



## ACL/AoA's Family Caregiver Support Programs: An Overview

Presented to the NAPA/FACA Meeting  
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### About ACL

The Administration for Community Living (ACL): A new operating division within the U.S. Department of Health & Human Services


Brings together:

- Administration on Aging (AoA)
- Office on Disability (OD)
- Administration on Intellectual & Developmental Disabilities (AIDD)

Charged with developing policies and improving supports for seniors and persons with disabilities of all ages.




## ACL's Authorizing Statutes & Programs

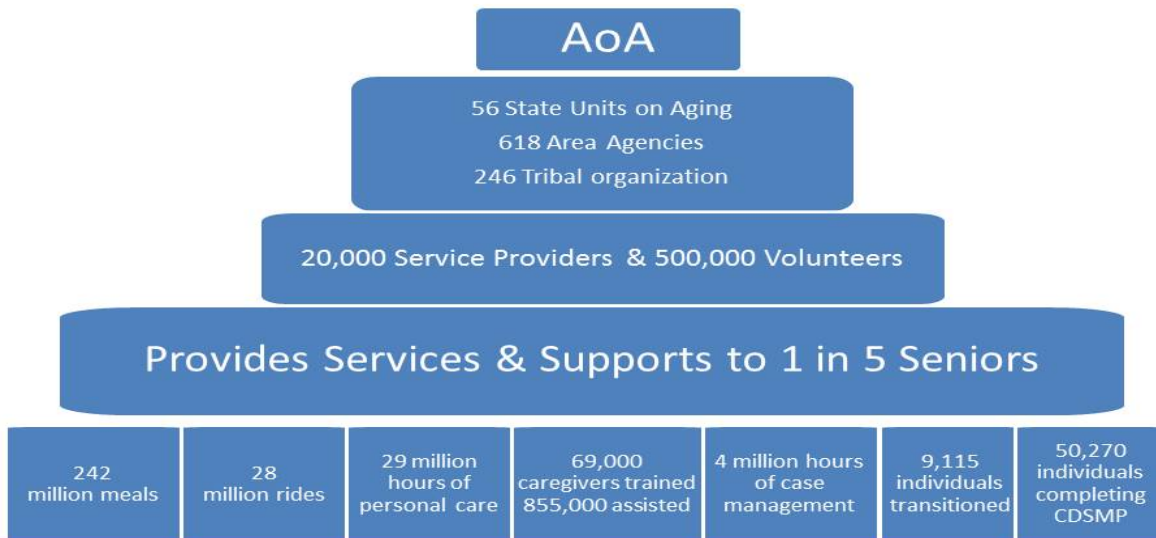
- **Older Americans Act of 1965** (as amended)
  - **Public Health Service Act Programs**
    - Section 398 – Alzheimer's Disease Supportive Services Program (ADSSP)
    - Title XXIX – Lifespan Respite Care Program
  - **Health Insurance Portability and Accountability Act of 1996** (HIPAA) – Health Care Fraud and Abuse Control (HCFAC) funds
    - Senior Medicare Patrol
  - **Developmental Disabilities Assistance and Bill of Rights Act of 2000** (DD Act)
  - **Help America Vote Act** (HAVA)
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## The U.S. Administration on Aging

- Created in 1965 – Older Americans Act
  - Focal Point and advocate for older persons and their caregivers
  - Supports the Aging Services Network
    - 56 state and territorial Units on Aging
    - 618 Area Agencies on Aging
    - 246 Tribal and Native Organizations
    - Thousands of providers/volunteers
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## Aging Network: Supporting 11 Million Older Adults and Family Caregivers



## AoA/Aging Network Programs and Services

### Older Americans Act (OAA) Programs

- Supportive Services (Title III B) – adult day care, information, case management, transportation
- Nutrition Services (Title III C 1 & 2)
- Preventive Health Services (Title III D)
- National Family Caregiver Support Program (Title III E)
- Elder Rights Programs – elder abuse, ombudsman (Title VII)
- National Demonstrations (Title IV)
- Native American Programs (Title VI)

### Other National Programs (non-OAA)

- Alzheimer's Disease Supportive Services Program (Public Health Services Act)
- Lifespan Respite Care Program (Public Health Services Act)
- Senior Medicare Patrol (SMP)



## ACL's Caregiver Support Programs

### **The National Family Caregiver Support Program (NFCSP)**

- Title III E & VI C of the Older Americans Act – 2000
- Family caregivers as service recipients
- Administered through the aging network
- States funded via formula: number of individuals age 70+
- 2014 Appropriation: \$145.5 million
- Flexible package of high-value supportive services:
  - Information
  - Access Assistance
  - Counseling, Support Groups, Training
  - Respite
  - Supplemental Services



## The NFCSP: Eligible Service Recipients

- Family caregivers (18+) of older adults (60+)
- Family caregivers (18+) of individuals with Alzheimer's disease/related dementia (any age)
- Grandparents and relative caregivers (55+) of children (under age 18)
- Grandparent and relative caregivers (55+) of adult children (18-59) with a disability



## The NFCSP: Outputs and Outcomes

- Who was served (FY 2011 Data)
  - Access Assistance – 1.1 million contacts for family caregivers
  - Counseling/training – 138,427 caregivers
  - Respite – 69,000 caregivers received 6.3 million hours
- What they said (2012 National Survey Data)
  - 90% of caregivers felt services made them better caregivers
  - 81% of family caregivers rated services as “excellent” (47%) or “very good” (34%)
  - 77% of caregivers able to provide care longer

## ACL's Caregiver Support Programs

### **Alzheimer's Disease and Support Services Program (ADSSP)**

- Since 2008 - 85 grants to states awarded
  - As of May 2014 - 41,951 people served
- Grantees have translated 10 evidence-based caregiver interventions
- Presently supporting 45 grants in 18 states
  - 11 states translating 8 evidence-based interventions
  - 4 states implementing innovative programs
  - 4 states doing systems integration (coupled with evidence-based interventions)
  - 5 states working on dementia capability – No Wrong-Door/Single Point of Entry

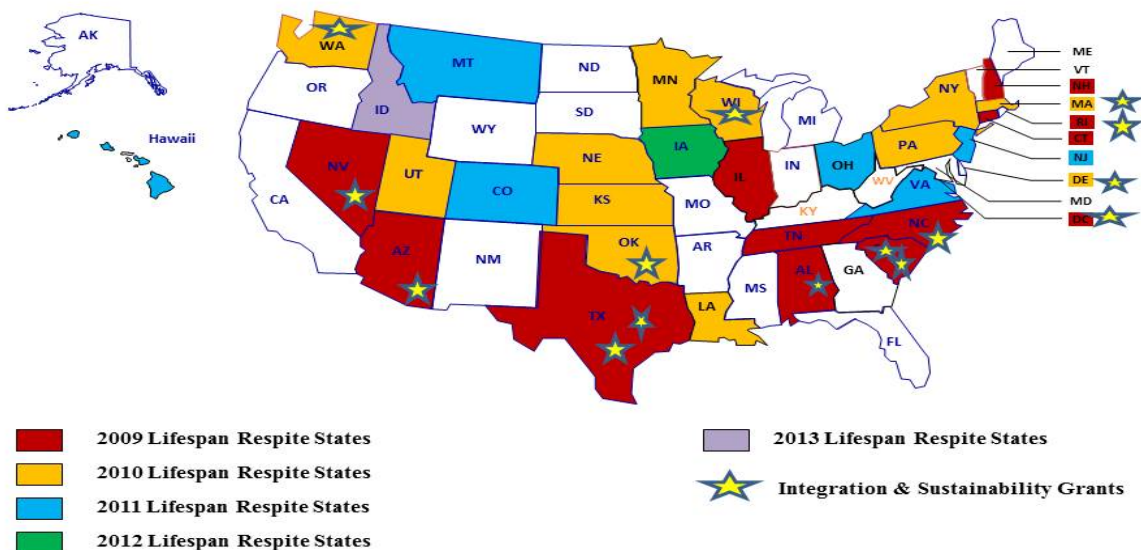
## ACL's Caregiver Support Programs

### The Lifespan Respite Care Program

Lifespan respite programs are defined as: *"Coordinated systems of accessible, community-based respite care services for family caregivers of children or adults with special needs"* (PL109-442 – Lifespan Respite Care Act of 2006)

- Annual Appropriation: approximately \$2.4 million/year
- Competitive grants to states to resolve challenges and barriers associated with respite services:
  - Multiple programs, funding streams, access points
  - Service affordability and quality
  - Confusing and restrictive eligibility criteria & narrow targeting
  - Lack of providers, training and service gaps

### Lifespan Respite States (as of 2013)





## Looking Ahead at Family Caregiver Support

- Increasing focus on complex care and medical tasks
- Focus on the development of natural and peer supports
- Greater use of evidence-based approaches
- Replication and translation of evidence-based interventions
- Caregiver assessment
- The role of family caregivers in care transitions
- The use of technology to reduce caregiver burden and stress



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