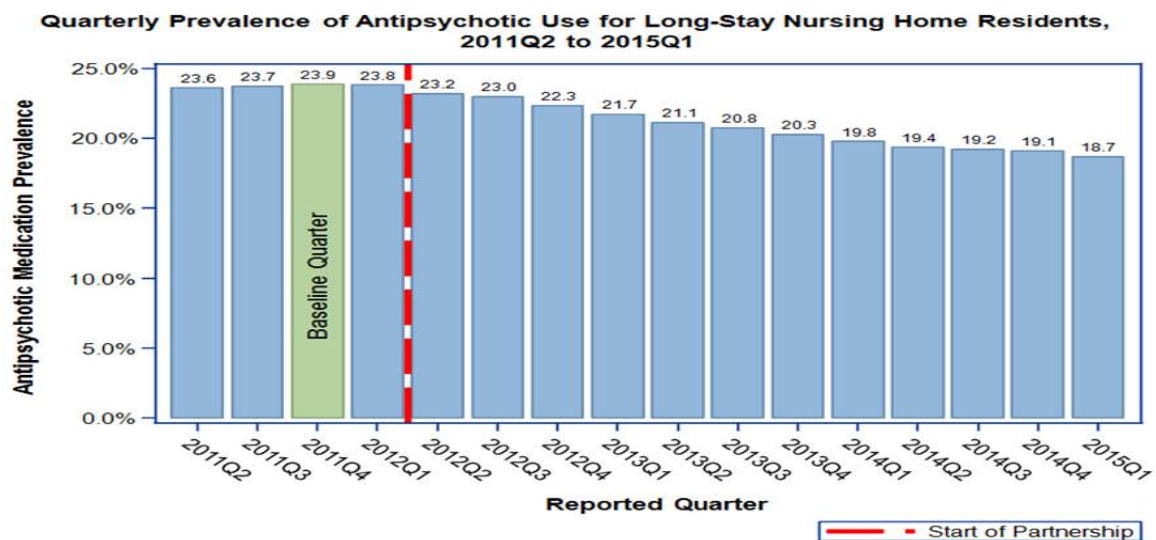
- Enable Innovation
- Foster learning organizations
- Eliminate disparities
- Strengthen infrastructure and data systems

Goals

- Make care safer
- Strengthen person and family centered care
- Promote effective communications and care coordination
- Promote effective prevention and treatment
- Promote best practices for healthy living
- Make care affordable

11

Quarterly Prevalence of Antipsychotic Use for Long-Stay Nursing Home Residents, 2011Q2 to 2015Q1



National Partnership to Improve Dementia Care in Nursing Homes

2015 & 2016 Goals:

- Reduce the national prevalence of antipsychotic medication use in long-stay nursing home residents:
 - By 25 percent by the end of 2015
 - By 30 percent by the end of 2016
- Discover ways to implement new practices:
 - To enhance quality of life
 - To protect residents from substandard care
 - To promote goal-directed, person-centered care approaches

<http://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2014-Press-releases-items/2014-09-19.html>

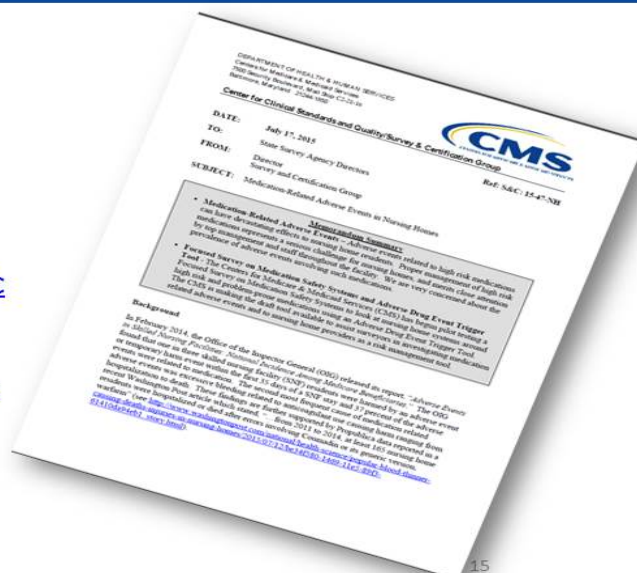
Adverse Events in Nursing Homes

- **Focused Survey on Medication Safety Systems**
 - Identify preventable adverse drug events that have occurred or may occur
 - Determine whether facilities identify residents' risk factors for adverse drug events and implement individualized interventions to eliminate or mitigate those risk factors
 - Determine if the facility has implemented effective systems to prevent adverse drug events as well as recognize and respond to adverse drug events that do occur in order to minimize harm for the individual and prevent recurrence of the event

Adverse Drug Event Trigger Tool

Released via Survey & Certification Policy Memo 15-47 on July 17, 2015

<http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions.html>



National System to Report Staffing for each Nursing Home

- Levels, turnover, and tenure Auditable back to payroll data
- Section 6106 of the Affordable Care Act
- Funding provided by the IMPACT Act of 2014
- Finalized through FY16 SNF PPS Rule as 42 CFR 483.75(u) (<https://www.federalregister.gov/articles/2015/08/04/2015-18950/medicare-program-prospective-payment-system-and-consolidated-billing-for-skilled-nursing-facilities>)
- Information and technical specifications posted at: <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Staffing-Data-Submission-PBJ.html>
- Voluntary submission by facilities: October 2015
- Mandatory submission: July 2016

Preventable Hospitalizations in Nursing Homes

- CMS's Medicare-Medicaid Coordination Office is working with the Innovation Center to test clinical interventions or care models that improve the health of long-stay nursing home residents (many with ADRD)
- Seven "Enhanced Care and Coordination Providers" are implementing the project in 144 nursing facilities across the U.S.
- Early results for quality improvement, cost and utilization are promising including reduced hospitalizations, functional decline, antipsychotic use, pressure ulcers, & catheter use
- Evaluation Report is at:
<http://innovation.cms.gov/Files/reports/irahnfr-secondevalrpt.pdf>

HRSA, w/ACL

- HRSA funded New Jersey Geriatric Education Center to produce free 5-module web-based program on the inter-professional approach to assessment and management of Alzheimer's disease and dementia
 - Alzheimer's Disease: Overview
 - <https://hrsa.connectsolutions.com/p1422rhde5c/>
 - Role of Neuropsychology and occupational therapy in dementia
 - <https://hrsa.connectsolutions.com/p1afruz1bed/>
 - <https://hrsa.connectsolutions.com/p6cmw78igsu/>
 - Dementia Behaviors & Interventions
 - <https://hrsa.connectsolutions.com/p7c2zkojsvy/>
 - Optimizing Care Management for people with dementia, Families, and Caregivers
 - <https://hrsa.connectsolutions.com/p78jdn2qho/>
 - Palliative Care in End Stage Dementia
 - <https://hrsa.connectsolutions.com/p1feferkbbsc/>

IHS w/ VA, ACL & Alzheimer's Association

- **Caregiver Support**
 - REACH into Indian Country involves training and certification in this VA-adapted caregiver intervention
 - Results from collaboration among the VA, IHS, and ACL. IHS and ACL are collaborating with the Memphis Caregiver Center in implementation
 - Over 3 years goal is to implement intervention in 50+ Tribal communities
 - 31 individuals from 17 Tribal communities trained, with 5 certified
- **Increase Awareness and Engagement**
 - IHS and ACL presentations at the National Indian Council on Aging, the National Title VI Training, and at regional Tribal meetings
 - Articles in the IHS Primary Care Provider
 - Native American Calling radio show on August 4, 2015 about Alzheimer's disease and on October 1 on Caregiving in ADRD, reaching across Indian Country
 - Alzheimer's Association will be meeting with the Health Directors of the United South and Eastern Tribes on October 26, 2015 to discuss adaptation of the Road Map for Tribal communities
- **Education and Workforce Development**
 - The Banner Health Institute held the *Inaugural National Conference on Alzheimer's disease/Dementia in Native American Communities: Impact, Issues and Next Steps* on October 15 and 16, with participation by ACL and IHS.
 - The Alzheimer's Association will be presenting at the CMS/IHS/ACL LTSS webinar series on October 28, building bridges between state chapters and Tribal communities.

NIA Research & Communication Highlights (w/CDC & ACL)

- **Funding initiatives:**
 - NIH recently issued two funding announcements inviting applications for basic and translational research on caregiving for individuals with Alzheimer's disease (AD), at the individual, family, community, and population level.
 - <http://grants.nih.gov/grants/guide/pa-files/PA-15-348.html> (R01 applications)
 - <http://grants.nih.gov/grants/guide/pa-files/PA-15-351.html> (R21 applications)
 - Scope includes interventions to reduce caregiver burden and improve patient outcomes; population- and community-based research on the scope and impact of AD caregiving; improved characterization of informal and formal caregiving; and the burden of caregiving across the full spectrum of the disease.
- **NIA's Current Portfolio in Caregiving/LTSS (covers the following topics)**
 - Psychological and physical health impact on caregivers
 - Economic costs of caregiving
 - Surrogate communication and decision-making
 - Caregiving components of large scale epidemiologic and longitudinal studies
 - Interventions, tools and trainings for caregivers
 - Paid and unpaid caregiving in the context of LTSS
 - Dementia caregiving
- **2015 NIA/CDC/ACL Webinar Series (Similar series in previous years)**
 - Webinar 1 - September 2015: Alzheimer's & Dementia: Resources You Can Use
 - Webinar 2 - October 2015: What's Happening in Alzheimer's Research?
 - Webinar 3 - November 2015: Caregivers Supporting People with Dementia: New Research and Technology
 - Over 1000 register and 700 participate in each
 - http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx

VA w/ ACL

- **REACH VA (Resources for Enhancing All Caregivers Health in the VA)**
 - 2012 modified REACH VA intervention rolled out to the VHA system
 - Modified intervention has four core sessions during two to three months, with the option for additional sessions based on caregiver need, desires, goal attainment, and clinician judgment.
 - Results published in The Gerontologist in November 2014
 - Caregivers experienced significant decreases in burden, depression, anxiety, number of troubling behaviors reported, caregiving frustrations, stress symptoms.
 - Memphis Caregiver Center has provided training, certification, and coaching to 151 VA sites in providing the intervention with 614 staff trained and 255 certified with 705 Caregivers enrolled and 2390 caregiver sessions.
- **Veteran-Directed Home and Community Based Services (VD-HCBS)**
 - Veterans of all ages can manage their home and community based services while living in their homes and communities.
 - Part of ACL's Community Living Program , which serves Veterans in 28 states and 50 VA Medical Centers
 - Over 1,400 Veterans served

VA Education w/ CMS

- Online Veterans Health Library resources on key dementia topics
www.veteranshealthlibrary.org/Search/SearchResults.pg?SearchPhrase=Dementia&SearchType=keyword&SearchOperator=And.
- VA Office of Rural Health has posted a 20-module video series to aid caregivers of a person with dementia <http://www.ruralhealth.va.gov/education/dementia-caregivers/index.asp>
- VA Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs) & National VA Parkinson's Disease Consortium have posted videos for families dealing with Parkinson's disease and its complications, including memory problems <http://www.parkinsons.va.gov/patients.asp>
- VA Office of Telehealth Services has developed a Dementia Disease Management Protocol for their coordinators who support caregivers of Veterans with dementia living at home
- VA Community Living Centers received access and support in implementing CMS' *Hand in Hand* training materials
- 20 VA Geriatric Research, Education, and Clinical Centers include dementia in relevant staff education www.va.gov/grecc
- Two of the 10 VA Mental Illness Research, Education, and Clinical Centers (MIRECCs) have a major focus on dementia. www.mirecc.va.gov