Supporting Family Caregivers in America:
Collaborative Opportunities for State, Local, Tribal and Territorial Health Departments
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Looking Ahead: The Demographics

U.S. Census Bureau: THURSDAY, JUNE 25, 2020:
“65 and Older Population Grows Rapidly as Baby Boomers Age.”
“Working-Age Population Not Keeping Pace with Growth in Older Americans

Old-Age Dependency Ratio
• 2020 – 3.5 working-age adults for every 1 person of retirement age
• 2060 – 2.5 working-age adults for every 1 person of retirement age
• In 2017 family caregivers in the U.S. provided an est. **34 billion hours** of care to an adult with limitations in daily activities (ADLs/IADLs).

• Estimated economic value of their unpaid contributions was approximately **$470 billion**.
All out-of-pocket expenditures on U.S. health care in 2017 was $366 billion – More than $100 billion less

It is three times as much as total Medicaid spending on LTSS including nursing home care ($154 billion in 2016);
The Value of Caregiving in Perspective

- Total spending from all sources of PAID LTSS including post-acute care was $366 billion in 2016.
- The total combined value added to the U.S. economy by the agriculture/forestry and mining sectors total $438 billion in 2017.
Societal Trends and Sustainability

- Continuing women’s growth in the workplace
- Fewer children/smaller families
- Aging of the population: by 2035 those age 65 and older will outnumber children under the age of 18 for first time in U.S. history (source: U.S. Census Bureau)
- Possibility of shrinking paid caregiver workforce
Native Migration: In Search of the Missing Cohorts in Indian Country

• Estimated 464,000 AI/ANs are older than age 65
• That number is expected to triple by 2050
• Elders 85+ will increase by 8X in 2050
CDC BRFSS Caregiving Data

CAREGIVING

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

1 in 5 adults are caregivers

WHO ARE CAREGIVERS?
58% are women
19% are 65 years old or older
1 in 3 are caring for a parent or parent-in-law
9% of caregivers are providing care to someone with dementia

LENGTHY
Nearly half have provided care for at least two years

INTENSE
Almost a third have provided care for at least 20 hours per week

HOW DO CAREGIVERS HELP?
80% manage household tasks
Over 50% assist with personal care

FUTURE CAREGIVERS
1 in 6 non-caregivers expect to become caregivers within 2 years

cdc.gov/aging

CDC Department of Health and Human Services Centers for Disease Control and Prevention

CAREGIVING AMONG WOMEN

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

1 in 4 Women are caregivers

WHO ARE CAREGIVERS?
20% are 65 years old or older
37% are caring for a parent or parent-in-law
10% are providing care to someone with dementia

LENGTHY
Half have provided care for at least two years

INTENSE
Nearly 1/3 have provided care for at least 20 hours per week

HOW DO CAREGIVERS HELP?
Over 80% manage household tasks

FUTURE CAREGIVERS
Nearly 60% assist with personal care

1 in 6 non-caregivers expect to become caregivers within 2 years

cdc.gov/aging

CDC Department of Health and Human Services Centers for Disease Control and Prevention

CDC Ready
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ACL is…

- Administration on Aging (AoA)
- Administration on Disability (AoD)
- Administration for Intellectual and Developmental Disabilities (AIDD)
- The Independent Living Administration
- Paralysis Resource Center; Limb Loss Resource Center
- State Health Insurance Assistance Programs (SHIPs)
- National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR)
- Workforce Innovation and Opportunity Act programs (WIOA)
- Traumatic Brain Injury (TBI) Program

ACL is charged with developing policies and improving supports for seniors and persons with disabilities of all ages.
Maximize the independence, well-being and health of older adults, people with disabilities across the lifespan, and their families and caregivers
Family Caregiving is…

• Regularly looking in on or calling a friend or loved one to see how they are doing or if they need assistance
• Helping with, or doing, routine tasks for someone, such as grocery shopping, bill paying, household chores, or transportation
• Assisting with medications or personal care tasks
• Communicating with health care professionals or other providers, services and agencies on someone’s behalf
• Providing complex medical care like wound care; changing IVs; operating medical equipment/devices
Family Caregiving Today: A Snapshot

- **Caregiving in the U.S.: 2020** (NAC/AARP, 2020)
- More than 1 in 5 (23%) of Americans are family caregivers to adults or children
  - 53 million adults
  - Up from 43.5 million in 2015
  - 61% female; 39% male
- Twenty-three percent say caregiving has made their health worse
- Caregivers have a range of information and support needs
Family Caregiving Today: A Snapshot

- Common caregiver support needs include:
  - Respite – 38% believe it would be helpful (only 14% have used)
  - Education and information on a variety of topics
    - Care recipient safety at home (26%)
    - Managing their own stress (26%)
    - Navigating services, systems, paperwork (25%)
Programs & Initiatives to Support Family Caregivers

ACL’s Portfolio:
- National Family Caregiver Support Program (NFCSP)
- Lifespan Respite Care Program
- Alzheimer’s Disease Program Initiative (ADPI)
  - State and Community Grants
  - National Alzheimer’s Disease Resource Center (NADRC)
  - Alzheimer’s Call Center

Additional (non-ACL) Programs to Consider
- VA Caregiver Support Program
- State and local programs/services
Connecting with Caregiver Support Programs and Services

• The Eldercare Locator (www.eldercarelocator.gov)
• National Respite Locator (www.archrespite.org/respitelocator)
• Aging and Disability Resource Center (ADRC)
• www.Alzheimers.gov
For Further Information
greg.link@acl.hhs.gov
www.acl.gov
Caregiving in Indian Country

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www.itcaonline.com
ITCA was established to support 21 Tribal Nations in Arizona
- Taking action on matters that affect the tribes collectively and individually
- Promote tribal sovereignty
- Strengthen tribal governments

1952

1965
The Older Americans Act

1976
Arizona Indian Council on Aging (AICOA) – Tribal elder advisory board was formed.

1979
ITCA-Area Agency on Aging, Region 8 was established
- Title III and VII programs for 17 tribes
- Title VI for 4 tribes
- To administer the OAA Programs & other grants
## ITCA-AAA Title III and VI Programs

### Title III
- □ Congregate Meals
- □ Home Delivered Meals
- □ Transportation
- □ Socialization and Recreation
- □ Caregiver Information & Referral
- □ Caregiver Training
- □ Caregiver Outreach
- □ Powerful Tools for Caregivers
- □ Respite for Caregivers
- □ A Matter of Balance
- □ EnhanceFitness
- □ Chronic Disease Self Management Program
- □ Long Term Care Ombudsman
- □ State Health Insurance Assistance Program (SHIP)/Senior Medicare Patrol (SMP)

### Title VI
- □ Congregate Meals
- □ Home Delivered Meals
- □ Transportation
- □ Chore Service
- □ Nutrition Education
- □ Information & Assistance
- □ Caregiver Training
- □ Outreach
According to the Centers for Disease Control:

• Over 80% assist with household tasks
  - Instrumental Activities of Daily Living

• Over 50% help with personal care
  - Activities of Daily Living

Who are the future caregivers?

• Nearly 1 in 5 Native Americans expect to become caregivers within two years
• Half of caregivers (48%) report their health to be excellent or very good, and 17% report fair or poor, compared to their non-caregiver peers, who report at a lower 10%

• Long-term caregiving: Of those providing care for five or more years, this number raises to 20% reporting fair or poor health, with a strong correlation to household income
Challenges Faced by Native American Caregivers

- Different perspective on caregiving culturally
- Rural communities – isolation from support services, health care services, long-term care facilities, etc.
- Place elders' health before their own health
- Fear of seeking medical attention
- Limited availability of medical equipment supplies
- Stress as a primary caregiver in a traditional setting
How Caregiving Can Affect the Health of the Native American Caregiver

- Withdrawal from friends, family and other loved ones
- Loss of interest in attending cultural ceremonies and other activities
- Feeling blue, irritable, hopeless and helpless
- Changes in appetite, weight or both
- Changes in sleep patterns
- Getting sick more often; missing doctor’s appointments
- Emotional and physical exhaustion
- Physical injuries due to lack of training
• Information - to assist with in-home care and how to access health services for the care recipient
• Transportation – to access care services for the caregiver and care recipient
• Training - personal care, assistive technology, home safety, stress management, medication management, Alzheimer's Disease/Dementia
• Support Groups – to provide a safe space for caregivers to share stories, give and get advice and validation, vent, and build friendships
• Respite - to alleviate caregiver stress
Caregiver Program Services with ITCA-AAA

- Information & Assistance
- Outreach
- Counseling, Support Groups & Training
- Respite Services
- Supplemental Services

Other opportunities:

Annual Title VI National Conference
Regional Title VI Trainings
Title VI Webinars

Coordination of Title III & VI – Evidence Based Health Promotion
Building Successful Networks

- Develop programming unique to the culture and traditions of the Tribal community (language, art, music, food)
- Include community members, family caregivers, care recipients in the planning of programs and services
- Partner with Health Services and Community Providers
- Utilize Tribal, Regional, State, and National Resources
Resources

- National & Native American Caregiver Support Programs
- National Resource Center on Native American Aging (NRCNAA)
- Tribal Elderly or Senior Centers
- Area Agency on Aging
- State Aging and Disability Resource Center (ADRC)
- Faith-based organizations
- Alzheimer’s Resource Agencies
- Indian Health Services (IHS)
- U.S. Department of Veterans Affairs
- Senior Corps Senior Companions & Foster Grandparents Programs
Sources


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This webinar is archived at: www.chronicdisease.org/page/CancerPrograms

• Healthy Brain Roadmap: State & Local Partnerships to Address Dementia: https://www.cdc.gov/aging/healthybrain/roadmap.htm
• Healthy Brain Roadmap for Indian Country: www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html
• NACDD Healthy Aging/Healthy Brain: https://www.chronicdisease.org/page/HealthyAging
• NACDD Alzheimer Interest Group: Contact Thea Griffin at thea.griffin@health.ny.gov, or at (518) 473-5376
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