

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

VA



U.S. Department
of Veterans Affairs

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 clarify 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)

KEY AREAS	KEY INSIGHTS
Standardization of Current Program	<ul style="list-style-type: none"> • A lack of clear eligibility criteria results in an influx of applications from ineligible dyads. • Unclear eligibility criteria leads to inconsistent interpretation and execution of CSP's guidance across sites, often resulting in the enrollment of ineligible dyads. • Dyads are confused and upset by discharges and tier reductions, which is intensified by inconsistent communication from the program. • Because mental and physical injuries require different types of caregiving, separate evaluation criteria may be more appropriate.
Considerations for PCAFC Program Expansion	<ul style="list-style-type: none"> • 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. • 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. • VA providers do not understand the caregiving services provided by CSP and frequently refer ineligible dyads to the PCAFC. • VA providers often do not recognize Caregivers and fail to include them in the care planning of their Veterans. • Veterans and Caregivers desire clearly communicated information about the PCAFC and the criteria for eligibility.
Impacts of Stipend Dependence	<ul style="list-style-type: none"> • Dyad success requires Caregivers, Veterans, providers, and staff to understand and embrace the possibility of the Veteran's recovery. • Over time, Caregivers become dependent on receiving a stipend. When the stipend decreases or stops, dyads find themselves financially unprepared. • 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.

Resources and References

- VA; <https://www.VA.gov>
 - VA Welcome Kit; <https://www.VA.gov/Welcome-Kit/>
 - VEO; <https://www.VA.gov/VE/>
 - Community Resources, Information, and Toolkits; <https://www.VA.gov/VE/Engagement/Resources.asp>
 - VA Welcome Kit and Quick Start Guides; <https://www.VA.gov/Welcome-Kit/>
 - Veterans Journey Map; <https://innovation.ed.gov/files/2016/08/journeysofveteransmap.pdf>
 - Mission Act Tools; <https://vaww.insider.va.gov/MISSION-Act/>
 - National Resource Directory; <https://nrd.gov/>
- 

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

HHS/CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)



CMS EFFORTS TO SUPPORT CAREGIVERS

Family Caregiving Advisory Council
August 2019

Medicaid Program – A Snapshot

- 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](https://www.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.

Medicare At A Glance

➤ 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

HHS/ADMINISTRATION FOR CHILDREN AND FAMILIES (ACF)

HHS/OFFICE OF THE NATIONAL COORDINATOR (ONC)

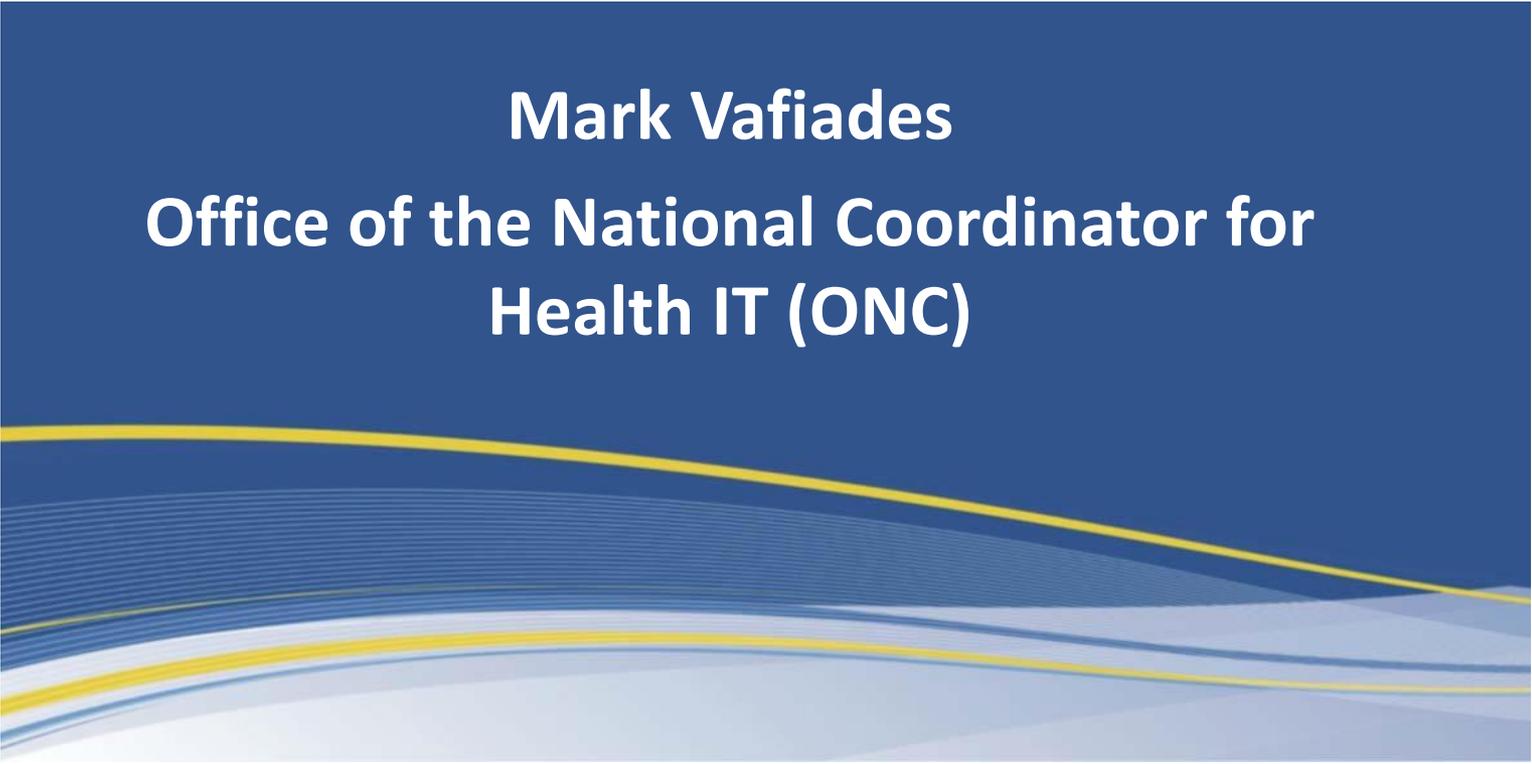
Improving Care Coordination between Care Settings and Caregivers



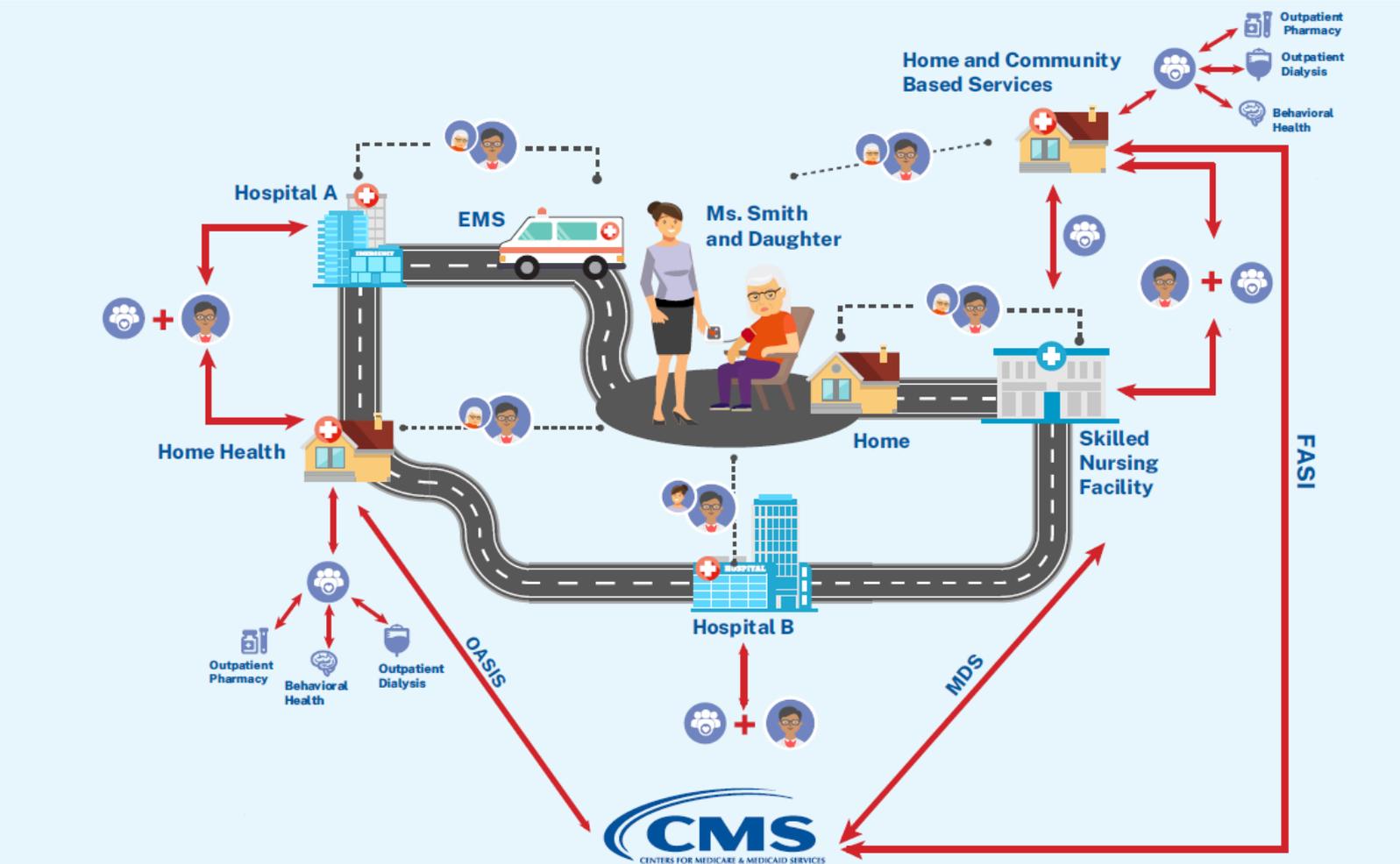
Mark Vafiades



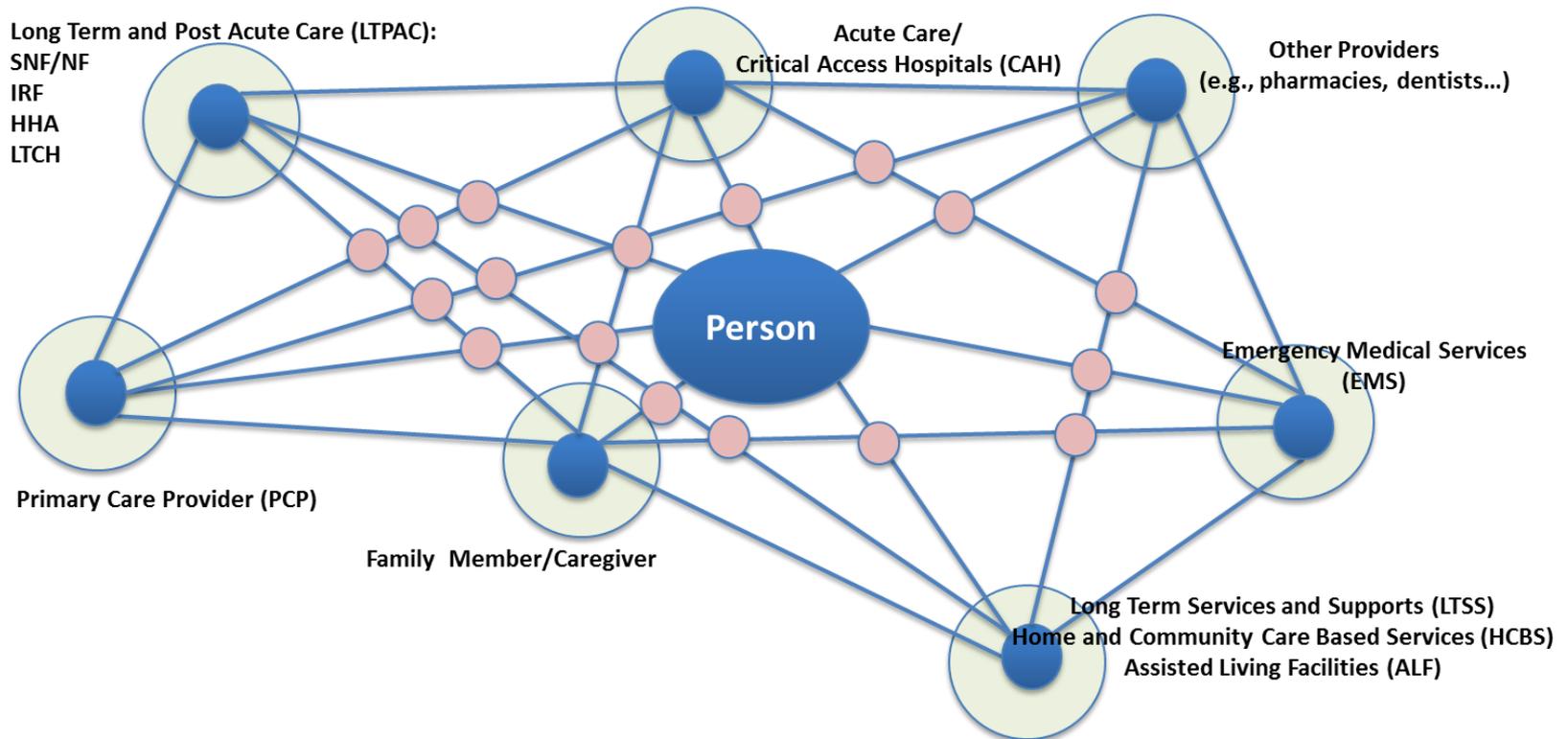
Office of the National Coordinator for
Health IT (ONC)



The Patient Story



Data Availability and Real-time Exchange



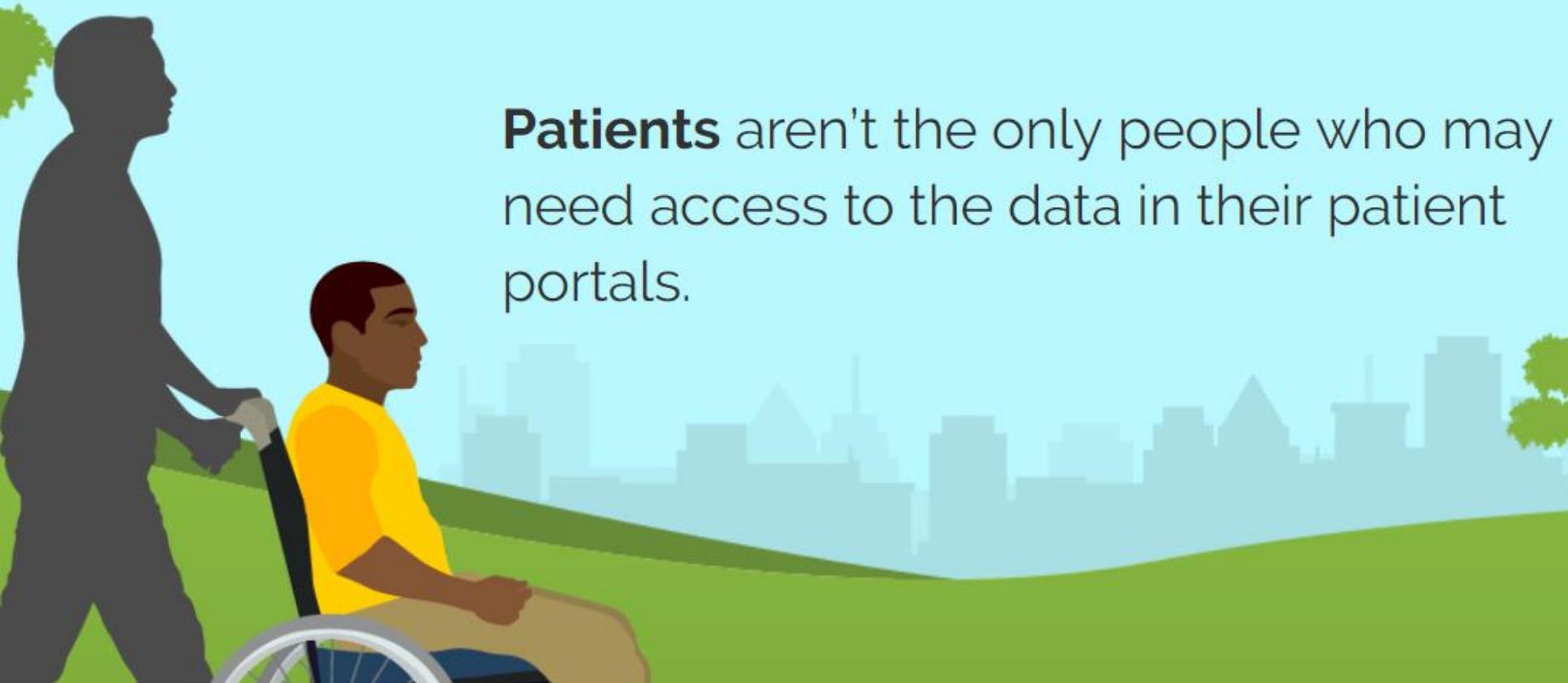
Support data availability in real-time. Electronic information is exchanged and used by health IT systems without special effort on the part of the user.

Allow Access for Caregivers

Get started

Patient Access to the EHR

Patients aren't the only people who may need access to the data in their patient portals.



Caregiver Access to the EHR

An illustration showing a caregiver in a blue shirt pushing a person in a wheelchair. The person in the wheelchair is a dark silhouette. They are walking on a green hill with a city skyline in the background under a light blue sky.

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

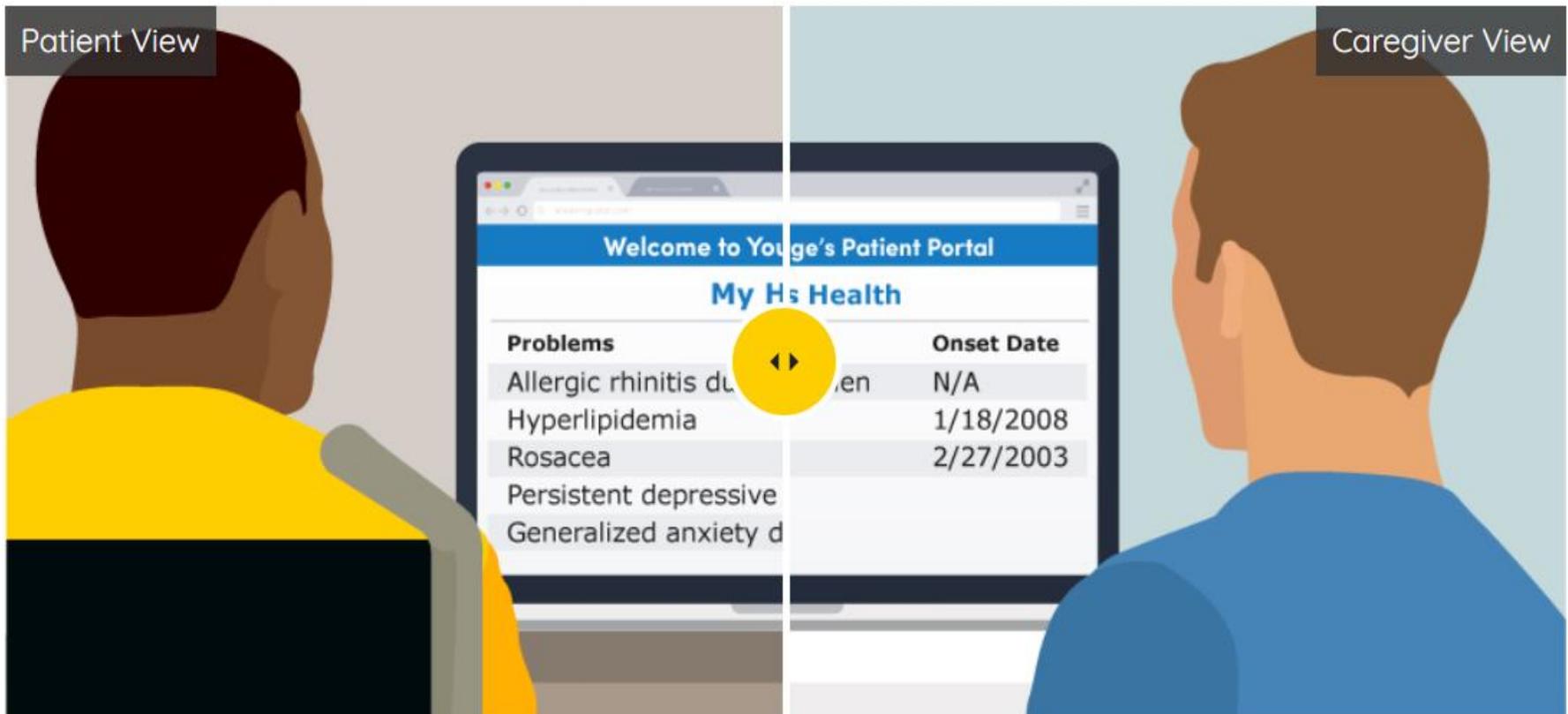
Patient Portal Access

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

Patient Portals Access

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.**



21st Century Cures Act

Key provision in Cures:

- Patients should be able to access all their Health information on their smartphone at no charge.

Resources

ONC Patient Engagement Playbook:

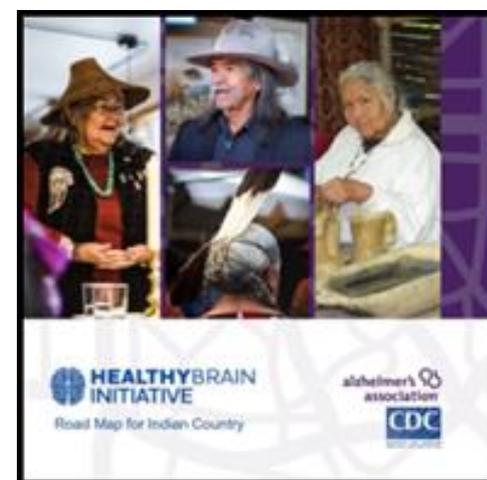
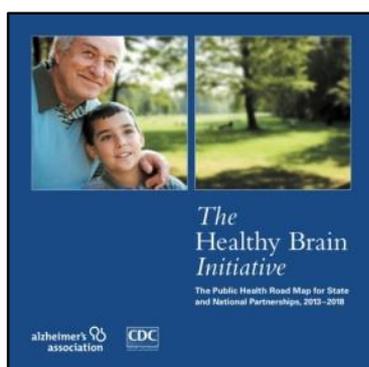
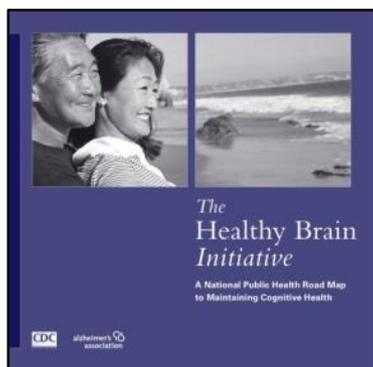
Chapter 4: *Allow portal access for caregivers*

- <https://www.healthit.gov/playbook/pe/chapter-4/>
- [Healthit.gov](https://www.healthit.gov)
- Mark Vafiades- mark.vafiades@hhs.gov

CENTERS FOR DISEASE CONTROL & PREVENTION



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 challenges of caring for persons with Alzheimer's and other dementias can become difficult and overwhelming, especially when intensive care is needed for long periods of time. For many, however, caregiving is also a rewarding experience, bringing family members closer together in time of great need.

In 2017, 16 million family members and friends provided 18.4 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of more than \$232 billion.¹

Public health can play a central role in offering information, guidance, and supportive resources to caregivers to help them provide effective dementia care and attend to their own well-being. Public health can also work with partners to facilitate access to affordable, evidence-informed services, programs, interventions, and supports to reduce stress and improve coping, self-efficacy, and overall health. Some of the many resources that public health can help expand, promote, or tailor to specific populations include:

- Community-based programs for physical activity, chronic disease self-care, and caregiver education;
- Peer support groups and social gatherings for people affected by dementia;
- Online support and information resource centers;
- Apps for caregivers and persons living with dementia and GPS tracking devices;
- Home healthcare services and home modification programs;
- Adult day and respite care;
- Advanced care and advanced financial planning;
- Transportation services; and
- Information and referral services.

COMPELLING DATA

Nearly half of all caregivers (48%) who care for an older adult do so for someone with Alzheimer's or another dementia.²

About one in three Alzheimer's caregivers report their health has gotten worse due to care responsibilities, compared with one out of five caregivers of other older adults.³

Among caregivers for people with Alzheimer's and other dementias:

- Nearly one in four are "sandwich generation" caregivers — caring for both an older adult and a child.⁴
- Nearly 60% rate the emotional stress of caregiving as high or very high. As many as 40% report symptoms of depression.⁵
- Caring for people with Alzheimer's can have a negative effect on employment, income, and financial security. Among caregivers for people with Alzheimer's and other dementias who are employed full or part time, 57% said they had to go into late, leave early, or take time off because of their caregiving responsibilities. In addition, 18% had to go from full to part time, 16% took a leave of absence, and 5% turned down a promotion due to the burden of caregiving.⁶
- Only half of employers have policies that support caregivers: 53% offer flexible work hours/paid sick days, 32% offer paid family leave, 23% offer employee assistance programs, and 22% allow telecommuting.⁷



For the Full HBI Road Map, data, ready-to-use resources, and case studies, visit: alz.org/publichealth or cdc.gov/aging

THE CAREGIVING ACTION AGENDA

The Healthy Brain Initiative's (HBI) *State and Local Public Health Partnerships to Address Dementia, The 2018–2023 Road Map* charts a course for state and local public health agencies and their partners to act quickly and strategically to prepare all communities by stimulating changes in policies, systems, and environments. Many of the Road Map's 25 expert-developed actions would help meet the needs of dementia caregivers.

EDUCATE & EMPOWER

E.3 Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and well-being.

E.4 Promote prevention of abuse, neglect, and exploitation of people with dementia.

E.5 Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia.

E.6 Strengthen knowledge about, and greater use of care planning and related tools for people in all stages of dementia.

E.7 Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence.

DEVELOP POLICIES & MOBILIZE PARTNERSHIPS

P.1 Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia.

P.5 Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers.

P.6 Assure public health plans that guide emergency preparedness and emergency response address the special needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people with dementia.

ASSURE A COMPETENT WORKFORCE

W.2 Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.

W.3 Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.

W.4 Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnosis and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.

W.7 Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services.

MONITOR & EVALUATE

M.1 Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022.

M.2 Support national data collection on dementia and caregiving.

M.3 Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.

M.4 Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact.

M.5 Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers.

PUBLIC HEALTH STRATEGIES TO SUPPORT CAREGIVERS

The following are examples of how public health departments are supporting dementia caregivers.

NEW YORK

New York State

Department of Health

(NYSDOH) expanded caregiver and clinical

supports across the state

through its Alzheimer's

Disease Caregiver

Support Initiative (ADCSCI)

Grounded in an effective model program developed by

New York University (NYU) and others, ADCSCI promotes

early diagnosis and has a protocol for providing education,

care consultation, and a plan for medical and social

services to persons living with Alzheimer's and their

caregivers — thereby helping facilitate clinical-community

linkages.

To augment its \$2 million annual budget, NYSDOH

prepared a funding proposal based on data documenting

impact of evidence-based support models and state

surveillance data on caregiving and cognitive impairment.

The proposal called for adapting the model for statewide

implementation — with the ultimate outcome of keeping

people living with Alzheimer's dementia in the community

longer and reducing caregiver stress. After several years,

the department's proposal was included in the governor's

budget, and bipartisan legislative approval resulted in an

annual \$25 million infusion to the NYSDOH budget for

an expanded array of services. The scope of New York

State's investment enabled extensive scale in both service

availability and utilization. In the first year, community

support services for people with dementia and their

caregivers reached approximately 13,000 individuals and

families; as the expanded capacity reaches maturity, it is

expected to serve many more New Yorkers each year.

NEW MEXICO

New Mexico Department

of Health partnered with

the state's Aging and Long-

Term Services Department

to encourage caregivers of

people with memory loss

or dementia to participate

in a free Savvy Caregiver

course. Graduates learn how to

handle the challenges of

caring for a family member with Alzheimer's and other

dementias and care for themselves. A second course,

developed by Stanford University, educated persons with

chronic conditions and their caregivers on topics such as:

managing common chronic disease conditions, participating

in treatment decisions, problem-solving and adhering to

treatment plans, making advance directives, and

maintaining a healthy lifestyle.

The health department chose to co-market the courses

because older adults living with dementia are more likely

than their peers to have multiple chronic conditions,

including hypertension, heart disease, or diabetes. As an

additional way to support people affected by dementia, the

health department posted information on cognitive decline

and dementia on the New Mexico Department of Health

website.

The Full HBI Road Map, other examples of strategies used by state public health agencies, and additional resources are available at alz.org/publichealth and cdc.gov/aging.

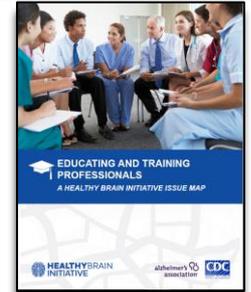
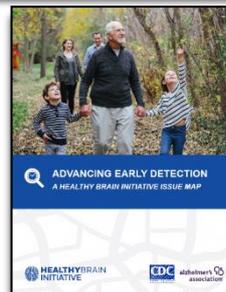
Data to guide your efforts can be found on your state's portal at alz.org/publichealth and at the Centers for Disease Control and Prevention's Healthy Aging Data Portal at cdc.gov/aging.

Disclaimer

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January 2019

www.cdc.gov/aging/healthybrain/roadmap.htm



CAREGIVING DATA FOR ACTION



CAREGIVING

2015–2017 Behavioral Risk Factor Surveillance System (BRFSS) Data from adults in 44 States, Puerto Rico, and the District of Columbia



1 in 5 adults are caregivers

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

PRESTACIÓN DE CUIDADOS

Datos del Sistema de Vigilancia de Factores de Riesgo del Comportamiento (BRFSS), del 2015 al 2017, correspondientes a adultos hispanos en 44 estados, Puerto Rico y el Distrito de Columbia



1 de cada 5 adultos hispanos se encarga de prestar cuidados

Los ENCARGADOS DE CUIDADOS se ocupan de atender o asistir en forma habitual a un AMIGO o FAMILIAR con problemas de salud o una discapacidad

ALASKA CAREGIVING



2017 Behavioral Risk Factor Surveillance System (BRFSS) Data



1 in 5 adults are caregivers

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

CAREGIVING CAN BE

LENGTHY
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?

Over 80% manage household tasks

50% assist with personal care



FUTURE CAREGIVERS

1 in 7 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
cdc.gov/aging
CS 11/2014 February 2014



Caregiving for Family and Friends — A Public Health Issue

Caregiving is an important public health issue that affects the quality of life for millions of individuals. Caregivers provide assistance with another person's social or health needs. Caregiving may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation. It also may involve emotional support and help with managing a chronic disease or disability. Caregiving responsibilities can increase and change as the recipient's needs increase, which may result in additional strain on the caregiver.^{1,2} Caregivers can be unpaid family members or friends or paid caregivers.^{3,4} Informal or unpaid caregivers are the backbone of long-term care provided in people's homes. In particular, middle-aged and older adults provide a substantial portion of that care in the US, as they care for children, parents or spouses.^{5,6} These informal caregivers are the focus of this brief.^{1,2}

Caregiving can affect the caregiver's life in a myriad of ways including his/her ability to work, engage in social interactions and relationships, and maintain good physical and mental health.⁷ Caregiving also can bring great satisfaction and strengthen relationships, thus enhancing the caregivers' quality of life. As the population ages and disability increases, it is critical to understand the physical and mental health burden on caregivers, the range of tasks caregivers may perform, and the societal and economic impacts of long-term chronic diseases or disability.⁸ Gathering information on these topics enables us to plan for public health approaches to assist individuals as well as their communities and maintain the health of caregivers and care recipients.⁹

Informal caregivers provide regular care or assistance to a friend or family member who has a health problem or disability.¹⁰



Alzheimer's Disease and Healthy Aging Data Portal

The Alzheimer's Disease and Healthy Aging Data Portal provides easy access to national and state level CDC data on a range of key indicators of health and well-being for older adults, including:

- Caregiving
- Subjective Cognitive Decline
- Screenings and vaccinations
- Mental health

These indicators provide a snapshot of currently available surveillance information, and can be useful for prioritization and evaluation of public health interventions.

Explore Alzheimer's Disease and Healthy Aging Data By Location

Explore Alzheimer's Disease and Healthy Aging Data for all indicators for one location: the U.S., a region, or a state.

Location (Select one) GO



Explore Alzheimer's Disease and Healthy Aging Data By Indicator

Explore Alzheimer's Disease and Healthy Aging Data for one indicator for all available locations.

Category (Select one) GO

Create Custom Reports and Visualizations

Go to the Alzheimer's Disease and Healthy Aging Data Portal to create a custom report, customize visualizations, download data, and more.

[Alzheimer's Disease and Healthy Aging Data Portal](#)

Alzheimer's Disease and Healthy Aging Data Publications
State of Alaska in America's Data Briefs
Healthy Aging and Disease Burden
Caregiving Indicators
Subjective Cognitive Decline Indicators

www.cdc.gov/aging

CAREGIVING AMONG AFRICAN AMERICAN ADULTS

2015–2017 Behavioral Risk Factor Surveillance System (BRFSS) Data from African American adults in 44 States, Puerto Rico, and the District of Columbia



Nearly 1 in 4 African American

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

CAREGIVING AMONG AMERICAN INDIAN/ALASKA NATIVE ADULTS

2015–2017 Behavioral Risk Factor Surveillance System (BRFSS) Data from American Indian and Alaska Native adults in 44 States, Puerto Rico, and the District of Columbia



1 in 4 American Indian/Alaska Native

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

CAREGIVING AMONG HISPANIC ADULTS

2015–2017 Behavioral Risk Factor Surveillance System (BRFSS) Data from Hispanic adults in 44 States, Puerto Rico, and the District of Columbia



1 in 6 Hispanic

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

PRESTACIÓN DE SERVICIOS ENTRE ADULTOS HISPANOS

Datos del Sistema de Vigilancia de Factores de Riesgo del Comportamiento (BRFSS), del 2015 al 2017, correspondientes a adultos hispanos en 44 estados, Puerto Rico y el Distrito de Columbia



1 de cada 6 adultos hispanos se encarga de prestar cuidados

Los ENCARGADOS DE CUIDADOS se ocupan de atender o asistir en forma habitual a un AMIGO o FAMILIAR con problemas de salud o una discapacidad

¿QUIÉNES SON LOS ENCARGADOS DE CUIDADOS?

PRESTAR CUIDADOS PUEDE SER

UN PROCESO LARGO
Casi la mitad han prestado cuidados por al menos dos años



UN PROCESO INTENSO
Una tercera parte los han provisto por un mínimo de 20 horas semanales



¿CÓMO AYUDAN LOS ENCARGADOS DE CUIDADOS?

Cerca del 80% se ocupa de las tareas del hogar



Más del 50% asiste con el cuidado personal

El 58% son mujeres

El 19% son mujeres de 65 años o más

El 36% está cuidando a sus padres o padres políticos

El 8% cuida a alguien con demencia



FUTUROS ENCARGADOS DE CUIDADOS

Casi 1 de cada 4 personas que NO ESTÁN ENCARGADAS DE PRESTAR CUIDADOS en la actualidad espera HACERLO dentro

HHS/ASSISTANT SECRETARY FOR PLANNING AND EVALUATION (ASPE)



Office of the Assistant Secretary for Planning and Evaluation

OFFICE OF DISABILITY, AGING, AND
LONG-TERM CARE POLICY

HELEN LAMONT, PH.D.

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

HHS/SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

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 Headquarters

Date: May 24, 2019



SAMHSA
Substance Abuse and Mental Health
Services Administration

SAMHSA's Mission Statement

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.

SAMHSA Programs Supporting Caregivers

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

SAMHSA Programs Supporting Caregivers

Center for Mental Health Services

- Children and Family Programs
 - Tribal Behavioral Health Grants - <https://www.samhsa.gov/grants/grant-announcements/sm-19-005>
 - Infant and Early Childhood Mental Health Grant Program <https://www.samhsa.gov/grants/grant-announcements/sm-18-018>
 - National Child Traumatic Stress Initiative – Category III Community Treatment and Services (CTS) Centers <https://www.samhsa.gov/grants/grant-announcements/sm-16-005>
- Consumer and Family Network Grants
 - Statewide Family Network - <https://www.samhsa.gov/grants/grant-announcements/sm-19-004> -
 - Statewide Consumer Network Program - <https://www.samhsa.gov/grants/grant-announcements/sm-19-002>
- Project LAUNCH - <https://www.samhsa.gov/grants/grant-announcements/sm-19-007>
- Children’s Mental Health Services
 - Grants for the Expansion and Sustainability of the Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances <https://www.samhsa.gov/grants/grant-announcements/sm-19-009>

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>
 - State Pilot Grant Program for Treatment of Pregnant and Postpartum Women <https://www.samhsa.gov/grants/grant-announcements/ti-17-016> Children and Families
 - Enhancement and Expansion of Treatment and Recovery Services for Adolescents, Transitional Aged Youth and their Families <https://www.samhsa.gov/grants/grant-announcements/ti-18-010>
- 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>

HHS/FOOD AND DRUG ADMINISTRATION (FDA)

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

FDA

#PEAC2019

Tuesday, September 10, 2019 • Gaithersburg, MD



TMJA
The TMJ Association, Ltd.

NORD
National Organization
for Rare Disorders

GLOBAL
HEALTHY
LIVING
FOUNDATION

ICAN
International Children's Advisory Network

COPD
FOUNDATION

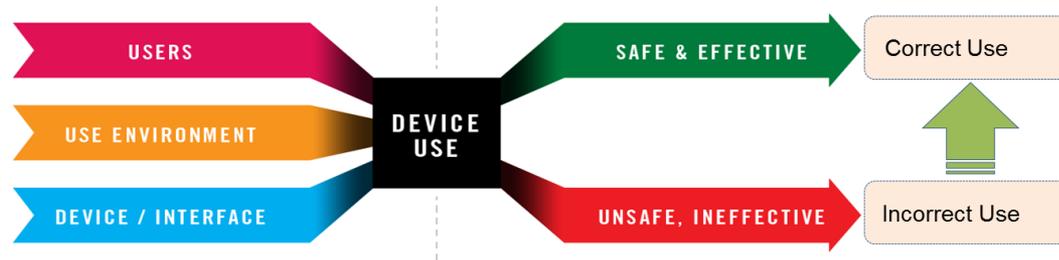
JDRF

FACES &
VOICES
OF RECOVERY

naac
National Alliance for Caregiving

Patient & Caregiver Connection
Provides FDA timely access to aggregated patients' voices

Human Factors Review & Research (FDA CDRH)



- 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

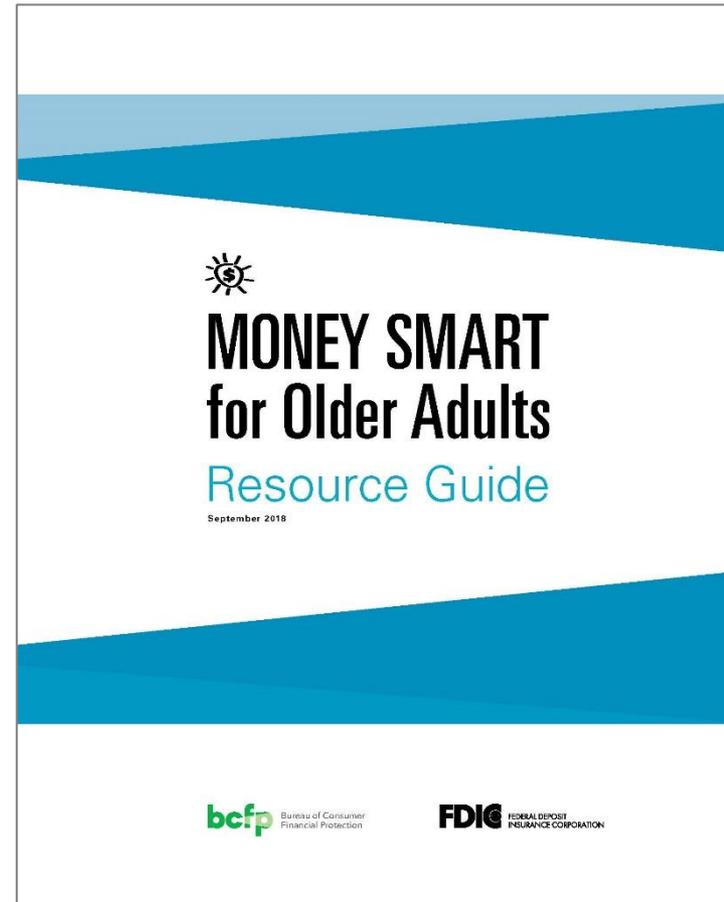
olderamericans@cfpb.gov



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



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

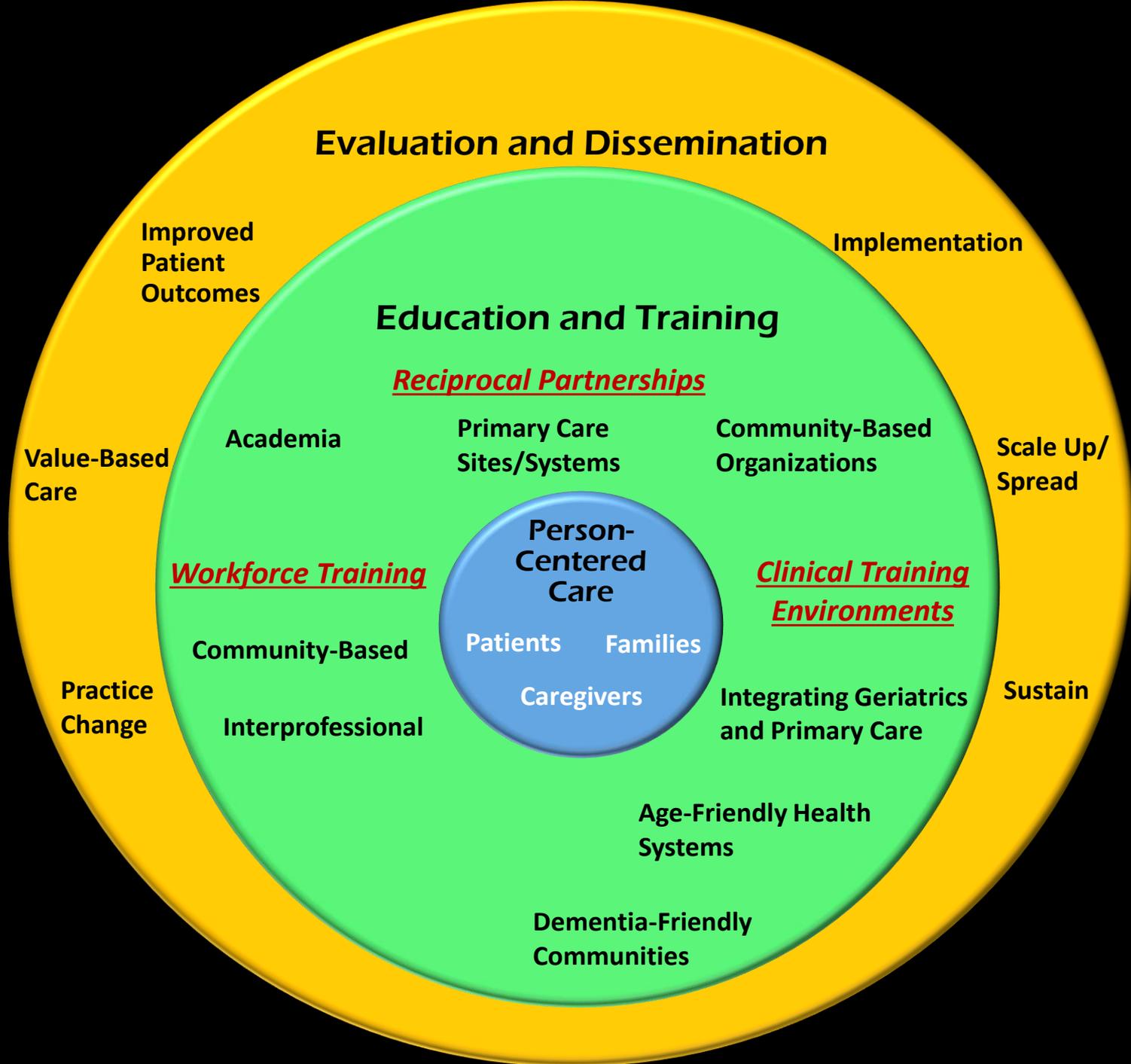


Geriatrics Workforce Enhancement Program

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.





Caregiving Training Curriculum: Alzheimer's Disease and Related Dementias

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

Geriatrics Academic Career Awards Program

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)

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

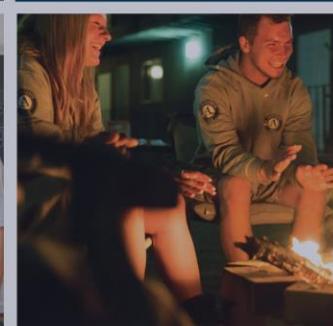
Developed by CDC in collaboration with IHS and Alzheimer's Association
Data from 2015-2017 Behavioral Risk Factor Surveillance System (BRFSS)

- 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.
- <https://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html>

CORPORATION FOR NATIONAL AND COMMUNITY SERVICE



Corporation for
**NATIONAL &
COMMUNITY
SERVICE** ★★ ★



SENIOR CORPS

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 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



- 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

THE NATIONAL INSTITUTES OF HEALTH/NATIONAL INSTITUTE ON AGING

Family Caregiving Research at The National Institutes of Health

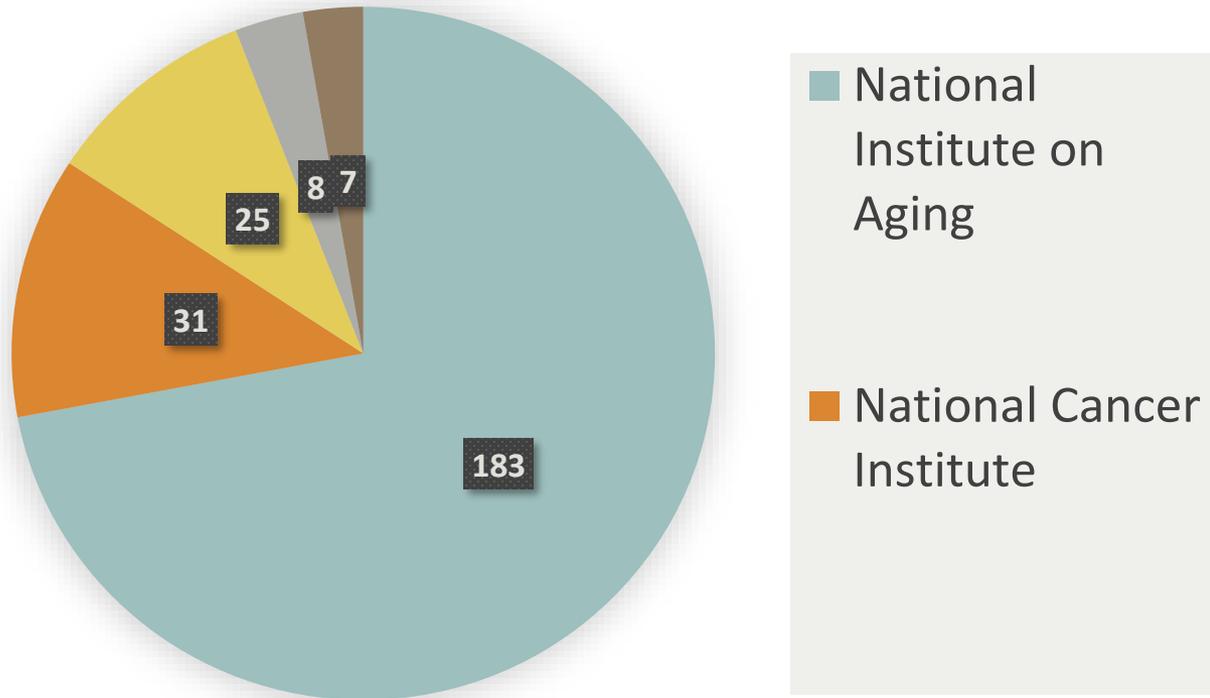
Caregiving research definition: Research involving caregiving (the act of doing) rendered by a caregiver (the doer) on an individual (care recipient) across the care continuum and the full spectrum of the disease/illness/disability trajectory process.

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



Selected Funding Opportunity Announcements

IC	Title	Activity code
NCI	Innovative Approaches to Studying Cancer Communication in the New Information Ecosystem	R21/R01
NCI	Improving Outcomes for Pediatric, Adolescent and Young Adult Cancer Survivors	U01
NINR	Addressing Caregiver Symptoms through Technological Tools	R21/R01
NINR	Promoting Caregiver Health Using Self-Management	R01
NIA	<p>Notice to Specify High-Priority Research:</p> <ul style="list-style-type: none"> Behavioral and Social Science Priority Areas in Dementia Caregiver Research; Behavioral and Social Science Priority Areas in Dementia Care Research: Programs and Services for Persons with Dementia 	R21/R01
NIA	Interpersonal Processes in Alzheimer's Disease and Related Dementias Clinical Interactions and Care Partnerships	R01
NIA	Lucidity in Dementia	R21
NIA	Assistive Technology for Persons with Alzheimer's Disease and Related Dementias and Their Caregivers	R41/R42 & R43/R44
NIA	Development of Socially-Assistive Robots (SARs) to Engage Persons with Alzheimer's Disease (AD) and AD-Related Dementias (ADRD), and their Caregivers	R41/R42 & R43/R44

USDA/DIVISION OF FAMILY AND CONSUMER SCIENCES



United States
Department of
Agriculture

National Institute
of Food
and Agriculture

www.nifa.usda.gov
[@USDA_NIFA](https://twitter.com/USDA_NIFA)

The logo for the National Institute of Food and Agriculture (NIFA), featuring the letters "NIFA" in a large, white, sans-serif font. The background is a green gradient with a stylized white outline of a leaf or plant.

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.



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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



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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



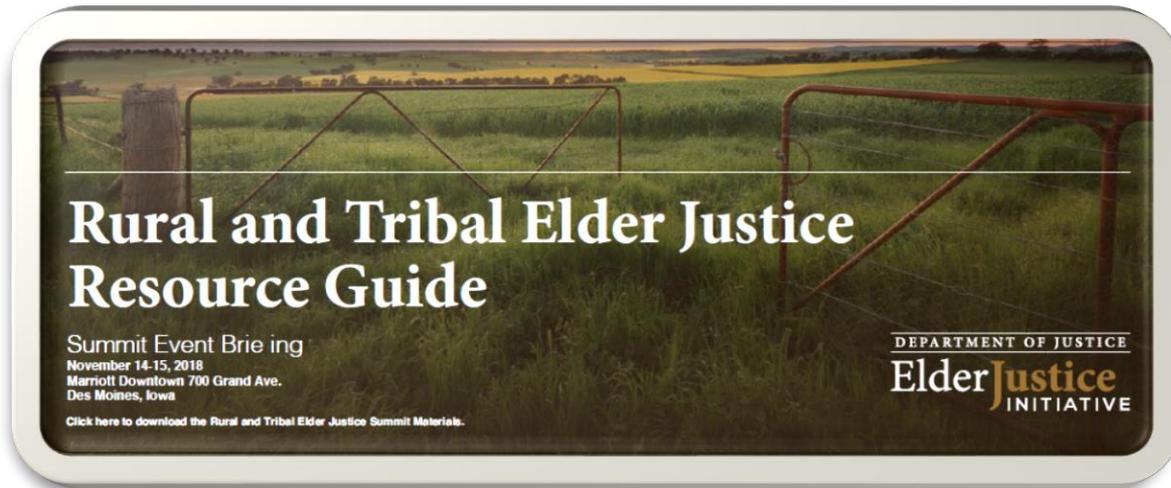
United States
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and Agriculture

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NIFA

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>