OVERVIEW OF FEDERAL PROGRAMS AND INITIATIVES IN SUPPORT OF FAMILY CAREGIVERS
U.S. DEPARTMENT OF VETERANS AFFAIRS
VA Support and Services to Veterans Caregivers

Dr. Lynda Davis
Chief, Veterans Experience Office

White House /VA Hotline: 1-855-948-2311
VA Caregiver Support Line: 1-855-260-3274
Deploy VSignals Surveys for Feedback

When Veterans leave feedback about caregivers or caregivers leave feedback in the Outpatient Services Surveys, they leave specific comments regarding:

COMPLIMENTS:
- Staff respecting Veterans while visiting VHA facilities.
- Staff at VA facilities making sure Caregivers are informed and prepared to assist Veterans.
- The ease and convenience of managing prescriptions and scheduling appointments online for Veterans under care of a Caregiver.

CONCERNS:
- Difficulties with the Caregivers Support Program.
- Feeling as though there is a lack of support for Caregivers from the VA.
- Timeliness of response from the VA after filling out caregiver paperwork.

RECOMMENDATIONS:
- Recommending the VA sets up auto-refills for prescriptions.
- Recommending improving the clarity for the process of a family member of a Veteran becoming a Caregiver.
- Recommending that Veterans and Caregivers could come to the VA for lab work up to a week before their scheduled appointment.
Establish Center of Excellence

VA established the Elizabeth Dole Center of Excellence (CoE) for Veteran and Caregiver Research on Sep 7, 2018 to promote innovative, data-driven and integrated approaches to improve services for Veterans and their Caregivers.

The CoE will implement 4 projects based on input from the scientific literature, clinician experience, and prior work with Veterans and Caregivers:

1. Pilot interventions to
   - Support caregivers
   - Meet primary care needs of high need / high risk Veterans
   - Capture functional status at the point of care
2. Identify metrics that matter to Veterans and caregivers to more effectively and holistically assess outcomes
3. Use data analytics to determine which services are most effective in keeping Veterans at home, allowing VA to deliver the right care to the right Veteran
4. Understand the experiences of children & youth caregivers to better support their needs
Create the ‘Choose Home’ Initiative

Create comprehensive, integrated alternatives to nursing home placements, to allow Veterans who are aging, or have complex care needs, to Choose Home.

LOA 1: Create a Personal, Comprehensive CH Plan
- 21 site pilot in progress (Report out 9/19)
- Algorithm developed for those at risk (e.g. 22K Veterans)

LOA 2: Strengthen Community Partnerships and Navigation
- Signed an MOU with Corporation for National Community Services - 5 pilot sites designated
- Expectation to prepare volunteers to support Veteran caregivers in communities

LOA 3: Establish a Center of Excellence for Veteran and Caregiver Research
- Established COE named for Senator Elizabeth Dole
- 4 Identified research areas
## Implement Legislation (MISSION Act – PCAFC)

<table>
<thead>
<tr>
<th>KEY AREAS</th>
<th>KEY INSIGHTS</th>
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<tbody>
<tr>
<td><strong>Standardization of Current Program</strong></td>
<td>- A lack of clear eligibility criteria results in an influx of applications from ineligible dyads.</td>
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<td>- Unclear eligibility criteria leads to inconsistent interpretation and execution of CSP’s guidance across sites, often resulting in the enrollment of ineligible dyads.</td>
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<td>- Dyads are confused and upset by discharges and tier reductions, which is intensified by inconsistent communication from the program.</td>
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<td>- Because mental and physical injuries require different types of caregiving, separate evaluation criteria may be more appropriate.</td>
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<tr>
<td><strong>Considerations for PCAFC Program Expansion</strong></td>
<td>- Veterans of the pre-9/11 service era have a different set of health conditions and caregiving needs. However, criteria for enrollment into the PCAFC must remain standardized for consistency of program delivery.</td>
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<td>- Staff feel overextended because of their large panel sizes and range of responsibilities, which directly impacts the quality of service provided to Caregivers and Veterans.</td>
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<td>- VA providers do not understand the caregiving services provided by CSP and frequently refer ineligible dyads to the PCAFC.</td>
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<td>- VA providers often do not recognize Caregivers and fail to include them in the care planning of their Veterans.</td>
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<td>- Veterans and Caregivers desire clearly communicated information about the PCAFC and the criteria for eligibility.</td>
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<tr>
<td><strong>Impacts of Stipend Dependence</strong></td>
<td>- Dyad success requires Caregivers, Veterans, providers, and staff to understand and embrace the possibility of the Veteran’s recovery.</td>
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<td>- Over time, Caregivers become dependent on receiving a stipend. When the stipend decreases or stops, dyads find themselves financially unprepared.</td>
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<td>- The PCAFC stipend is linked to the Veteran’s caregiving needs. If dyads become financially dependent on the stipend, it may sometimes hamper Veteran recovery.</td>
</tr>
</tbody>
</table>
Resources and References

- VA; [https://www.VA.gov](https://www.VA.gov)
- VA Welcome Kit; [https://www.VA.gov/Welcome-Kit/](https://www.VA.gov/Welcome-Kit/)
- VEO; [https://www.VA.gov/VE/](https://www.VA.gov/VE/)
- VA Welcome Kit and Quick Start Guides; [https://www.VA.gov/Welcome-Kit/](https://www.VA.gov/Welcome-Kit/)
ADMINISTRATION FOR COMMUNITY LIVING
ACL Programs & Initiatives to Support Family Caregivers

• Older Americans Act (OAA)
  – Title III-B – Supportive Services
  – Title III E - National Family Caregiver Support Program (NFCSP)
  – Title VI – Native American Programs

• Alzheimer’s Disease Program Initiative (ADPI) – as of 2018
  – Alzheimer’s Disease Supportive Services Programs (ADSSP)
  – Alzheimer’s Disease Initiative/Specialized Supportive Services (ADI/SSS) Programs

• Lifespan Respite Care Program of 2006
ACL Programs & Initiatives to Support Family Caregivers

• National Alzheimer’s Disease Call Center
• Eldercare Locator
• *Strengthening Financial Literacy and Preparedness for Family Caregivers*
• Rehabilitation Research and Training Center (RRTC) for Family Supports/NIDILRR
• ADRC/No Wrong Door Program
CMS EFFORTS TO SUPPORT CAREGIVERS

Family Caregiving Advisory Council
August 2019
Direct Supports

- Respite services authorized under 1915(c) home and community-based services (HCBS) waivers for individuals meeting an institutional level of care, and 1915(i) HCBS state plan option for individuals with less acute needs.

- Certain Medicaid benefits allow for coverage of care coordination and case management, which may support caregivers with locating, coordinating and monitoring of services needed by a Medicaid beneficiary.

- Program of All-inclusive Care for the Elderly (PACE) providing interdisciplinary services in multiple locations, including Adult Day Health Centers, facilitating caregivers retaining employment.

Indirect Supports (across multiple state plan and waiver authorities)

- Home modifications, such as wheelchair ramps, bathroom accommodations
- Personal care services – assistance with eating, dressing, bathing, etc.
- Hospice care

Visit Medicaid.gov for more information on many of these provisions. CMS is available for technical assistance on determining which authority would be most useful in accomplishing state goals for supporting caregivers.
Direct Supports

- The hospice benefit includes limited respite care services in a Medicare-certified inpatient facility
- Caregivers of beneficiaries with ESRD can receive dialysis training
- Assessment services for beneficiaries with signs of dementia include caregiver identification, knowledge, needs, social supports, and willingness of caregiver to take on caregiving tasks

Indirect Supports

- Medicare Advantage plans’ optional supplemental benefits could include caregiver supports such as access to companion care and social/community organizations, personal care, environmental modifications, transportation, as well as other services
- The chronic care management (CCM) and complex CCM service, and the transitional care management service can indirectly benefit caregivers
- Medicare’s advance care planning service can also help caregivers
Improving Care Coordination between Care Settings and Caregivers

Mark Vafiades
Office of the National Coordinator for Health IT (ONC)
Support data availability in real-time. Electronic information is exchanged and used by health IT systems without special effort on the part of the user.
Allow Access for Caregivers

Get started
Patients aren’t the only people who may need access to the data in their patient portals.
Caregivers often need that information too — including parents, spouses, adult children, and others.
Almost 1 in 5 Americans serve as caregivers for children, parents, spouses, or other loved ones.

Of these caregivers:

Nearly 1 in 4 accessed their care recipient’s online medical record at least once in 2017

More than 2 in 5 who accessed their care recipient’s online medical record used the patient’s login and password
Patient Portal Access

Many patient portals allow you to set up separate access for caregivers. Using this feature can help:

- Get you out of the middle, so you’re not a go-between for patients and caregivers
- Simplify information sharing — cutting down on confusion and calls to your office
- Improve a patient’s care and compliance at home
In some portals, patients can set access levels — so their caregiver can see some information while other sensitive data stays private. **Click and drag the slider to see the difference.**
Key provision in Cures:

- Patients should be able to access all their Health information on their smartphone at no charge.
ONC Patient Engagement Playbook:
Chapter 4: *Allow portal access for caregivers*

- [https://www.healthit.gov/playbook/pe/chapter-4/](https://www.healthit.gov/playbook/pe/chapter-4/)
- Healthit.gov
- Mark Vafiades- [mark.vafiades@hhs.gov](mailto:mark.vafiades@hhs.gov)
Public health strategies to promote brain health, address dementia, and help support caregivers

www.cdc.gov/aging
Healthy Brain Initiative State/local Road Map, 2018-2023

Issue Maps

SUPPORTING CAREGIVERS to Make Alzheimer’s Our Next Public Health Success Story

THE CAREDIVING ACTION AGENDA

PUBLIC HEALTH STRATEGIES TO SUPPORT CAREGIVERS

www.cdc.gov/aging/healthybrain/roadmap.htm
The principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development, and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis.
Policy Research

- Evaluate and study innovative healthcare and LTSS models for older adults and people with disabilities.

- Initiate and support policy research on informal caregiving
  - First (2011) and second (2015) rounds of the National Study on Caregiving
  - *Informal Caregiving for Older Americans: An Analysis of the National Study of Caregiving*
  - *A Profile of Older Adults with Dementia and their Caregivers*
  - Use of Assistive Technology to Reduce Caregiver Burden
  - Economic Impacts of Programs to Support Caregivers
  - Informal Caregiver Supply and Demographic Changes
  - Improving Health and Long-Term Care Modeling Capacity
  - Role of Informal Caregivers in Integrated Healthcare Systems
Implementing the National Alzheimer’s Project Act (NAPA)

- Convene federal partners and non-federal experts for quarterly meetings
- Write and annually update National Plan to Address Alzheimer’s Disease
  - Goal 3: Expand Supports for People with AD and Their Families
    - Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being.
- Focus on supporting family caregivers
- 2017 and 2020 National Dementia Care and Service Research Summits
Family Caregiving Advisory Council: SAMSHA’s Overview

Rosemary Payne, MSN, BSN, RN
Senior Nurse Advisor
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
SAMHSA’s mission is to reduce the impact of substance abuse and mental illness on America’s communities.

SAMHSA accomplishes this through providing leadership and resources – programs, policies, information and data, funding, and personnel – to advance mental and substance use disorders prevention, treatment, and recovery services in order to improve individual, community, and public health.
Center for Mental Health Services
   – Children and Family Programs
   – Consumer and Family Network Grants
   – Project LAUNCH
   – Children’s Mental Health Services

Center for Substance Abuse Treatment
   – Pregnant and Postpartum Women
   – Children and Families
   – Criminal Justice Activities
Center for Mental Health Services

- Children and Family Programs
  - Tribal Behavioral Health Grants - [https://www.samhsa.gov/grants/grant-announcements/sm-19-005](https://www.samhsa.gov/grants/grant-announcements/sm-19-005)
  - National Child Traumatic Stress Initiative – Category III Community Treatment and Services (CTS) Centers [https://www.samhsa.gov/grants/grant-announcements/sm-16-005](https://www.samhsa.gov/grants/grant-announcements/sm-16-005)

- Consumer and Family Network Grants

- Project LAUNCH - [https://www.samhsa.gov/grants/grant-announcements/sm-19-007](https://www.samhsa.gov/grants/grant-announcements/sm-19-007)

- Children’s Mental Health Services

Center for Substance Abuse Treatment

- Pregnant and Postpartum Women
  - Services Grant Program for Residential Treatment for Pregnant and Postpartum Women [https://www.samhsa.gov/grants/grant-announcements/ti-17-007](https://www.samhsa.gov/grants/grant-announcements/ti-17-007)
  - Children and Families

Criminal Justice Activities

- Grants to Expand Substance Abuse Treatment Capacity in Family Treatment Drug Courts [https://www.samhsa.gov/grants/grant-announcements/ti-19-001](https://www.samhsa.gov/grants/grant-announcements/ti-19-001)
FDA CDRH Notable Activities

• **Patient Engagement** – understanding & incorporating patient perspectives in our work

• **Health of Women, Pediatrics & Special Populations** – advancing health through innovation, collaboration and research

• **Digital Health** – facilitating innovative, safe and effective technologies that can be used in the home setting (e.g., wearables) and to support decision making (e.g., clinical decision support software for patients and caregivers)

• **Collaboration with Sponsors** – work with manufacturers to make technologies and the information they provide about them more user friendly (e.g., human factors)
Patient Engagement at FDA CDRH

Goal: Understand & incorporate patient perspectives in our work

Patient Engagement Advisory Committee Meeting
Cybersecurity in Medical Devices

#PEAC2019

Tuesday, September 10, 2019 • Gaithersburg, MD

Patient & Caregiver Connection
Provides FDA timely access to aggregated patients’ voices
CDRH human factors engineers work closely with device users (patients, caregivers, Health Care Professionals) and designers to study how users perceive and interpret information and interact with medical devices.

Why?

- To reduce the risk of use error that could lead to serious harm or compromised medical care
- To provide easier-to-use devices
- To advance the evaluation methods for safety and effectiveness of medical devices → more timely, consistent, and transparent regulatory process
CONSUMER FINANCIAL PROTECTION BUREAU (CFPB)
Family Caregiving Advisory Council

Consumer Financial Protection Bureau
Office of Financial Protection for Older Americans

consumerfinance.gov/olderamericans
olderamericans@cfpb.gov
Money Smart for Older Adults

- An awareness program developed in collaboration with the FDIC
- Identify scams, fraud and other forms of exploitation
- Instructor guides available for download
- Resource guide available in bulk at no charge
- Available in English and Spanish

consumerfinance.gov/moneysmart
Managing Someone Else’s Money

- Help for financial caregivers handling the finances for a family member or friend who is incapacitated
- Guides for four common types of financial caregivers:
  - Agents under a Power of attorney
  - Guardians and conservators
  - Trustees
  - Social Security and VA representatives
- Includes tips on protecting assets from fraud and scams.
- Available in English and Spanish

consumerfinance.gov/managing-someone-elses-money
Health Resources and Services Administration’s Caregiving Activities

Joan Weiss, PhD, RN, CRNP, FAAN
Senior Advisor
Division of Medicine and Health Resources and Services Administration
Geriatrics Workforce Enhancement Program

Purpose

• Develop a healthcare workforce to provide value-based care
• Improve health outcomes for older adults
• Maximize patient and family engagement, and
• Integrate geriatrics and primary care.
• In FY 2017, trained 26,600 caregivers.
Evaluation and Dissemination

Value-Based Care
Improved Patient Outcomes
Practice Change

Education and Training

Reciprocal Partnerships
Primary Care Sites/Systems
Community-Based Organizations

Workforce Training
Community-Based
Interprofessional
Academia

Clinical Training Environments
Integrating Geriatrics and Primary Care
Age-Friendly Health Systems
Dementia-Friendly Communities

Person-Centered Care
Patients
Families
Caregivers

Scale Up/Spread
Sustain
Purpose

• Assist providers in understanding and addressing caregiver needs
• Assist family and other caregivers to take care of their own health and manage the challenges of caregiving
Purpose

• Support the career development of individual junior faculty as academic geriatrics specialists
• Provide clinical training in geriatrics, including the training of interprofessional teams of healthcare professionals
• Allopathic medicine, osteopathic medicine, dentistry, nursing, pharmacy, psychology, social work, and allied health
Required CMS Merit-Based Incentive Payment System (MIPS) Measures

- **Dementia Caregiver Education and Support:** Percentage of patients, regardless of age, with a diagnosis of dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes AND referred to additional resources for support within a 12 month period.

- **Care Plan:** Percentage of patients aged 65 years and older who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan.
INDIAN HEALTH SERVICE (IHS)
Provision of evidence-based caregiver support services as an element of care for individuals with Alzheimer’s disease and related dementias.

• 2015-2018: REACH into Indian Country – in partnership with VA and ACL, funded by the Rx Foundation through the Memphis Caregiver Center at the University of Tennessee Health Sciences Center (UTHSC).
  • 80 caregiver coaches trained and certified in 56 distinct Tribal communities.
  • Delivery of REACH services to 55 caregivers.
  • Caregiver support activity is unevenly distributed among the 50+ communities in which caregivers have been certified.
  • Need for ongoing training, certification, support for the services.

• 2016-2018: Ave 5,436/yr PHN contacts with patients who have a diagnosis of dementia.

• Next steps:
  • Identify additional training resources for PHNs in evidence-based Caregiver Support.
  • Develop tools and resources to support PHN Caregiver Support Services
INDIAN HEALTH SERVICE (IHS)

Infographic: Caregiving among American Indian and Alaska Natives Adults
Developed by CDC in collaboration with IHS and Alzheimer’s Association
Data from 2015-2017 Behavioral Risk Factor Surveillance System (BRFSS)

• 1 in 4 AI/AN adults are Caregivers
• Half have provided care for more than 2 years
• Almost half have provided care for at least 20 hours per week.
• 56% are women
• 16% are aged 65 or older
• 35% are caring for a parent or parent in-law
• 7% are providing care for someone with dementia
• Nearly 1 in 5 adults not currently providing care can expect to become a caregiver in the next 2 years.

Senior Corps Volunteers

- **Foster Grandparent**
  - Low-income - 200% poverty level
  - Receive a small tax-free stipend
  - Serve in schools, Head Start and other child-centered facilities
  - Serve as tutors, mentors
  - Support at-risk/special needs children

- **Senior Companion**
  - Low-income - 200% poverty
  - Receive a small, tax-free stipend
  - Supports independence
  - Serve homebound individuals
  - Serve a minimum

- **RSVP**
  - Any income level
  - Serve in diverse roles based on community need
  - Recruit and manage other volunteers
  - No limitations on number of hours served
  - No financial compensation
Senior Corps Caregiver Support

• **Senior Companion Volunteer Services**
  - Respite for family and other caregivers
  - Door-to-door transportation to medical and other appointments
  - Grocery-shopping
  - Meal preparation
  - Light housekeeping
  - Friendly visits
  - Other simple chores
  - No cost to recipient

• **RSVP Volunteer Services**
  - Respite for family and other caregivers
  - Door-to-door transportation to medical and other appointments
  - Grocery-shopping
  - Errands/other simple chores
  - Friendly visits—home/hospice
  - Light housework
  - Meals on Wheels delivery
  - Retrofits for in-home safety
  - No cost to recipient
Senior Corps Caregiver Support

• Volunteer Requirements
  – Must be age 55 or older
  – Submit to and pass background check
  – Possess valid driver’s license/car insurance

• Volunteer Benefits
  – Accident and liability insurance (during volunteer service)
  – Mileage reimbursement
  – Volunteer recognition
Family Caregiving Research at The National Institutes of Health

**Caregiving research definition:** Research involving caregiving (the act of doing) rendered by a caregiver (the doer) on an individual (care recipient) across the care continuum and the full spectrum of the disease/illness/disability trajectory process.

Parent's normative caregiving in the wellness spectrum for children/adolescents is not applicable; caregiving for the aging elderly population across the wellness to illness spectrum is applicable.

**Central topics of interest**
- Elder abuse
- Burden and benefits
- Economics
- Disparity
- Complexity of care
- End-of-life care
- Development of tools, programs, educational materials, technologies, interventions to promote care outcomes & assist caregivers
- Improving quality of life
- Bereavement
- High-risk caregivers
- Resiliency
- Decision-making
# Grants 2014 to present

- National Institute on Aging: 25, 8, 7
- National Cancer Institute: 31
- Total: 183
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<thead>
<tr>
<th>IC</th>
<th>Title</th>
<th>Activity code</th>
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<tbody>
<tr>
<td>NCI</td>
<td>Innovative Approaches to Studying Cancer Communication in the New Information Ecosystem</td>
<td>R21/R01</td>
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<tr>
<td>NCI</td>
<td>Improving Outcomes for Pediatric, Adolescent and Young Adult Cancer Survivors</td>
<td>U01</td>
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<tr>
<td>NINR</td>
<td>Addressing Caregiver Symptoms through Technological Tools</td>
<td>R21/R01</td>
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<tr>
<td>NINR</td>
<td>Promoting Caregiver Health Using Self-Management</td>
<td>R01</td>
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<tr>
<td>NIA</td>
<td>Notice to Specify High-Priority Research:</td>
<td>R21/R01</td>
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<td>• Behavioral and Social Science Priority Areas in Dementia Caregiver Research;</td>
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<tr>
<td></td>
<td>• Behavioral and Social Science Priority Areas in Dementia Care Research: Programs and Services for Persons with Dementia</td>
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<tr>
<td>NIA</td>
<td>Interpersonal Processes in Alzheimer's Disease and Related Dementias Clinical Interactions and Care Partnerships</td>
<td>R01</td>
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<tr>
<td>NIA</td>
<td>Lucidity in Dementia</td>
<td>R21</td>
</tr>
<tr>
<td>NIA</td>
<td>Assistive Technology for Persons with Alzheimer's Disease and Related Dementias and Their Caregivers</td>
<td>R41/R42 &amp; R43/R44</td>
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<tr>
<td>NIA</td>
<td>Development of Socially-Assistive Robots (SARs) to Engage Persons with Alzheimer's Disease (AD) and AD-Related Dementias (ADRD), and their Caregivers</td>
<td>R41/R42 &amp; R43/R44</td>
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Division of Family and Consumer Sciences

Presentation to the Family Caregiving Advisory Council (FCAC) Federal Partners

August 28-29, 2019
DFCS strengthens the reach of knowledge gain and skills learned by individuals by promoting community-based programs delivered through the Cooperative Extension System that focus on adult development and aging.
DFCS provides national leadership and administrative oversight for projects that involve integrated, potentially interdisciplinary, and multistate activities that focus on adult development and aging.

- Children, Youth, and Families at Risk (CYFAR) Sustainable Community Projects

- AgrAbility – Assistive Technology Program for Farmers with Disabilities

- Smith Lever Special Needs Grant Program

- The Rural Health and Safety Education Grant Program
DFCS provides national leadership and administrative oversight for projects that involve integrated, potentially interdisciplinary, and multistate activities that focus on adult development and aging.

• Preventing Financial Exploitation of Older Adults (W-2191 | 2012-2017)

• Examining Elder Family Financial Exploitation to Inform Prevention Education

• Elder Financial Exploitation: Family Risk and Protective Factors

• Aging in Place: Home and Community in Rural America
USDA/NIFA partners with the Department of Justice and other federal agencies in developing strategies/recommendations that impact older adults and caregivers.

View all resources from the Rural and Tribal Elder Justice Summit at https://www.justice.gov/elderjustice/rural-and-tribal-resources