Inventory of Federal Caregiver Support Programs and Initiatives

**Prepared by**

The Administration for Community Living

**In coordination with**

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# Background and Overview

When Congress passed the [Recognize, Assist, Include, Support, and Engage Family Caregivers Act](https://acl.gov/sites/default/files/about-acl/2018-10/PLAW-115publ119%20-%20RAISE.pdf), it established the Family Caregiving Advisory Council (the council) and authorized the development of a National Family Caregiving Strategy by federal agencies in collaboration with the council. When this strategy is established and implemented, federal, state, and local partners will take steps to assist family caregivers in providing the best care possible while supporting their own physical and mental health, emotional well-being, and financial needs in the process.

An important step in the development of the strategy is to identify and document existing federal programs and initiatives that assist family caregivers. Specifically, the RAISE Act called for:

“The Advisory Council’s initial report under paragraph (1) shall include— (A) **an inventory and assessment of all federally funded efforts to recognize and support family caregivers and the outcomes of such efforts, including analyses of the extent to which federally funded efforts are reaching family caregivers and gaps in such efforts.**”

This document presents information about more than 50 federal programs and initiatives collected by the council with support from the Administration for Community Living (ACL).

**TERMINOLOGY USED IN THIS INVENTORY**

In this document and throughout the council’s work, the word “family” is used broadly to denote those with biological or legal connections and families of choice. It also acknowledges the fact that “family caregiver” is not the same as “next of kin.” The person receiving support has the right to decide and designate who their preferred family caregiver is—it should never be decided by social services or medical professionals.

The council uses the term “family caregiver” in its broadest and most inclusive sense to encompass:

***“All unpaid individuals of all ages who are caring for individuals with disabilities, chronic or other health conditions, and/or functional limitations*.”**

This term includes family members, partners, friends, kinship and grandfamily caregivers, and the untold millions of youth across the nation who care for family members regardless of the type of assistance needed. It includes part-time caregivers and full-time caregivers. While it is used as a singular noun in this report, the council also recognizes that in some families, multiple individuals serve in this role.

However, it is important to note that the program descriptions that follow the introductory material in this document were submitted by individual agencies. Some federal programs define “family caregiver” as required under statute. When defined in statute, the definition may differ from the definition used elsewhere in this document.

## Incremental Progress in Recognizing Family Caregivers

With the passage of the RAISE Act, Congress took an important step in continuing more than four decades of legislative progress on behalf of family caregivers. In 1966, President Lyndon B. Johnson established what is now known as the President’s Committee for People with Intellectual Disabilities (PCPID). This committee advises the President on ways to improve the quality of life experienced by people with intellectual disabilities and their families.

While the Great Society programs of the 1960s did not include specific provisions for caregivers, by 1975 Congress had amended the [Older Americans Act](https://acl.gov/about-acl/authorizing-statutes/older-americans-act) (OAA), which was signed into law in 1965, to include funding for adult day care services. While the statute did not directly refer to adult day care as respite care for caregivers, it laid the groundwork to providing caregivers options for addressing their respite and related needs.

In 1978, Congress clarified the use of adult day services as a form of family respite care, placing it within a coordinated system of community long-term care services. This was significant because it formally established investments in the well-being of the family caregiver as a means of supporting the person receiving support. Additional amendments to the OAA in the 1980s further solidified recognition—supported by research—of the significant positive impact the well-being and ability of caregivers can have on people living with Alzheimer’s disease and related dementias. Expansions to Medicare and Medicaid in the 1980s continued the process of beginning to formally recognize the role of family caregivers. In 1981, family caregivers benefited indirectly from the addition of Medicaid’s home and community-based services waiver programs. The following year, Congress added a hospice benefit to Medicare that specifically included respite care for caregivers.

In 1990, the passage of the [Americans with Disabilities Act (ADA)](https://www.ada.gov/) prohibited, among other things, discrimination of a caregiver based on “association with” an individual with a “disability” as defined by the ADA.

This increasing recognition of caregivers continued through the 1990s with the inclusion in the OAA of training, counseling, and information services for caregivers, in addition to in-home respite care and expansion of eligibility limits. The [Family Caregiver Support Act of 1993 (S.1072),](https://www.congress.gov/bill/103rd-congress/house-bill/2002/text?r=4643) for example, sought to amend the Social Security Act to enable states to establish programs to support unpaid caregivers. Also in 1993, the [Federal Family and Medical Leave Act](https://www.dol.gov/agencies/whd/fmla) established worker rights of up to 12 weeks of unpaid, job-protected leave to care for oneself or certain family members: child, spouse, or parent. During that time, a number of states rolled out caregiver initiatives offering such services as respite, information and resources, support groups, case management, and education and training programs.

In June 1999 a landmark Supreme Court decision in [*Olmstead v. L.C., 527 U.S. 581*](https://www.ada.gov/olmstead/olmstead_about.htm) held that “unjustified segregation” of people with disabilities is against the law under the ADA. As a result, many states have expanded their home and community-based services (HCBS) systems as part of their larger efforts to achieve *Olmstead* compliance.

The establishment of the [National Family Caregiver Support Program](https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program) (NFCSP) in 2000 marked a significant expansion in support for family caregivers by formally recognizing family caregivers and providing a range of services to allow them to help their family members remain independent for as long as possible. These services include connecting caregivers to private and voluntary agencies that can assist them, counseling and training, and respite care options. Even more importantly, NFCSP funding is provided to every state, territory, and tribe, requiring the establishment of a basic set of services and supports available to family caregivers.

That same year, the [Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)](https://acl.gov/node/106) stipulated that the [56 State DD councils](https://acl.gov/sites/default/files/programs/2016-11/Councils_factsheet.pdf) include representation by people with disabilities and their caregivers, guardians, and/or parents, paving the way for more family-centered community services, individualized supports, and other forms of assistance (ACL, 2017).

In 2006, the Lifespan Respite Act expanded access to respite to people of all ages across the nation. It sought to increase availability of respite options for family caregivers of children and adults with physical, cognitive, and intellectual disabilities.

In 2010, the [Caregivers and Veterans Omnibus Health Services Act (PL 111-163)](https://www.govinfo.gov/app/details/PLAW-111publ163) directed the U.S. Department of Veterans Affairs to establish a Program of General Caregiver Support Services (PGCSS) and a Program of Comprehensive Assistance for Family Caregivers (PCAFC), collectively referred to as VA’s Caregiver Support Program (CSP), thus establishing caregiver support in the nation’s largest integrated health care system. The National Academies of Sciences, Engineering, and Medicine convened an expert committee in 2014 to examine what is known about the nation’s family caregivers of older adults. The final report, [Families Caring for an Aging America](https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america), found that while the need for family caregivers across the nation is growing, efforts to address that need proactively were modest at best. Accordingly, the report recommended that Congress convene a council to develop a National Family Caregiving Strategy (National Academies of Sciences, Engineering, and Medicine, 2016). That recommendation engendered the passage of the RAISE Family Caregivers Act of 2017.

Not all legislative activity on behalf of family caregivers has occurred at the federal level. Numerous states have begun enacting legislation to better recognize and support family caregivers. In 2014, AARP successfully advocated for the [Caregiver Advise, Record, Enable (CARE) Act](https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf) to support caregivers when patients go into the hospital and to help caregivers understand what will be needed when patients are discharged to their homes (Reinhard, Young, Ryan, & Choula, March 2019). While provisions vary by state, to date 44 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands have implemented CARE Act policies that require hospitals to advise people of their opportunity to identify a family caregiver (Reinhard, Young, Ryan, & Choula, March 2019).

The forthcoming National Family Caregiving Strategy will build on these previous efforts and the significant achievements from states such as Pennsylvania, Wisconsin, and Washington that have pioneered innovative caregiver support initiatives. When completed, the strategy will chart a course for the U.S. to better support family caregivers in ways that truly address their needs. It will identify actions that communities, providers, governments, and others can take to recognize and support the family caregivers who put their own lives on hold to assist a broad cross-section of Americans every day.

Since the formation of the council, additional legislation has been passed that advances recognition and inclusion of family caregivers. The [MISSION Act of 2018](https://www.congress.gov/115/bills/s2372/BILLS-115s2372enr.pdf), expanded access to the VA’s PCAFC to caregivers of eligible veterans of all eras, in a phased approach. Previously, only caregivers of eligible veterans who incurred or aggravated a serious injury on or after September 11, 2001 were eligible for this Program. This expansion represented one of the largest federal investments to date in a comprehensive program to support caregivers.

## Previous Efforts to Tabulate Federal Programs

An inventory of existing federal programs and initiatives to support family caregivers as authorized in the RAISE Act has never been undertaken. Two previous inventory efforts offer guidance on how to plan and begin such an undertaking. In 2007, Centers for Medicare & Medicaid Services (CMS) released a white paper, [CMS Support for Caregivers](https://www.cms.gov/Outreach-and-Education/Outreach/Partnerships/downloads/CMSCaregivers91907.pdf), that listed all CMS programs and initiatives that support caregivers. While its purpose was to serve as an education and outreach tool for organizations that work on behalf of caregivers, the document provided a model of an inventory of programs to support caregivers, in part because it was comprehensive. The document included the nine legal authorities under which CMS could support family caregivers, and separately listed all activities to support caregivers in the areas of information, respite care, assessment, training, direct payments to caregivers, and research. There was considerable variation in program scope within the document, ranging from multi-million dollar initiatives, such as the section 1915(c) HCBS waivers and/or section 1115(a) demonstrations within Medicaid, to more discrete efforts such as a series of quarterly conference calls.

In 2011, the Obama administration embarked on a much broader effort to create a comprehensive inventory of all federal programs and provide that information in one central website, [Performance.gov](https://www.performance.gov/). Its creation was required by the 2010 [Government Performance and Results Modernization Act](https://www.performance.gov/cx/assets/files/PLAW-111publ352.pdf) (GPRAMA) in order to provide Congress and the public a clearer picture of the programs that exist across the federal government. In 2013, an initial inventory was released providing descriptions of 1,524 program submitted by 24 agencies.

In 2014, the [Government Accountability Office (GAO) reported](https://www.gao.gov/assets/gao-15-83.pdf) that initial effort had fallen short of fully realizing its original goal. One of the reasons cited for this shortfall was that in soliciting program information, the Office of Management and Budget (OMB) had allowed for significant discretion on the part of respondents which led to a variety of approaches for defining what constitutes a federal program and led to inconsistences in the details collected. Those differences in definition and level of detail resulted to what the GAO called a “lack of comparability” within agencies and across programs included in the inventory.

### Understanding the Challenge

In response to the requirements of the RAISE Act, in 2020, the council and staff at ACL embarked on an information-gathering effort to begin developing an inventory of federal programs and initiatives that provide some form of direct or indirect assistance to family caregivers.

While efforts to understand the needs of and to assist family caregivers exist across federal agencies (e.g., ACL, CMS, Department of Labor), strategic planning about how government can support family caregivers is conducted within specific agencies, which increases decentralization and information siloes and inhibits coordination and cross-cutting analysis across programs. The development of a federal inventory of programs to assist family caregivers would provide greater visibility into existing programs and facilitate efforts by the council to identify program gaps, recommend actions to close those gaps, and improve coordination across agencies. The council’s hope is that in so doing, they will also improve outcomes for family caregivers and the people they support while achieving program efficiencies.

### Information-Gathering Process

ACL staff reviewed both of these previous efforts in the planning phases of developing the inventory of caregiver programs. Noted lessons learned include the need for consistent definition of family caregiver, which does not exist at this time, and the importance of targeting respondents best situated within a given agency to provide accurate and comprehensive information.

Given the complexity and critical importance of this issue and the vast landscape of federal agencies, the council determined that it would begin its information-gathering efforts by surveying the agencies mentioned in the RAISE Act and those represented on the council. From there, it would seek referrals and recommendations to other agencies in the executive branch to expand the information collected. This report includes the information gathered as of May 2021. The council anticipates that the development of the inventory will be an iterative process that will proceed in parallel with the implementation of the National Family Caregiver Strategy, which includes recommendations about defining and measuring caregiving programs.

Council members from both the RAISE Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren Advisory Council representing federal agencies responded to a call for information from the ACL Administrator. Each federal council representative was responsible for surveying his or her home institution to gather specific knowledge important to caregivers and their families and communities, and the staff and organizations who care for those caregivers. Council members also provided referrals to agencies not represented on the council, such as the Treasury Department, to ensure a broad collection of information. When complete, the council will use this information to increase transparency and improve alignment of caregiving support efforts across the federal government while at the same time avoiding duplication of effort and the creation of gaps in service when developing the National Family Caregiving Strategy.

As of May 2021, the council had collected information from the following agencies:

* AmeriCorps
* Consumer Financial Protection Bureau
* U.S. Department of Education
* U.S. Department of Health and Human Services (10 operating divisions)
* U.S. Department of Labor
* U.S. Department of Veterans Affairs

In addition to receiving input from federal agencies, the council received recommendations of programs to include from the public, which were submitted through ACL’s 2019 request for information (RFI) seeking information on the experiences of family caregivers. Some of those suggestions are included in this document. The RFI also yielded many comments that validated the need for a resource that lists all available programs to assist family caregivers. Multiple responses suggest that existing programs do not meet the diverse needs of family caregivers or the volume of the caregiving population. For example, RFI comments indicate that caregivers are not aware of existing programs or do not feel existing programs are flexible enough to meet their needs. Members of the council also suggested programs for inclusion and provided edits for this document.

### Initial Findings

Within the responses from these agencies, as expected, there was considerable variability in how agencies defined support to caregivers, program scope, level of administration, services provided, and targeted consumers. *In fact, one of the main revelations of the inventory is that there does not exist across the federal government a definition of what a caregiver is, nor are there clear definitions of what constitutes a program, as the GAO previously noted.* Some agencies referred to collections of resources as “programs,” where others used the same term to describe multi-billion-dollar efforts that addressed a range of caregiver needs.

The inventory process identified 50 plus total programs, although not all federal agencies participated. Three programs funded by the federal government were identified as ones that are holistically caregiver-centered and provide an array of services for a wide range of caregiver needs:

* ACL with its National Family Caregiver Support Program and Lifespan Respite Care Program.
* The Veterans Health Administration (VHA)’s Caregiver Support Program.
* HHS’ Administration for Children and Families (ACF) Kinship Navigator Program.

However, because by Congressional mandate each of these programs is limited to a subset of the population linked to the mission of the agency, the reach of these programs is limited. In addition, despite identifying a range of programs that offer some level of support to family caregivers, in the initial review, the council was not able to assess or measure to what extent those programs met the existing needs of the nation’s millions of family caregivers.

Different congressional authorities and legislative priorities have created a piecemeal approach to various aspects of caregiving. There are no programs that cover the broad array of supports for caregivers of people with disabilities of all ages. In other ways, the piecemeal approach has led to overlaps between disparate programs. For example, six separate programs operated by three different federal agencies address—to some degree—the needs of rural caregivers. The programs, such as the Rural Health Care Services Outreach Program, a series of grants funded by the Health Resources and Services Administration (HRSA), tended to address isolation, much-needed improvements to care delivery, and access to timely, quality care in rural settings. However, it was not clear on initial review which of these efforts included practical resources that might benefit, for example, a rural caregiver in need of transportation to a medical appointment—an important challenge for rural caregivers. Nor were any programs identified in 2020 that addressed the pressing need among rural individuals for improved telecommunications and broadband access, and increased digital literacy.

In addition, several agencies identified person-centered initiatives and programs. An example of this is the Patient Listening Sessions offered by the U.S. Food and Drug Administration (FDA). Programs such as this are not aimed specifically at caregivers, but caregivers are important stakeholders who benefit from their existence. If those person-centered services were removed, it is likely that more tasks would fall to the family caregiver.

In sum, the council found that the federal government provides programs (inventory effort collected more than 50 program descriptions) that provide some level of support to family caregivers. However, this figure belies the fact that one of the most commonly cited concerns of family caregivers is the lack of consistent government support. This appears throughout the literature and in the ACL RFI, and reflects the experience of multiple council members and public participants in council deliberations. Moreover, the existing patchwork of family caregiver programs is not flexible and culturally sensitive enough to address the needs of diverse populations nor the size of the caregiving population. This was particularly evident in RFI comments indicating caregivers are not aware of existing programs or do not feel existing programs are flexible enough to meet their needs.

The programs identified during the information-gathering process were diverse in size, scope, and mission. There also appeared to be four root causes for the development and maintenance of federal caregiver support efforts:

* Caregiver specific funding was authorized or mandated by way of legislation.
* Caregiver support programming was developed because it was wrapped into a set of services and supports that addressed the needs of the given population.
* Caregiver support was an area of interest that was through specific funding lines as demonstration projects, or through research grants.
* Caregiver support education was considered so critical that the organization developed services or educational strategies within existing budget lines.

Because of these foundational disparities, the programs identified rarely appeared to be holistically caregiver-centered in their design. Rather, the support of the caregiver was often a secondary focus of the effort. For example, the programs administered by HHS focus on health care or social services, even though some services to caregivers are available. Programs administered by the Department of Education, focus, as one would expect, on childhood education. There does not appear to be a unifying set of definitions of caregiving or of ways of measuring caregiver needs and tracking efficacy. As previously noted, there is no consensus on the statistical prevalence of caregiving. This suggests that there are differing perspectives across federal agencies of the need for interventions to support family caregivers.

These disparities create dissonance between existing programs, which reduces the effectiveness of broad caregiver support efforts. A summary comparison of the list of submitted program descriptions against the five priority (recommendations) areas identified by the council and adopted in November 2020 reveal significant gaps in programs and initiatives that focus on increasing awareness of family caregiving and those that address its related financial challenges. At the same time, while there were a relatively robust number of programs that appeared to conduct research or engage in data collection about caregiving, there does not appear to be coordination across these efforts or a consistent mechanism for information sharing. Finally, while the greatest number of programs offered services and supports to assist caregivers, the anecdotal findings of the RFI suggest that those services are difficult to access and many caregivers do not know they exist, suggesting a need for a mechanism for national coordination of information about services and supports, similar to the Kinship Navigator programs, described here.

In addition, funding mechanisms also varied considerably, which can affect administrative flexibility. Some of the federal efforts, such as the National Family Caregiver Support Program, are funded by way of public law and legislative authority. Other organizations appear to have developed pathways within their operations to pursue supports and strategies that have been found to be important and effective within a unique population served by the agency or within of the area expertise of the agency. An example of this is the [National Family Support Technical Assistance Center](https://www.samhsa.gov/national-family-support-technical-assistance-center) funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), which provides support to family and caregivers of children who experience serious mental illness and/or substance use disorders

Most of the programs identified were modest in size and funding. Only three agencies offered programs that focused specifically on the needs of the caregiver as a primary driver of program design:

* ACL with the NFCSP and the Lifespan Respite Care Program.
* The VHA’s Caregiver Support Program.
* HHS’ ACF Kinship Navigator Program.

Because by congressional mandate each of these programs is limited to a subset of the population linked to the mission of the agency—the reach of these programs is limited. Funding for these programs is also limited. This fragmentary and disparate approach creates missed opportunities for more comprehensive support that comes at significant risk to the ability of family caregivers to support their family members over time. It also hampers the ability to develop and evaluate best practices for caregiver support because most existing programs focus on populations defined by specific, but disparate factors such as disease (cancer caregiving), Medicaid status, age of the caregiver or person receiving care (National Family Caregiver Support Program). These categorizations limit the ability to collect data that reflects the true complexity and heterogeneity of family caregiver needs.

A significant limitation of the information-gathering process was the fact that even within specific agencies, not all programs were easily identifiable as direct or indirect sources of support to family caregivers. It quickly became clear to ACL staff that developing the inventory would necessarily be an iterative process as awareness increases across the federal government about systemic information gathering as a necessary step in developing programs that support family caregivers. For this reason, the Inventory of Federal Caregiver Support Programs and Initiatives will be updated over time with updates provided to the council.

## Existing Federal Approaches to Assisting Caregivers

Over recent decades, a number of approaches have emerged to support family caregivers including direct support programs that address a range of caregiver needs, single service approaches where specialists offer interventions that fill specific caregiving gaps, training and education initiatives aimed at increasing confidence and efficacy among caregivers, and peer-to-peer interventions that include counseling, training, and respite. Often, successful efforts begin in communities or states, as either grass roots efforts or part of a demonstration project.

In fact, existing federal efforts to support caregivers were often an attempt to bring to scale successful approaches tested at the state and local levels. A proven example of this is the National Family Caregiver Support Program, which had its genesis in several successful state caregiver programs. Despite limited funding, since the passage of the National Family Caregiver Support Act in 2000, a growing body of federal programs and initiatives have emerged to coordinate and disseminate information, best practices, and services for family caregivers. Congress’ call for a National Family Caregiving Strategy—which is to be informed by the development of an inventory of existing federal programs—is an important step in the realization of a vision where caregivers across the nation can receive the assistance they need in a coordinated and efficient manner.

### Overarching Considerations of Effective Caregiver Support

While there are many ways to assist caregivers, the recognized first step involves understanding caregiver needs in relation to the care needs of the person receiving support. Without a systematic approach to assessing the overall needs of the family, developing a comprehensive system of support for the caregiver is compromised, which, in turn, exposes the family caregiver to negative consequence linked to the caregiving experience (e.g., burden, stress, depression, poorer than expected health outcomes).

Over the past two decades there have been increasing calls from professional societies, advocacy organizations, and consensus committees for a standardized, universally available assessment of the family caregiver as an important component of a person- and family-centered care planning process. Thus, the development of numerous approaches and tools focused on caregiver assessment have merged in recent years. Some are designed for specific populations. Others are designed to be a comprehensive assessment of a variety of caregiving situations. Two evidence-based approaches to caregiver assessment are 1) the [BRI Care Consultation](https://www.benrose.org/-/bricareconsultation) used with caregivers of adults with dementia and other conditions, and 2) a comprehensive caregiver assessment tool, the [Tailored Caregiver Assessment and Referral](https://www.tailoredcare.com/) (TCARE).

Caregiver assessments can take place in the home or a clinical setting—or in some cases over the phone or via telehealth. A typical assessment might involve a trained professional or peer caregiver asking the family caregiver—in a non-judgmental way—about:

* Their caregiving tasks.
* Their comfort level and confidence performing these tasks (including the use of or interest in using technologies related to caregiving).
* Their overall emotional and physical well-being.
* Their own goals.
* Their ability and willingness to continue to be a caregiver.
* The types of supports they feel would be most helpful to them.
* Their legal and financial needs.
* The levels of paid and unpaid support they currently have.
* Their basic eligibility for existing services and supports (level of impairment, household or individual income, VA status, etc.).

**Caregiver Assessment: A Tool for Understanding What the Caregiver Needs**

Caregiver assessment is a systematic process of gathering information about (1) the caregiver’s specific problems, needs, strengths, and resources; (2) the needs of the person receiving support; (3) the caregiver’s ability to help meet those needs; and (4) caregiver interactions or relationships with health care teams and/or LTSS systems. The findings of the assessment form the basis of a support plan tailored to the needs of the caregiver and can include care consultation, training, respite, and other supports (Feinberg & Houser, Assessing Family Caregiver Needs: Policy and Practice Considerations, 2021).

The answers to these questions form the basis of a culturally sensitive plan for helping the caregiver continue to provide support. Interventions could involve education and counseling, offering potential respite opportunities, soliciting other family members to assist with caregiving, role modeling caregiving for the caregiver, and fostering the idea that the family caregiver is not alone. As noted previously, caregiver assessments have the potential to improve caregivers’ understanding of their needs, as well as understand their ability to continue to provide support, and when implemented across populations, have the potential to provide meaningful meta-analysis about systemic caregiving needs, and to identify gaps in programming.

### Comprehensive Direct Support Programs

Across the federal government, there are programs, supports, and other interventions designed to support family caregivers. One proven approach to directly supporting caregiving is with a model of programming that offers multiple, flexible services options that are responsive to caregiver needs as they change over time (Avison, et al., 2018). Typically, these models include information and/or training for caregivers, assistance with navigating services (including understanding options for supports), counseling and/or training of community mental health professionals to better understand and address caregiver-specific needs, and respite care. Other ancillary services may include employment assistance, transportation, or advice on accessing services and supports. These direct support models also can support indirect services and infrastructure development through research and policy development that leverages their work with family caregivers.

The federal government funds three specific programs that are structured to directly address a broad array of caregiver issues for eligible family caregivers:

* TheNFCSP, established in 2000 and operated by ACL, the NFCSP provides grants to states and territories that fund Area Agencies on Aging to provide a range of services that assist family and informal caregivers to care for their family members at home for as long as possible. Services to family caregivers include:
	+ Information for caregivers about a range of supports, resources, and services available.
	+ Assistance in gaining access to services that help connect caregivers with services offered by private, public, and voluntary agencies or through insurance.
	+ Caregiver education/training, individual counseling, and support to help caregivers better manage their responsibilities and cope with the stress of caregiving.
	+ Respite care provided by trained caregivers either delivered at home or at adult day care or other facilities, so that caregivers can rest or attend to their own needs.
	+ Supplemental services such as transportation, home modifications, and medical or incontinence equipment.
* The[VA Caregiver Support Program](https://www.caregiver.va.gov/)(CSP) offers an array of supports and services to family members and friends who care for veterans, including on-line courses, face-to-face classes, telephone support, and peer support. These services are offered in addition to the support provided to families and caregivers across VA by clinicians as part of a veteran’s care. Every VA medical center has dedicated Caregiver Support Program staff who assist with information and referrals to these programs. Many of the following programs are also available to veterans who serve as the family caregiver to a non-veteran:
	+ Six-week online workshop for caregivers of veterans of all eras, with text support.
	+ Caregiver self-care courses.
	+ Website and a Caregiver Support Line.
	+ Telephone education and support groups.
	+ Peer support.
* [Kinship Navigator Program](https://www.acf.hhs.gov/cb/resource/pi1901)s are funded by the Administration for Children and Families (ACF). These services assist kin and grandparent caregivers in communities across the nation in learning about and accessing programs and resources to meet the needs of the children they are raising, to provide help for the family as a whole to safeguard stability, and to promote partnerships among public and private agencies. Kinship navigator programs are not intended to provide services; rather, they improve caregivers’ knowledge of services and assist them in identifying and accessing the services they need (Child Welfare Information Gateway, 2019).

These federal programs are models that show promise for holistically supporting the needs of family caregivers. A [comprehensive evaluation of the NFCSP](https://acl.gov/news-and-events/announcements/new-report-national-family-caregiver-support-program-nfcsp-outcome) conducted from 2016 to 2018, found that “caregiver use of the services made available by the NFCSP helped them continue in their role for longer periods, an important factor in delaying or preventing the institutionalization” (Avison, et al., 2018).

Meanwhile, in an evaluation of the suite of caregiver services offered at the Atlanta VA Health Care System, the caregiver support programming was found to be beneficial to caregivers through such mechanisms as increased knowledge of dementia, greater social support, increased self-efficacy to care for the veteran, behavior modification, and an emphasis on caregiver well-being (Biello, et al., 2019).

**Kinship Navigators Help Kin and Grandparent Caregivers Navigate a Path to Success**

Kinship navigator programs seek to provide information, offer referral, and follow-up services to grandparents and other relatives raising children to link them to the benefits and services that they or the children need. [SHARE New Mexico](https://sharenm.org/kinship-navigation) is a successful example of an effective kinship navigation program embedded within a more comprehensive family caregiver program. SHARE serves as a “first stop” to connect caregivers with existing resources such as family support, trauma assistance, support groups, legal aid, benefits assistance, and community resources.

Positive outcomes for those receiving kinship navigator services include:

* Safety: Relative caregivers receiving navigator services achieved identified safety goals for their families.
* Permanency: Children in the care of relative caregivers receiving navigation services had higher rates of permanency through legal guardianship and reunification with parents.
* Well-being: Results showed that kinship navigator programs were successful at ameliorating the needs of grandfamilies (Generations United, 2020).

For more on kinship navigator programs, refer to Generations United’s [tip sheet on elements of a successful kinship navigator program](http://www.grandfamilies.org/Portals/0/Documents/FFPSA/KN-tip%20sheet%20final2%20%281%29.pdf).

The significant challenge, as noted, relates to scalability. Each of these promising programs limit eligibility to specific caregiver populations—in this case, Veterans, adults and/or their caregivers, or grandparent caregivers. Millions of family caregivers do not fall into these groups and do not have access to a comprehensive direct support caregiver program. Instead, they are left to fashion their own support systems while juggling the needs of the family member they care for and their own well-being. It is worth noting that even within the programs, access is not equally distributed. There are often lengthy waitlists for many of these programs and significant unmet need around the country for services for individuals who meet eligibility criteria.

### Single-Service Approaches

An alternative to the wrap-around model of caregiver support is the use of stand-alone programs—such as respite care, counseling, or support groups --that address discrete caregiver needs. A key example of an effective single service is the [Lifespan Respite Care Program](https://acl.gov/programs/support-caregivers/lifespan-respite-care-program), which is administered by ACL. The program helps build and sustain “systems of accessible, community-based respite care for family caregivers of children and adults of all ages with special needs.”

This is important because respite has been found in several studies to improve family caregiver resilience, and benefit their physical and emotional health. One study found that respite can improve resilience in caregivers of people living with dementia, which is often a particularly intense form of caregiving, especially, when people are in the advanced stages of the illness (Robert & Struckmeyer, 2018).

**Respite Care: An Essential Caregiver Support**

While caregivers report significant emotional and spiritual rewards from the caregiving experience, they also experience physical and emotional issues as a result of the demands of their caregiving responsibilities. The concept of respite as a supportive service is based on the premise that giving caregivers a break from daily, ongoing caregiving responsibilities will benefit their physical and emotional health and enable them to provide caregiving support for longer. Despite the benefits, respite remains an underutilized support for family caregivers. To advance understanding of the value of respite, the ARCH National Respite Network and Resource Center convened a work group in 2015 to develop a research agenda for respite care. The work group defined the term “respite care” as:

*“Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system.”*

For more information on currently available respite care programs, refer to [Section III. Existing Federal Approached to Assisting Caregivers](file:///Q%3A%5CRAISE%20and%20SGRG%20Acts%5C1RAISE%5CReport%20to%20Congress%5CClearance%5C1st%20Round%20HHS%20Clearance-June%2011%20Revisions%5CReport%5CRAISE%20Act%20Report%20to%20Congress%206.17.21_2pm.docx#_III._The_Experience_1).

Single-service interventions, like respite care services, benefit from greater flexibility and adaptability to changing environments. However, many caregivers experience barriers to accessing these services. The COVID-19 pandemic has increased awareness among families of the need for respite at the same time that, due to risk of infection for both care providers and the people receiving support, many services have suspended operations. Recognizing the need for increased awareness of the value of respite and greater access to services, the council developed Recommendation 3.2, which specifically focuses on expanding use of respite care.

### Training and Education

A significant body of research has shown that caregivers need education and information to be more successful in their roles. Family caregivers need trusted information on a range of topics from how to perform functions necessary to provide care (e.g., dressing changes, managing pain, etc.) to how to deal with behaviors (in the case of dementia) and managing stress and emotional challenges that can come with being a caregiver.

A successful example of the effectiveness of caregiver education and training at the federal level is ACL’s [Alzheimer’s Disease Programs Initiative](https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease) (ADPI). Caregivers of people living with dementia receive training to manage the complex emotions and grief associated with dementia and to manage challenging behaviors. ADPI is dedicated to meeting this challenge by developing what is known as “dementia capability” in states and expanding it in communities. This effort involves funding community-based projects that include training and education specifically for family caregivers of people living with dementia. The program seeks to expand the network of local knowledge and support by training members of the surrounding community in how to recognize the signs of dementia and interact with people living with dementia.

To date, ADPI has trained a wide array of individuals including paid caregivers, social workers, attorneys, financial professionals, law enforcement, first responders, food service workers, and small business owners. Together, this expansion of community-wide understanding of the needs of people living with dementia and their caregivers provides a foundation for more effective systems of services and supports.

Training is not the only effective method of educating caregivers so they can be successful in their role. Outreach in the form of educational materials also plays an important role. The Consumer Financial Protection Bureau produces [Managing Someone Else’s Money guides](https://www.consumerfinance.gov/consumer-tools/managing-someone-elses-money/) for the millions of family caregivers who manage money or property. Since 2013, when the guides became available, more than 1,411,038 copies of the guides have been requested for distribution at libraries, community centers, social services providers, legal aid offices, and financial institutions.

Education and training is an area ripe for development because caregiver research has shown “that education and skills training can improve caregiver confidence in managing daily care challenges” (National Academies of Sciences, Engineering, and Medicine, 2016). Increased mastery can boost caregiver confidence, which in turn can lead to reductions in stress and perception of burden.

### Peer-to-Peer Approaches

Peer support models pair individuals new to a caregiving situation with someone who has previous experience in the role. Nearly a third of family caregivers have been providing support for five or more years (AARP and National Alliance for Caregiving, 2020). These family caregivers have amassed significant knowledge and expertise that is different from the kinds of support formal systems offer. In many cases, these experienced family caregivers are ideally positioned to lend their perspectives and expertise to others with less experience in the role. Peer-to-peer supports can help to reduce reliance on the formal system; as such, it is effective for where there may not be many formal supports available.

For people with IDD the role of family is unique, and often central in the support and care provided across the lifespan. From 2012-2017, ACL funded the [Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities](http://supportstofamilies.org/) to discover integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services. One of the key approaches identified was peer-to-peer support. One of the reasons for this was that parents of individuals with IDD trying to identify and access appropriate services often find the systems of support complicated and overwhelming. Peer support enables families to navigate systems more effectively, learn from the experiences of other families, feel less alone, and gain hope, ideas, and information.

Caregiver peer support is not readily available in existing service delivery models. One notable federal exception is the [Caregiver Peer Support Mentoring Program](https://www.caregiver.va.gov/support/Peer_Support_Mentoring_Program.asp) which is available as part of VA’s Caregiver Support Programming.

## Future Steps for the Federal Inventory

The inventory development process was made complex by the variability of existing programs and the fact that, in a number of cases, even within specific agencies, designated respondents were not fully aware of all efforts underway that supported or assisted family caregivers at their specific agency. It quickly became clear to the council and ACL staff that developing the inventory would necessarily be an iterative process, updated over time through an ongoing engagement with federal partners and regular dialogue with the council.

# Inventory of Federal Caregiver Support Programs and Initiatives

## AmeriCorps

### AmeriCorps Seniors

#### PROGRAM NAME: Foster Grandparent Program

**TARGET CAREGIVER POPULATION**: Kinship Families and Grandfamilies (i.e., offers seniors age 55 and older opportunities to serve as mentors, tutors, and loving caregivers for socioeconomically disadvantaged children and youth from birth to 21 years of age).

**URL(s):** <https://americorps.gov/serve/fit-finder/americorps-seniors-foster-grandparent-program>

**AUTHORITY:** Domestic Volunteer Service Act of 1973, 45 CFR Part 2552 and § 2553.11.

**SUMMARY:** The AmeriCorps Seniors Foster Grandparent program is a community-based, direct services, volunteer program that provides critical community support to the nation’s community organizations and their residents. AmeriCorps Seniors volunteers who serve as Foster Grandparents become one-on-one tutors, mentors, and friends to young people with exceptional needs, where they act as role models to reinforce important life values. In 2017, around 22,000 Foster Grandparent volunteers helped approximately 150,000 children through a nationwide network of organizations.

The Foster Grandparent program is an intergenerational program where volunteers have the sole mission to help strengthen the education and emotional development of children at risk of falling behind in school, many of whom are being raised by grandparents. As tutors and mentors, these non-relatives provide a consistent and stabilizing older adult presence in the lives of the children they serve. Also, many Foster Grandparent volunteers are also themselves, grandparents to young children. Grandparents are supported through the Foster Grandparent program as the program supports the educational and emotional development of some of the children being raised by their grandparents. This support falls under several strategic focus areas that include education, healthy futures, and veterans and military families who are also supported by the volunteers in this program.

#### PROGRAM NAME: The RSVP Program

**TARGET CAREGIVER POPULATION**: Family Caregivers; Kinship Families and Grandfamilies.

**URL(s):** <https://americorps.gov/serve/fit-finder/americorps-seniors-rsvp>

**AUTHORITY:** Domestic Volunteer Service Act of 1973, 45 CFR Part 2552 and § 2553.11.

**SUMMARY:** The RSVP program is a community-based, direct services, volunteer program that provides critical community support to the nation’s community organizations and their residents.

In addition, grandparents receive support through the RSVP program through several focus areas that include education, economic opportunity, healthy futures, and veterans and military families. For example, RSVP volunteers help teach money management to those grandparents who might be challenged with developing family budgets and securing credit. They also help educate grandparents on issues around financial exploitation and avoiding frauds and scams. Additionally, in the education realm, RSVP volunteers also teach English to grandparents for whom English might be a second language.

**Note**: The RSVP program engages and models several health-related interventions in the ACL evidence exchange. These include:

* A Matter of Balance (older adult falls-prevention program).
* Chronic Disease Self-Management Program (intervention for improved management of chronic diseases).
* Seniors Reach (intervention for reduced isolation and depression).

#### PROGRAM NAME: Senior Companion Program

**TARGET CAREGIVER POPULATION(S)**: Family Caregivers.

**URL(s):** https://americorps.gov/serve/fit-finder/americorps-seniors-senior-companion-program

**AUTHORITY:** Domestic Volunteer Service Act of 1973, 45 CFR Part 2551.

**SUMMARY:** AmeriCorps Seniors provides grants to qualified agencies and organizations for the purpose of engaging adults age 55 and over in meaningful volunteer service through the Senior Companion program.

The AmeriCorps Seniors Senior Companion program is a community-based, direct service, volunteer program that provides critical community support to the nation’s community organizations and their residents. Since 1974, as a peer-to-peer program, Senior Companion volunteers have made a difference by providing assistance and friendship to adults who have difficulty with daily living tasks, such as shopping or paying bills. This assistance from Senior Companion volunteers helps their neighbors to retain their dignity and remain independent in their homes rather than having to move to more costly institutional care.

Additionally, Senior Companion volunteers provide respite and other services for family caregivers, allowing them time to conduct their own business and/or just to refresh from caregiver responsibilities.

One key difference between AmeriCorps Seniors and other volunteering opportunities is the provision of a small hourly stipend for volunteers who have incomes up to twice the poverty line. While most volunteers reported joining service for altruistic reasons, close to one-third had an underlying financial reason. The modest stipend provided by AmeriCorps Seniors helps remove the barriers to volunteering and ensures participants do not incur additional costs while serving.

## Consumer Financial Protection Bureau (CFPB)

#### PROGRAM NAME: Office for Older Americans

**TARGET CAREGIVER POPULATION(S):** Family Caregivers, Kinship Families and Grandfamilies (also aging services providers, service coordinators, nursing home and assisted living administrators and staff, and patient advocates).

**URL(s):** <https://www.consumerfinance.gov/practitioner-resources/resources-for-older-adults/>

**AUTHORITY:** 12 U.S.C. § 5493(g). The CFPB, through its Office for Older Americans, is charged with developing initiatives designed to protect consumers, 62 and older, from unfair, deceptive, and abusive practices, and assist them with current and future financial choices.

**SUMMARY:** The CFPB, through its Office for Older Americans, is charged with developing initiatives designed to protect consumers, 62 and older, from unfair, deceptive, and abusive practices, and assist them with current and future financial choices. 12 U.S.C. § 5493(g). The Office for Older Americans engages in research, policy, and educational initiatives, designed to help protect older consumers from financial harm and help older consumers make sound financial decisions as they age.

Programs and initiatives for older adults and their caregivers are primarily focused on financial education and the prevention of elder financial exploitation. These programs and initiatives include:

Money Smart for Older Adults (MSOA)-Money Smart for Older Adults is a module-based fraud-prevention program that provides older adults and their caregivers with information and tips to help prevent common scams and other types of elder financial exploitation. A wide range of intermediaries from financial institutions to adult day care and community service providers use MSOA guides and presentations to improve and increase awareness in their own communities.

Managing Someone Else’s Money (MSEM)-The Managing Someone Else’s Money guides help financial caregivers, also called fiduciaries, understand their role, detect, and prevent financial exploitation, and access relevant social services. Each guide focuses on one of four different fiduciary roles: power of attorney, trustees, court-appointed guardians, and government fiduciaries. State-specific guides are also available for 10 states.

Fraud prevention placemats, handouts, and activity sheets-Free fraud prevention placemats, handouts, and activity sheets help older adults and their families recognize and avoid common scams. They can be used by meal delivery programs, faith-based organizations, financial institutions, senior centers, or other groups in a variety of ways.

Protecting Residents from Financial Exploitation: A guide for nursing homes & assisted living facilities-This guide helps congregate care administrators and staff protect residents from financial exploitation through prevention and early intervention. Caregivers and patient advocates can use the guide as a trustworthy reference for best practices in preventing financial exploitation in congregate care settings.

Single and bulk orders of copies of CFPB materials are available to the public through the Government Printing Office website at: <https://pueblo.gpo.gov/CFPBPubs/CFPBPubs.php?NavCode=XA&CatID=28>

## U.S. Department of Health and Human Services (HHS)

### Administration for Children and Families (ACF)

#### PROGRAM NAME: Title IV-E Guardianship Assistance Program (GAP)

**TARGET CAREGIVER POPULATION(S):** Kinship Families and Grandfamilies (i.e., relatives who have assumed legal guardianship of eligible children that they previously cared for as foster parents). As of November 2020, 38 states, the District of Columbia, Puerto Rico, the Virgin Islands, and several tribes participate in the program

**URL(s):** <https://www.acf.hhs.gov/cb/resource/title-iv-e-guardianship-assistance>

**AUTHORITY:** P.L. 110-351; Title IV-E of the Social Security Act; Section 471(a)(28). Section 473(d) of the Social Security Act (the Act) establishes eligibility and other requirements for the title IV-E GAP. Federal financial participation (FFP) using the applicable Federal medical assistance percentage is available for kinship guardianship assistance payments pursuant to section 474(a)(5) of the Act.

**SUMMARY:** The **Children’s Bureau** partners with federal, state, tribal, and local agencies to improve the overall health and well-being of our nation’s children and families. The Children’s Bureau provides support and guidance to programs that focus on:

* **Strengthening families** and preventing child abuse and neglect.
* **Protecting children** when abuse or neglect has occurred.
* Ensuring that every child and youth has **a permanent family** or family connection.

The Guardianship Assistance Program provides federal financial participation to states, Indian tribes, tribal organizations, and tribal consortia (tribes) who, as part of their approved title IV-E Foster Care and Permanency program, opt to provide guardianship assistance payments to relatives who have assumed legal guardianship of eligible children that they previously cared for as foster parents.

Guardianship assistance is intended to prevent inappropriately long stays in foster care and to promote the healthy development of children through increased safety, permanency, and well-being. Title IV-E agencies must negotiate and enter into a written, binding kinship guardianship assistance agreement with the prospective relative guardian, and provide the prospective relative guardian.

Beneficiaries include children eligible for Title IV-E foster care maintenance 1) residing for at least 6 months in the home of the prospective relative guardian; 2) state or tribe determined permanency options of home or adoption are not appropriate; 3) child demonstrates strong attachment to guardian and prospective guardian commitment; 4) child age 14 and older consulted regarding kinship guardianship arrangement.

#### PROGRAM NAME: Kinship Navigator Program

**TARGET CAREGIVER POPULATION(S):** Kinship Families and Grandfamilies (i.e., grandparents, relatives and kin raising children in their homes, either through foster care or outside the child welfare system).

The Children’s Bureau partners with federal, state, tribal, and local agencies to improve the overall health and well-being of our nation’s children and families. The Children’s Bureau provides support and guidance to programs that focus on:

* **Strengthening families** and preventing child abuse and neglect.
* **Protecting children** when abuse or neglect has occurred.
* Ensuring that every child and youth has a **permanent family** or family connection).

**URL(s):** State Kinship Care Contacts available at: <https://www.childwelfare.gov/topics/outofhome/kinship/>

Title IV-E Prevention Services Clearinghouse: <https://preventionservices.abtsites.com/>

**AUTHORITY:** (PL) 115 -123 Bipartisan Budget Act - Title VII Family First Prevention Services Act (amended Title IV-E of the Social Security Act).

**SUMMARY:** Kinship Navigator Programs assist kinship caregivers in learning about, finding, and using programs and services to meet the needs of the children they are raising and their own needs. They are intended to avoid duplication or fragmentation of services and to promote effective partnerships among public and private agencies (including 2-1-1/3-1-1 information systems, and ombudsman support) to ensure kinship caregiver families are served and connected appropriately. They are intended to be planned and operated in consultation with kinship caregivers and organizations representing them, youth raised by kinship caregivers, relevant government agencies, and relevant community-based or faith-based organizations. Kinship navigators establish information and referral systems that link kinship caregivers, kinship support group facilitators, and kinship service providers to each other, eligibility and enrollment information for federal, state, and local benefits, and relevant legal assistance. Kinship Navigator programs promote partnership between public and private agencies and others to increase knowledge around the needs of kinship care families and others who foster children in foster care under the state.

#### PROGRAM NAME: Administration for Native Americans (ANA)

**TARGET CAREGIVER POPULATION(S): Family Caregivers;** Kinship Families and Grandfamilies. All Native Americans, including federally recognized tribes, American Indian and Alaska Native organizations, Native Hawaiian organizations, and Native populations throughout the Pacific Basin (including American Samoa, Guam, and the Commonwealth of the Northern Mariana Islands).

**URL(s):** <https://www.acf.hhs.gov/ana>

**AUTHORITY:** Section 803(a) of the Native American Programs Act of 1974 (NAPA), 42 U.S.C. 2991b.

**SUMMARY:** The Administration for Native Americans (ANA) is a program office within the Department of Health and Human Services’ Administration for Children and Families. ANA promotes self-sufficiency for Native Americans by providing discretionary grant funding for community-based projects, and training and technical assistance to eligible tribes and Native organizations.

The Administration for Native Americans (ANA) funds community-based projects under the Social and Economic Development Strategies (SEDS) program. Focus areas include:

* Social Development: Projects that develop and implement culturally appropriate strategies to meet the social service needs and well-being of Native Americans.
	+ Addressing Mental Health.
	+ Community Health.
	+ Native Arts and Culture.
	+ Nutrition and Fitness.
	+ People with Disabilities and Community Living.
	+ Public Safety and Security.
	+ Strengthening Families and Parents.
	+ Substance Abuse, Smoking, and Vaping.
* Economic Development: Projects that promote the creation of a sustainable local economy to enhance the economic independence of Native people.
	+ Economic Stability.
	+ Food Sovereignty.
	+ Native Traditional Farming.
	+ Opportunity Zones.

The purpose of the SEDS and SEDS-Alaska (SEDS-AK) program is to promote social and economic self-sufficiency for American Indians, Alaska Natives, Native Hawaiians, and Native American Pacific Islanders from American Samoa, Guam, and the Commonwealth of the Northern Mariana Islands. The SEDS and SEDS-AK programs support the principle that social and economic development are inter-related and essential for the development of thriving Native communities. SEDS and SEDS-AK projects focus on one or more of the following three inter-related concepts that form a foundation for self-sufficiency: (1) social development that supports local access to, control of, and coordination with programs and services that safeguard the health, well-being, and culture of Native peoples; (2) economic development that fosters the development of stable, diversified local economies and economic activities that provide jobs and business opportunities that promote economic well-being and self-sufficiency in Native American communities; and (3) governance that assists tribes, Native organizations and Alaska Native village governments to increase their ability to enhance their administrative infrastructure and capacity to develop and enforce laws, regulations, codes, and policies that reflect and promote the interests of community members.

### Administration for Community Living (ACL)

#### PROGRAM NAME: ACL-Funded Resource Centers

**TARGET CAREGIVER POPULATION(S**): Family Caregivers; Kinship Families and Grandfamilies.

**URL:** <https://acl.gov/programs/strengthening-aging-and-disability-networks/national-resource-centers>.

**AUTHORITY:** Developmental Disabilities Act; Older Americans Act; Workforce Innovation and Opportunity Act; Help America Vote Act; Public Health Service Act; Health Insurance Portability and Accountability Act (HIPAA); Medicare Improvements for Patients and Providers Act (MIPPA); Elder Justice Act.

**SUMMARY:** ACL’s numerous resource centers provide information primarily for professionals and therefore offer indirect support to family caregivers. However, several also offer consumer information directly to family caregivers.

* Aging Network Business Practice, Planning and Program Development.
* Community Innovations for Aging in Place (CIAIP) Technical Assistance Center.
* Eldercare Locator.
* Lifespan Respite Technical Assistance Center.
* National Aging Information and Referral (I&R) Support Center.
* National Older Adults Equity Collaborative
* National Alzheimer’s and Dementia Resource Center.
* National Alzheimer’s Call Center.
* National Center for Benefits Outreach and Enrollment.
* National Center on Elder Abuse
* National Center on Law and Elder Rights
* National Center on Elder Abuse: National Indigenous Elder Justice Initiative
* National Clearinghouse for Long-term Care Information
* National Consumer Protection Technical Resource Center
* National Resource Center on Women and Retirement Planning
* National Falls Prevention Resource Center
* National Long-Term Care Ombudsmen Resource Center
* National Pension Assistance Resource Center
* National Resource Center on Chronic Disease Self-Management Education Programs
* National Resource Center on Lesbian, Gay, Bisexual, and Transgender (LGBT) Aging
* National Resource Center on Nutrition and Aging
* National Resource Centers on Native American Elders
* Senior Medicare Patrol National Resource Center
* State Health Insurance Assistance Program (SHIP) National Technical Assistance Center
* UCEDD Resource Center

#### PROGRAM NAME: Aging and Disability Evidence-Based Programs and Practices

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL**: <https://acl.gov/programs/strengthening-aging-and-disability-networks/aging-and-disability-evidence-based-programs>.

**AUTHORITY:** Developmental Disabilities Act; Older Americans Act; Workforce Innovation and Opportunity Act; Help America Vote Act; Public Health Service Act; Health Insurance Portability and Accountability Act (HIPAA); Medicare Improvements for Patients and Providers Act (MIPPA); Elder Justice Act.

**SUMMARY:** The purpose of the Aging and Disability Evidence-Based Programs and Practices is to help the public learn more about available evidence-based programs and practices in the areas of aging and disability, and to determine which of these may best meet their needs. The identified programs and practices address health and wellness, long-term services and supports (LTSS), caregiver and family support, and mental health promotion.

##### ACL’s Administration on Aging

#### PROGRAM NAME: National Family Caregiver Support Program

**TARGET CAREGIVER POPULATION(S):** Family Caregivers, Kinship Families and Grandfamilies.

**URL:** <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

**AUTHORITY:** Section 371 of the Older Americans Act of 1965, as amended, Title IIIE.

**SUMMARY**: Established in 2000, the NFCSP provides grants to states and territories, based on their share of the population age 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. Eligible caregivers include: adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older; adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer’s disease and related disorders; older relatives, not parents, age 55 and older providing care to children under the age of 18; and older relatives, including parents, age 55 and older providing care to adults age 18-59 with disabilities. NFCSP grantees provide five types of services: information to caregivers about available services; assistance to caregivers in gaining access to the services; individual counseling, organization of support groups, and caregiver training; respite care; and supplemental services, on a limited basis.

These services work in conjunction with other state and community-based services to provide a coordinated set of supports. Studies have shown that these services can reduce caregiver depression, anxiety, and stress as well as enable caregivers to provide care longer, thereby avoiding or delaying the need for costly institutional care.

#### PROGRAM NAME: Services for Native Americans (Title VI of the Older Americans Act)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies.

**URL:** <https://olderindians.acl.gov/>

**AUTHORITY:** In 1978, the OAA was amended to include Title VI which established programs for the provision of nutrition and supportive services for Native Americans (American Indians, Alaska Natives, and Native Hawaiians). The program has since expanded to include caregiver support services. Eligible tribal organizations receive grants in support of the delivery of home and community-based supportive services for their elders, including nutrition services and support for family and informal caregivers.

**SUMMARY:** Programs provide grants to eligible tribal organizations to promote the delivery of home and community-based supportive services, including nutrition services and support for family and informal caregivers, to Native American, Alaskan Native, and Native Hawaiian elders. These programs, which help to reduce the need for costly institutional care and medical interventions, are responsive to the cultural diversity of Native American communities and represent an important part of the communities’ comprehensive services.

Grants assist American Indian, Alaskan Native, and Native Hawaiian families caring for older relatives with chronic illness or disability, and grandparents caring for grandchildren. The program offers a variety of services that meet a range of caregiver needs, including information and outreach, access assistance, individual counseling, support groups and training, respite care, and other supplemental services.

Tribal organizations coordinate with other programs, including the Volunteers in Service to America (VISTA) program, to help support and create sustainable caregiver programs in Native American communities (many of which are geographically isolated). A core value of the Native American Caregiver Support Services, as expressed by tribal leaders, is that the program should not replace the tradition of families caring for their elders. Rather, it provides support that strengthens the family's caregiver role.

#### PROGRAM NAME: Alzheimer’s Disease Programs Initiative (ADPI)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL:** <https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease>

**AUTHORITY:** Titles II and IV of the Older Americans Act.

**SUMMARY:** In 1992, Congress created the Alzheimer’s Disease Supportive Services Program (ADSSP) to support state efforts to expand the availability of community-level supportive services for persons with Alzheimer’s disease and related dementias (ADRD). In 1998, Congress transferred the administration of the program to ACL. Between 2008 and 2017, ACL funded 108 ADSSP projects across the nation. In 2020, ACL publicized the Alzheimer’s Disease Programs Initiative, to provide funding to support and promote the development and expansion of dementia-capable HCBS systems. The dementia-capable systems resulting from program activities are expected to provide quality, person-centered services and supports that help people living with dementia and their caregivers remain independent and safe in their communities.

#### PROGRAM NAME: Lifespan Respite Care Program

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL:** <https://acl.gov/programs/support-caregivers/lifespan-respite-care-program>

**AUTHORITY:** Title XXIX of the Public Health Service Act (42 U.S.C 201). Eligible agencies are those administering the state’s program under the Older Americans Act of 1965 or Title XIX of the Social Security Act (Medicaid), or those designated by a governor to administer the state’s program under this title.

**SUMMARY:** Congress authorized the Lifespan Respite Care Program in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201). Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with disabilities. As of 2017, competitive grants of up to $200,000 each were awarded to eligible agencies in 37 states and the District of Columbia. Participating states have developed or built upon respite infrastructures to enhance or improve access to and receipt of respite services, and they are focusing on providing gap-filling respite services to family caregivers and working with ACL to develop program performance and outcome measures.

#### PROGRAM NAME: RAISE Family Caregiving Advisory Council

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL:** <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>

**AUTHORITY:** P.L. 115–119.

**SUMMARY:** The Recognize, Assist, Include, Support, and Encourage (RAISE) Family Caregivers Act, which became law on January 22, 2018, directs the Secretary of Health and Human Services (HHS) to develop a National Family Caregiving Strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers. To support the development and execution of the strategy, the RAISE Act also directs the establishment of the Family Caregiving Advisory Council. The council is charged with providing recommendations to the Secretary of HHS on effective models of both family caregiving and support to family caregivers, as well as improving coordination across federal government programs.

#### PROGRAM NAME: Advisory Council to Support Grandparents Raising Grandchildren

**TARGET CAREGIVER POPULATION(S):** Kinship Families and Grandfamilies.

**URL:** <https://acl.gov/programs/support-caregivers/supporting-grandparents-raising-grandchildren-0>

**AUTHORITY:** P.L. 115–196.

**SUMMARY:** Supporting Grandparents Raising Grandchildren Act established the Advisory Council to Support Grandparents Raising Grandchildren. The Advisory Council identifies, promotes, coordinates, and disseminates to the public information, resources, and the best practices available to help grandparents and other older relatives both meet the needs of the children in their care and maintain their own physical and mental health and emotional well-being.

##### ACL’s Administration on Disabilities

#### PROGRAM NAME: Centers for Independent Living

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL:** <https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>

**AUTHORITY:** Title VII Part C Section 721 of the Rehabilitation Act of 1973, as amended, Section 725 of the Rehab Act, Workforce Innovation and Opportunity Act of 2014, 29 U.S.C. 32.

**SUMMARY:** The Centers for Independent Living (CILs) program provides 354 discretionary grants to CILs, which are consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit agencies that provide independent living services. At a minimum, centers funded by the program are required to: provide information and referral, independent living skills training, peer counseling, individual and systems advocacy, and services that facilitate transition from nursing homes and other institutions to the community; provide assistance to those at risk of entering institutions; and facilitate transition of youth to postsecondary life. Individual CIL projects may also provide services to support caregivers.

#### PROGRAM NAME: Supporting Families Communities of Practice

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL:** <http://supportstofamilies.org/>

**AUTHORITY:** N/A.

**SUMMARY:** For people with intellectual and developmental disabilities, the role of family is unique, and often central in the support and care provided across the lifespan. From 2012-2017, ACL funded the Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities to discover integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services. One of the key approaches identified was peer-to-peer support. One of the reasons for this was that parents of individuals with IDD trying to identify and access appropriate services often find the systems of support complicated and overwhelming. Peer support enables families to navigate systems more effectively, learn from the experiences of other families, feel less alone, and gain hope, ideas, and information. An additional tool developed was the Charting the LifeCourse framework to help individuals with disabilities and families at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. A series of LifeCourse education and outreach materials are available at <https://www.myorderdesk.com/Catalog/?Provider_ID=1166751>.

#### PROGRAM NAME: University Centers for Excellence in Developmental Disabilities Education, Research & Service

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL:** <https://acl.gov/programs/aging-and-disability-networks/national-network-university>

**AUTHORITY:** Section 151(a) of the DD Act of 2000.

**SUMMARY:** University Centers for Excellence in Developmental Disabilities Education, Research & Service (UCEDDs) are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families. UCEDDs support activities that address a range of issues, from prevention and early intervention to supported employment. UCEDD activities also focus on supporting families and caregivers of individuals with developmental disabilities. Specific services and resources available through UCEDDs may vary, but many offer a variety of resources for families and caregivers, including education, training, skill building, planning, service coordination and referral, home modifications, assistive technology, and research.

##### ACL’s Center for Innovation and Partnership

#### PROGRAM NAME: Aging and Disability Resource Centers/No Wrong Door

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL:** <https://acl.gov/programs/aging-and-disability-networks/aging-and-disability-resource-centers>

**AUTHORITY: N/A.**

**SUMMARY:** Aging and Disability Resource Centers (ADRCs) across the country seek to address the frustrations many older adults, people with disabilities, and family members experience when trying to learn about and access long-term services and supports.

ADRCs raise visibility about the full range of available options; provide objective information, advice, counseling, and assistance; empower people to make informed decisions about their long-term services and supports; and help people access public and private programs. ADRCs provide unbiased, reliable information and counseling to people with all levels of income.

ADRCs are an important part of the No Wrong Door (NWD) system model. A collaboration between ACL, CMS, and the VHA, the NWD initiative supports states working to streamline access to long-term services and supports for older adults, people with disabilities, and their families**.** NWD systems simplify access to LTSS and are a key component of LTSS systems reform.

NWD systems provide information and assistance not only to individuals needing either public or private resources, but also to professionals seeking assistance on behalf of their clients, and to individuals planning for their future long-term care needs. NWD systems also serve as the entry point to publicly administered long-term supports, including those funded under Medicaid, the Older Americans Act, Veterans Health Administration, and state revenue programs.

#### PROGRAM NAME: Veterans-Directed Care Program (formerly known as the VD-HCBS Program)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers, Veterans.

**URL:** <https://acl.gov/programs/veteran-directed-home-and-community-based-services/veteran-directed-home-community-based>

**AUTHORITY: N/A.**

**SUMMARY:** In 2008, ACL, on behalf of HHS, began a partnership with Veterans Health Administration (VHA) to serve veterans of all ages at risk of nursing home placement through the Veteran Directed Care Program [formerly known as Veteran-Directed Home and Community-Based Services (HCBS)]. The purpose of the program is to have an LTSS system that is person centered and consumer directed, and that helps people at risk of institutionalization to continue to live at home and engage in community life. Through the program, the VHA increases access to HCBS to serve the growing demand of veterans who prefer independence at home over living in a nursing facility.

### ACL’s National Institute on Disability, Independent Living, and Rehabilitation Research

#### PROGRAM NAME: Rehabilitation Research and Training Center Programs

**TARGET CAREGIVER POPULATION(S):** Family Caregivers.

**URL:** <https://acl.gov/programs/research-and-development/rehabilitation-research-and-training>

**AUTHORITY** Title 29, Chapter 16, Subchapter II, Section 762 of the Rehabilitation Act of 1973, as amended.

**SUMMARY**: The Rehabilitation Research and Training Center programs are funded through ACL’s National Institute on Disability, Independent Living, and Rehabilitation Research. The programs conduct coordinated, integrated, and advanced programs of research, training, and information dissemination to improve rehabilitation methodology and service delivery systems; improve health and functioning; and promote employment, independent living, family support, and economic and social self-sufficiency for individuals with disabilities.

### Centers for Disease Control and Prevention (CDC)

##### National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control

#### PROGRAM NAME: Resources for Caregivers of Cancer Survivors

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (including caregivers of cancer patients and survivors).

**URL:** <https://www.cdc.gov/cancer/survivors/caregivers/index.htm>

**AUTHORITY**: Public Health Service Act – 42 U.S.C. § 241(a) and 247b (k) (2)

**SUMMMARY**: CDC’s [Division of Cancer Prevention and Control (DCPC)](https://www.cdc.gov/cancer/dcpc/about/) works to help cancer survivors live longer, healthier lives and provide resources for caregivers of cancer patients and survivors.

CDC works with public, non-profit, and private partners to develop and implement ways to help the growing number of cancer survivors and their caregivers in the United States. Additionally, CDC conducts research and surveillance and develops programs to assess the needs of cancer survivors and caregivers. For example, CDC’s [National Comprehensive Cancer Control Program (NCCCP)](https://www.cdc.gov/cancer/ncccp/) encourages its awardees to pay special attention to the needs of cancer survivors and their families in their communities. CDC also funds the [National Cancer Survivorship Resource Center,](https://www.cancer.org/health-care-professionals/national-cancer-survivorship-resource-center.html) a collaboration between the American Cancer Society and the George Washington University Cancer Institute. The center develops and distributes a broad range of informational materials, including [Tools for Cancer Survivors and Caregivers](https://www.cancer.org/health-care-professionals/national-cancer-survivorship-resource-center/tools-for-cancer-survivors-and-caregivers.html).

CDC also provides helpful tips and online resources that offer [Advice for Caregivers of Cancer Survivors](https://www.cdc.gov/cancer/survivors/caregivers/index.htm) including information regarding [Caring for Yourself](https://www.cdc.gov/cancer/survivors/caregivers/caring-for-yourself.htm), [Helping Cancer Patients and Survivors Stay Physically Healthy](https://www.cdc.gov/cancer/survivors/caregivers/helping-cancer-survivors-stay-healthy.htm), and [Helping Cancer Patients and Survivors Stay Mentally and Emotionally Healthy](https://www.cdc.gov/cancer/survivors/caregivers/helping-cancer-survivors-stay-mentally-emotionally-healthy.htm).

##### National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health

#### PROGRAM NAME: Alzheimer's Disease and Healthy Aging Program (AD+HAP)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (Including people living with Alzheimer’s disease and related dementias, informal or unpaid caregivers of family or friends, and organizations or programs serving older adults and caregivers).

**URL:** <https://www.cdc.gov/aging/about/index.htm#:~:text=The%20Alzheimer's%20Disease%20and%20Healthy,for%20people%2065%20and%20older>.

**AUTHORITY**: The Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act was signed into law on December 31, 2018 (P.L. 115-406) and amends the Public Health Service Act (Section 398A; 42 U.S.C. 280c-3-4).

**SUMMMARY**: The Alzheimer’s Disease and Healthy Aging Program, through BOLD and the Healthy Brain Initiative, works to support people living with Alzheimer’s disease and related dementias, informal or unpaid caregivers of family or friends, and organizations or programs serving older adults and caregivers, using the public health approach, emphasizing policy, systems, and environments. This is done through a variety of programs and initiatives, described below.

Healthy Brain Initiative & BOLD: The Healthy Brain Initiative [Road Map Series](https://www.cdc.gov/aging/healthybrain/roadmap.htm) has a strong emphasis on [caregiving](https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html) and [tribal communities](https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html). AD+HAP worked with tribal communities and partners to create a variety of [resources](https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html) for Indian Country. The third *Healthy Brain Initiative Road Map for State and Local Public Health* was released in late 2018 by AD+HAP and the Alzheimer’s Association, identifying 25 actions for public health professionals related to cognitive health, including cognitive impairment and caregiving for persons with cognitive impairment through 2023. In 2019, the first *Road Map for Indian Country* was released, identifying eight priority actions for Indian Country.

AD+HAP worked with the National Council for Urban Indian Adults to create wisdom keeper [videos](https://www.cdc.gov/aging/healthybrain/videos/index.html) specific to Indian Country for people with dementias and their caregivers. AD+HAP partnered with the Association of State and Territorial Health Officials (ASTHO) to develop culturally sensitive materials to educate and empower tribes and tribal populations about brain health and caregiving. The materials focus on cardiovascular risk factors related to brain health and caregiving issues for tribal communities. Additionally, AD+HAP developed an infographic describing subjective cognitive decline and related functional limitations and caregiving on American Indian/Alaska Native adults in order to educate stakeholders and policy makers on brain health in Indian Country. These are available in both English and Spanish.

Additionally, AD+HAP has developed a series of 5 Issue Maps that highlight specific sets of Road Map actions related to caregiving, risk reduction, early detection of Alzheimer’s disease and related dementias, and the education of health professionals. The associated planning tool was developed to guide state and local public health professionals through quick steps in selected Road Map items and getting started with implementation in their jurisdictions. Two podcasts were also produced discussing the updated *Road Map*.

The BOLD Infrastructure for Alzheimer’s Act was passed into law on December 31, 2018 (P.L. 115-406) and amends the Public Health Service Act (Section 398A; 42 U.S.C. 280c-3-4). It is designed to facilitate the translation of findings into public health practice. The activities outlined in BOLD are designed to create a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. It is designed to promote implementation of AD+HAP’s *Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* and the Healthy Brain Initiative Road Map for Indian Country.

Through [BOLD](https://www.cdc.gov/aging/funding/phc/index.html), AD+HAP funds one Public Health Center of Excellence (PHCOE) on Dementia Caregiving to focus on public health and systematic approaches to support spouses, partners, adult children, and other relatives and friends providing informal or unpaid help to people living with dementia. The first BOLD Public Health Centers of Excellence for Dementia Caregiving, which is a five-year award, was awarded in September 2020 to the University of Minnesota.

Additionally, through BOLD, AD+HAP funded 16 state, local, and tribal cooperative agreements with public health departments, and 2 additional BOLD Public Health Centers of Excellence on Dementia Risk Reduction and Diagnosis of Dementia. These recipients will increase education of public health officials and others on brain health, promote risk reduction, early detection and preventing avoidable hospitalizations, decreasing health disparities, and supporting caregiving and planning for people living with the disease.

BRFSS Data and Dissemination: AD+HAP collects and reports data on caregiving as part of public health surveillance efforts. Currently, the program uses the Behavioral Risk Factor Surveillance System ([BRFSS](https://www.cdc.gov/aging/healthybrain/brfss-faq.htm)) state-based survey to collect data on caregivers in states administering the [optional Caregiving module](https://www.cdc.gov/aging/publications/BRFSS-caregiver-brief-508.pdf) each year. Data and knowledge gathered from this telephone survey surveillance effort are then reported to public health professionals and the public in a variety of ways. AD+HAP curates an online, customizable [data portal](https://www.cdc.gov/aging/agingdata/index.html) that provides information regarding caregiving at various levels for different populations (e.g., national, state, race/ethnicity, gender, LGBT, veteran, and rural). AD+HAP authors and co-authors caregiving-focused scientific journal [articles](https://www.cdc.gov/aging/publications/journal.htm) using these and other data.

The [*State of Aging and Health in America: Data Brief Series*](https://www.cdc.gov/aging/publications/briefs.htm) are topic-specific documents focusing on public health issues related to older adults, developed by AD+HAP and the National Association of Chronic Disease Directors. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity, which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

Data and resources are disseminated on the program’s website and through data-focused products in English and Spanish such as state and population specific [infographics](https://www.cdc.gov/aging/data/index.htm), [podcasts and videos](https://www.cdc.gov/aging/publications/podcasts.htm) titled “Aging and Health Matters,” social media posts, an electronic newsletter to more than 67,000 subscribers, data [briefs](https://www.cdc.gov/aging/caregiving/caregiver-brief.html), and scientific presentations to partner organizations and at professional society meetings (e.g., The Gerontological Society of America).

Resources for Caregivers: AD+HAP supports unpaid caregivers of older adults through other information and online resources. They provide a downloadable, fillable [Care Plan](https://www.cdc.gov/aging/publications/features/caregivers-month.html) (in English and Spanish) to help caregivers balance their own life with the care they are providing. Care plans can reduce emergency room visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like Alzheimer’s disease and related dementias, resulting in better quality of life for all care recipients.

AD+HAP has developed a series of [web features](https://www.cdc.gov/aging/publications/features/index.html) and [podcasts](https://www.cdc.gov/aging/publications/podcasts.htm) on topics including helping people with Alzheimer’s disease and related dementias and their caregivers stay physically active, care plans for older adults and their caregivers, and the health of caregivers.

They created a 30-second [animated caregiving video](https://www.youtube.com/watch?v=SjK_7d_GQcA) to encourage caregivers to care for themselves and thus provide better care to their family member or friend. They have a variety of web content with [information for caregivers](https://www.cdc.gov/aging/caregiving/index.htm) of persons with disabilities in English and Spanish. They provide the [REACH OUT Caregiving Implementation Guide](https://chronicdisease.org/resource/resmgr/healthy_aging_critical_issues_brief/reachoutactionguide.pdf), providing a step-by-step approach to implementing REACH OUT, an evidence-based caregiver support program.

Emergency Preparedness: AD+HAP provides Emergency Preparedness information for caregivers of older adults and people with dementia. Additionally, AD+HAP connects users to CDC’s [COVID-19](https://www.cdc.gov/aging/covid19-guidance.html) information and guidance for older adults and their caregivers.

### Centers for Medicare & Medicaid Services (CMS)

#### PROGRAM NAME: Medicaid Program

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies.

**URL(s):** <https://Medicaid.gov>

**AUTHORITY: N/A.**

**SUMMARY:** The Medicaid program provides significant funding for long-term services and supports (LTSS), which include home, community, and institutional care. Medicaid-funded home and community-based services (HCBS) are optional services that states may choose to offer to beneficiaries with identified needs, to facilitate their continued residence in the community and to better their health outcomes. HCBS can be authorized under several Medicaid authorities.

Section 1915(c) waiver programs have been in existence since the early 1980s and provide home and community-based services to individuals who otherwise would require services in an institution (a nursing facility, hospital, or intermediate care facility for individuals with intellectual disabilities). While respite care is often the most well-known service that provides relief to caregivers (and respite may be provided under the waiver), many other services can assist caregivers in their daily efforts to provide care to loved ones. At the state’s discretion, waiver services can also include personal care services, case management, assistive technology, home modifications, day habilitation, and other services that can alleviate strain on caregivers. We further note that states can opt to fund family members who are caregivers as Medicaid providers.

Section 1915(i) programs are operated under the Medicaid state plan, and can provide, at state option, the same services available under 1915(c) waivers. The difference between these two programs is the population covered under each authority. The state constructs “needs-based criteria” to determine functional eligibility criteria for the program. Within statutory and regulatory parameters, states have discretion to determine those criteria. This authority can therefore be helpful to a broader array of Medicaid beneficiaries, including individuals with mental health or substance use disorder needs.

Section 1915(k) authorizes the Community First Choice state plan option, which also targets individuals who require an institutional level of care. Enhanced federal funding (a 6 percentage point increase in federal matching payments to states for service expenditures) is available for covered services. If a state elects to provide Community First Choice, the state must provide all of the following services:

(1) Assistance with ADLs, IADLs, and [health-related tasks](https://www.law.cornell.edu/definitions/index.php?width=840&height=800&iframe=true&def_id=ab9cf14df61d1f2375f7aa6167d4f830&term_occur=999&term_src=Title:42:Chapter:IV:Subchapter:C:Part:441:Subpart:K:441.520) through hands-on assistance, supervision, and/or cueing.

(2) Acquisition, maintenance, and enhancement of skills necessary for the [individual](https://www.law.cornell.edu/definitions/index.php?width=840&height=800&iframe=true&def_id=07826de14000168daa1b8b555bf98ce7&term_occur=999&term_src=Title:42:Chapter:IV:Subchapter:C:Part:441:Subpart:K:441.520) to accomplish ADLs, IADLs, and [health-related tasks](https://www.law.cornell.edu/definitions/index.php?width=840&height=800&iframe=true&def_id=ab9cf14df61d1f2375f7aa6167d4f830&term_occur=999&term_src=Title:42:Chapter:IV:Subchapter:C:Part:441:Subpart:K:441.520).

(3) Backup systems or mechanisms to ensure continuity of services and supports, as defined in [§ 441.505](https://www.law.cornell.edu/cfr/text/42/441.505) of this subpart.

(4) Voluntary training on how to select, manage and dismiss attendants.

At state option, benefits can also include purchases for items that are linked to an assessed need or goal in the individual’s person-centered plan. These services and supports include, but are not limited to expenditures that increase a beneficiary’s independence or substitute for human assistance, such as a microwave, when such a purchase meets an identified need and when Medicaid would have paid for the human assistance. States may also choose to allow expenditures for transition costs such as deposits for rent or utilities, purchasing bedding, basic kitchen supplies, and other necessities required for an individual’s transition to a home and community-based setting from a Medicaid funded institutional setting.

Person-centered planning requires that the independent assessment of the individual receiving HCBS and the individual’s person-centered service-plan (PCSP) adequately document reliance on unpaid caregivers to implement any elements of the plan, including the number of hours and intensity of supports. For 1915(c), under 42 CFR 441.301(c)(2)(v), for 1915(i) under 42 CFR 441.441.725(b)(5), and for 1915(k) under 42 CFR 441.540(b)(5), states are required to include in the PCSP the paid and unpaid services and supports that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports (unpaid supports provided voluntarily to the individual). This documentation and discussion in the development of the PCSP would build in services that augment/assist the individual and caregiver in the provision of services to achieve the individual’s goals.

Section 1945 of the Social Security Act authorizes Health Home programs for individuals with chronic conditions. States have the option to implement this program, and they have the discretion to determine the chronic conditions to target under the program. Health Homes provide coordination and linkage activities such as comprehensive care management, care coordination, health promotion, comprehensive transitional care (including appropriate follow-up, from inpatient to other settings), patient and family supports, referrals to community and social support services, and the use of health information technology to link services (as feasible and appropriate). This program operates under a “whole-person” philosophy, coordinating all primary, acute, behavioral health, and long-term services and supports to treat the whole person. States receive 90% federal match on Health Home services for the first eight quarters (ten quarters for substance use disorder focused programs only) from the approved effective date of the program.

Section 4802 of the Balanced Budget Act of 1997 authorized the establishment of the Program of All-Inclusive Care for the Elderly (PACE) as a state option. PACE is a program under Medicare, and states can elect to provide PACE services to Medicaid beneficiaries as an optional Medicaid benefit that allows people who otherwise need a nursing home-level of care to remain in the community. PACE covers all Medicare and Medicaid covered care and services, and other services that the PACE team of health care professionals decides are necessary to improve and maintain a participant’s health, and preserve and support the older adult’s family unit. Those include services such as adult day care, respite care, meals, home care and personal care.

Beyond these HCBS-related authorities, Medicaid state plan benefits provide states with options to offer an array of services to address the health care needs of beneficiaries that also have the effect of assisting caregivers with their responsibilities. Examples include personal care services, case management services, non-emergency medical transportation, and hospice care. Under the mandatory home health benefit, beneficiaries can receive medical supplies, equipment, and appliances. These state plan services are administered according to state-developed medical necessity criteria to determine who is eligible to receive the service.

Managed long-term services and supports (MLTSS) refers to the delivery of long-term services and supports through capitated Medicaid managed care programs. Increasing numbers of states are using MLTSS as a strategy for expanding home and community-based services, promoting community inclusion, ensuring quality, and increasing efficiency. Medicaid MLTSS programs can be operated under multiple federal Medicaid managed care authorities at the discretion of the state and as approved by CMS, including section 1932(a), 1915(a), section 1915(b), and section 1115. There are requirements and limitations related to each authority, and a managed care authority can be combined with other home and community-based authorities to operate the MLTSS program (for example, a concurrent section 1915(b)/1915(c) waiver).

Note: Additional information can be found on websites for individual state Medicaid agencies (a directory may be accessed at <https://medicaiddirectors.org/about/medicaid-directors/>), websites for state agencies operating programs for individuals with developmental disabilities (a directory may be accessed at <https://www.nasddds.org/state-agencies/>), and websites for state agencies operating programs for older adults and individuals with physical disabilities (a directory may be accessed at <http://www.advancingstates.org/about-nasuad/about-state-agencies/list-members>).

#### PROGRAM NAME: Medicare

**TARGET CAREGIVER POPULATION(S):** Beneficiaries (and in some cases their Family Caregivers benefit indirectly from these services).

**URL(s):** <https://Medicare.gov>

**AUTHORITY:** Medicare: Title XVIII of the Social Security Act.

**SUMMARY:** The Medicare program offers some limited caregiver supports:

* Advanced care planning services, which can benefit the caregiver and the beneficiary.
* Physician screening of health risks of caregivers, for the benefit of the Medicare beneficiary.
* Care management and chronic care management services.
* Cognitive assessment activities for individuals with signs of dementia, which includes caregiver identification, knowledge, needs, social supports, and willingness to take on caregiving tasks.
* Dialysis training for caregivers of individuals with End Stage Renal Disease.
* Hospice services, including time-limited respite care in a Medicare-certified facility.
* Optional supplemental benefits offered in Medicare Advantage managed care plans, which could include adult day health, personal care, environmental modifications, and transportation, which could indirectly benefit the caregiver.
* Hospital conditions of participation, required in both the Medicare and Medicaid programs, require certain caregivers to be involved in discharge planning.
* An aspect of the Primary Care First Demonstration, the Serious Illness Population option, has aspects of family and caregiver engagement.
* The Nursing Home Resource Center and the consolidated Medicare Compare websites have resources that can help caregivers locate important information.

### Food and Drug Administration (FDA)

#### PROGRAM NAME: Varies

**TARGET CAREGIVER POPULATION(S):** Patients

**URL(s):** See below

**AUTHORITY:** N/A

**SUMMARY:** The FDA has numerous patient-centered initiatives and programs. While the programs may be of interest to caregivers, these are not aimed at caregivers. More importantly, the FDA programs do not fit into the definitions and purposes of Pub. L. 115-119 – the “Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017” - particularly sections 2 and 3 (b)(1-6). Below is a list of the FDA programs that involve direct patient participation. Some of these programs may impact caregivers in a peripheral fashion – such as providing additional information about the patient’s disease, the use of certain drug products and devices, or may involve caregivers providing information to the FDA. These programs are directed primarily to improving drug and device development by including the patient’s voice in the development process.

##### FDA

[Expanded Access (EA)](https://www.fda.gov/news-events/public-health-focus/expanded-access): The FDA Expanded Access program (sometimes called “compassionate use”) is a potential pathway for a patient with a serious or life-threatening disease or condition to use an investigational medical product (drug, biologic, or medical device) for treatment outside of clinical trials when there are no comparable or satisfactory therapies available.

[FDA Patient Representative Program](https://www.fda.gov/patients/learn-about-fda-patient-engagement/about-fda-patient-representative-program)®: The FDA Patient Representative Program® is one of the agency’s primary mechanisms for recruiting patients and caregivers who have experience with a disease, condition, or medical device. FDA Patient Representatives are appointed as Special Government Employees (and sometimes Regular Government Employees) to participate in important agency directed assignments.

##### Center for Biologics Evaluation and Research (CBER)

[Patient Engagement Program](https://www.fda.gov/about-fda/center-devices-and-radiological-health/cdrh-patient-science-and-engagement-program): The FDA’s Center for Biologics Evaluation and Research’s patient engagement program incorporates patient and caregiver involvement in the Center’s regulatory work through PFDD meetings, patient listening sessions, external conferences, and patient organization meetings.

##### Center for Devices and Radiological Health (CDRH)

[Patient Engagement Advisory Committee (PEAC)](https://www.fda.gov/advisory-committees/committees-and-meeting-materials/patient-engagement-advisory-committee): The FDA’s Center for Devices and Radiological Health (CDRH) established PEAC meetings to help assure the needs and experiences of patients and caregivers are included as part of the FDA’s deliberations on complex, scientific issues related to medical devices.

[Patient and Caregiver Connection (PCC)](https://www.fda.gov/about-fda/cdrh-patient-science-and-engagement-program/cdrh-patient-and-caregiver-connection): The Patient and Caregiver-Partner Connection provides CDRH staff with access to aggregated patients’ and caregivers’ perspectives living with their specific disease and using medical devices in the diagnosis, treatment or management of their disease, as well current issues or trends related to medical devices.

##### Center for Drug Evaluation and Research (CDER)

[Patient Focused Drug Development (PFDD)](https://www.fda.gov/drugs/development-approval-process-drugs/cder-patient-focused-drug-development): Patient-focused drug development (PFDD) is a systematic approach to help ensure that patients’ experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation.

[Professional Affairs and Stakeholder Engagement (PASE)](https://www.fda.gov/about-fda/center-drug-evaluation-and-research-cder/professional-affairs-and-stakeholder-engagement): The CDER Professional Affairs & Stakeholder Engagement (PASE) hosts meetings and listening sessions providing a venue for patients, patient advocacy groups, and their caregivers, to share their experiences living with a disease or condition with FDA staff to help inform drug development.

##### Office of Patient Affairs (OPA)

[Patient Listening Sessions (PLS)](https://www.fda.gov/patients/learn-about-fda-patient-engagement/patient-listening-sessions): The FDA hosts a series of patient listening session meetings that allow patients and caregivers to share their experiences living with a disease or condition and share the most urgent needs with FDA staff to help inform medical product development. This is a collaboration with the National Organization for Rare Disorders (NORD) and the Reagan-Udall Foundation for FDA (RUF).

Patient Engagement Collaborative (PEC): The Patient Engagement Collaborative (PEC) is an ongoing forum of patients, caregivers, and patient advocacy organization representatives that work together to improve transparency, education, and communications between the patient community and the FDA. The group discusses how to achieve more meaningful patient and caregiver engagement in medical product development and other regulatory discussions at the FDA. This initiative is a collaboration with Duke University’s Clinical Trials Transformation Initiative (CTTI).

##### Oncology Center of Excellence (OCE)

[Project Community](https://www.fda.gov/about-fda/oncology-center-excellence/project-community): The OCE’s Project Community initiative seeks to improve the quality of bi-directional patient/advocate/community engagement with FDA oncologists and hematologists and people living in communities across the nation “beyond the beltway.” Online versions of educational pamphlets and an informational video have also been created for consumer use and are downloadable.

COVID-19 Listening Sessions: The OCE reached out to oncology stakeholders with COVID-19 Guidance Listening Sessions to better understand COVID-related experiences and the pandemic’s impact on cancer patients, advocacy groups, and oncology product development. The goal was two-fold: listen directly to cancer patient communities during difficult times and better inform OCE’s mission of achieving patient-centered regulatory decision-making through innovation and collaboration.

Conversations of Cancer Program: Trailblazing and dynamic OCE educational, public panel discussion series. Riveting cancer-related social issues in the series are inclusive and diverse.

[Project Patient Voice and Oncology Patient-Focused Drug Development](https://www.fda.gov/media/134806/download): An online platform for patients and caregivers along with their health care providers to look at patient-reported symptom data collected from cancer clinical trials.

[Project Facilitate](https://www.fda.gov/about-fda/oncology-center-excellence/project-facilitate): The OCE’s call center to assist oncology care providers in submitting Expanded Access requests.

### Health Resources and Services Administration (HRSA)

##### Federal Office of Rural Health Policy-Community Based Division

#### PROGRAM NAME: Rural Health Care Services Outreach Program

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (in rural communities).

**URL(s):** <https://data.hrsa.gov/tools/rural-health> (search by county or street address to determine rural eligibility).

<https://www.hrsa.gov/rural-health/community/outreach-program-awards>

**AUTHORITY:** 42 U.S.C. 254c(e). Public Law 116-136.

**SUMMARY:** The Outreach Program is a community-based grant program aimed towards promoting rural health care services by enhancing health care delivery in rural underserved populations in the local community or region. Through a consortia of local health care and social service providers, communities can develop innovative approaches to challenges related to their specific health needs that expand clinical and services capacity in rural communities.

The overarching goals for the Outreach Program are to 1) Expand the delivery of health care services to include new and enhanced services exclusively in rural communities; 2) Deliver health care services through a strong consortium, in which every consortium member organization is actively involved and engaged in the planning and delivery of services; 3) Utilize community engagement and evidence-based or innovative, evidence informed model(s) in the delivery of health care services; and 4) Improve population health and demonstrate health outcomes and sustainability.

Previously funded Outreach grant programs have brought care to over 2 million rural citizens across the country who often face difficulty gaining access to care. This includes projects focused on the full range of needs in rural communities from workforce, post-acute care services, long-term care services, emergency health care services, public health enhancement, and care coordination.

##### Bureau of Health Workforce, Division of Medicine and Dentistry, Medical Training and Geriatrics Branch

#### PROGRAM NAME: Geriatrics Workforce Enhancement Program (GWEP) Tele-Education Program

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (including patients, families, caregivers, direct care workers, health care providers, and health professions students, residents, fellows, and faculty).

**URL(s):** <https://www.hrsa.gov/grants/find-funding/hrsa-19-008>

**AUTHORITY:** PL 116-136. Public Health Service (PHS) Act Title VII, Sections 750 and 753(a), and PHS Act Title VIII, Section 865.

**SUMMARY:** The purpose of the GWEP Tele-Education Program is to support GWEP activities to advance COVID-19 related telehealth addressing these categories: 1) Prevent – promote the use of telehealth technologies to reduce risk of COVID-19; 2) Prepare – enhance readiness to respond to COVID-19 through telehealth technologies; and 3) Respond – provide access to telehealth technologies to limit spread of COVID19. This award provides flexibility in using the funding to prevent, prepare for, and respond to COVID-19 as needs evolve. Funding may support a wide range of in-scope activities. For example, funding may be used to support GWEP recipients planning to: 1) Train students and clinicians currently involved in health profession training on providing telehealth-enabled COVID-19 referral for screening and testing, case management, and outpatient care; and/or 2) Maintain primary care functionality away from physical sites, especially for COVID-19 positive, quarantined, elderly and individuals at a higher risk of severe illness. In addition, funds may be used to purchase Wi-Fi access, as well as iPads and other tablets, to be used during telehealth visits between providers and patients, families, and caregivers.

##### Maternal and Child Health Bureau (MCHB)

#### PROGRAM NAME: Family-to-Family Health Information Centers (F2F HICs)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (including patients, families, caregivers, direct care workers, health care providers, and health professions students, residents, fellows, and faculty).

**URL(s):** <https://www.hrsa.gov/grants/find-funding/hrsa-18-065>

<https://www.hrsa.gov/library/national-center-family-and-professional-partnerships-ncfpp>

**AUTHORITY:** Social Security Act, Title V, § 501(c) (42 U.S.C. § 701(c)), as amended by § 216 of the Medicare Access and Children’s Health Insurance Program (CHIP) Reauthorization Act of 2015 (P.L. 114-10), and § 50501 of the Bipartisan Budget Act of 2018 (P.L. 115-123).

**SUMMARY:** The goal of the F2F HICs Program is to promote optimal health for children and youth with special health care needs (CYSHCN) by helping families and health professionals to partner in health care decision-making and facilitating access to cost-effective, quality health care. The purpose is to provide information, education, technical assistance, and peer support to families of children and youth with special health care needs and the professionals who serve them.

The F2F HICs are statutorily required to:

* Assist families of CYSHCN in making informed choices about health care in order to promote good treatment decisions, cost effectiveness, and improved health outcomes.
* Provide information regarding the health care needs of, and resources available to CYSHCN.
* Identify successful health care delivery models for CYSHCN.
* Develop, with representatives of health care providers, managed care organizations, health care purchasers, and appropriate state agencies, a model for collaboration between families of CYSHCN and health professionals.
* Provide training and guidance regarding the care of CYSHCN.
* Conduct outreach activities to families of CYSHCN, health professionals, schools, and other appropriate entities and individuals.
* Staff centers with families of CYSHCN who have expertise in federal and state public and private health care systems, and with health professionals.

### Indian Health Service (IHS)

#### PROGRAM NAME: Varies

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies (i.e., American Indians and Alaska Natives defined in statute as eligible for services from IHS, a tribe or tribal Organization operating under the ISDEAA, or an Urban Indian Organization funded by IHS under the IHCIA).

**URL(s):** <https://www.ihs.gov/>

**AUTHORITY:** The United States Constitution, Article I, Section 8 specifically addresses the federal government’s primary role in dealing with Indians. Consistent with that authority, Congress enacted several statutes authorizing the federal government to provide health care services to American Indians and Alaska Natives. The Snyder Act of 1921 (25 U.S.C 13) and the Indian Health Care Improvement Act (IHCIA) [25 U.S.C. 1601-1685] provide specific legislative authority for Congress to appropriate funds specifically for the health care of Indian people.

In addition, numerous other laws, court cases, and executive orders reaffirm the unique relationship between tribal governments and the federal government.

The Indian Self-Determination and Education Assistance Act (ISDEAA) (P.L. 93-638, as amended), provide tribes the option of exercising their right to self-determination by assuming control and management of programs previously administered by the federal government.

**SUMMARY:** No distinct program or budget line for Caregiver Support. IHS clinical services provide caregiver support as a function of clinical care for elders. IHS Public Health Nursing (PHN) integrates caregiver support into usual outreach and support for frail elders and individuals with Alzheimer’s disease and related dementias.

The IHS partnered with the Administration on Aging/Administration for Community Living (AoA/ACL), the VA REACH Training Center, and the University of Tennessee Health Sciences Center in an effort funded by the non-profit Rx Foundation to adapt and spread the Resources to Enhance Alzheimer’s Caregiver Health (REACH) U.S. Department of Veterans Affairs (VA) model of caregiver support. According to data provided by the REACH Training Center in February 2018, over the three funded years of REACH into Indian Country, 80 caregiver coaches were trained and certified in 56 distinct tribal communities. Coaches were Public Health Nurses and caregiver support staff funded through Title VI of the Older Americans Act (ACL/AoA). These caregiver coaches reported delivery of REACH services to 55 caregivers. Caregiver support activity was unevenly distributed among the 50+ communities in which caregivers have been certified; in many of these communities no caregivers have been enrolled. The funding for that program has ended.

In follow-up to the REACH into Indian Country initiative, the IHS PHN program is working in partnership with the VA Geriatric Scholars Program on further supporting caregivers through the ABCD (Addressing Challenging Behaviors with Dementia) training for IHS and tribal programs. This effort is on hiatus as a result of the COVID-19 pandemic.

### National Institutes of Health (NIH)

#### PROGRAM NAME: National Institutes of Health, various programs

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies.

**URL(s):** [National Alzheimer’s Project Act](https://aspe.hhs.gov/national-alzheimers-project-act)

**AUTHORITY:** NIH is organized into 27 Institutes and Centers, and the Office of the Director, which each have their own mission and functions, separate appropriations, and statutory authorities. The majority of caregiving research funded at NIH falls within a combined Alzheimer’s disease and Alzheimer’s disease and related dementias (AD/ADRD) research, condition, and disease category, which was established by the NIH to facilitate its implementation of the [National Alzheimer’s Project Act](https://aspe.hhs.gov/national-alzheimers-project-act) (NAPA). Although caregiving research related to AD/ADRD is not separately reported, the NIH does publicly report its investments across all caregiving research.

**SUMMARY:** NIH’s mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. NIH carries out its mission through the conduct and support of intramural (primarily at NIH) and extramural (researchers and organizations outside of NIH) biomedical and behavioral research, research training, research infrastructure, and communications. As a grant-making Operating Division of HHS, NIH makes extramural awards through its Institutes and Centers in the form of grants, cooperative agreements, and contracts awarded to institutions of higher education, governmental organizations, non-profit research organizations, for-profit organizations, and individuals.

The National Institute on Aging (NIA): NIA’s [*Health Information*](https://www.nia.nih.gov/health) webpages cover a broad range of health topics and include numerous tips and resources on caregiver health and for [*family caregivers*](https://www.nia.nih.gov/health/topics/family-caregivers). The NIA [*Caregiving*](https://www.nia.nih.gov/health/caregiving) webpage presents tips for caregivers and caring for older adults, as well as information on long-distance caregiving, advance care planning, and planning for long-term care. The [*Alzheimer's Caregiving*](https://www.nia.nih.gov/health/alzheimers/caregiving) webpage addresses a broad range of topics specific to AD/ADRD care partners and families. NIA also provides [*Clinical Trials Information for the Public*](https://www.nia.nih.gov/research/clinical-trials#public), which includes clinical trials focused on caregiving.

The National Institute of Nursing Research (NINR): NINR’s website includes videos, tear-off pads, resource cards, fact sheets, a provider toolkit, and brochures for families with seriously ill children and health care providers as part of their [*Palliative Care: Conversations Matter®*](https://www.ninr.nih.gov/newsandinformation/conversationsmatter) campaign, aimed at increasing the use of palliative care for children and teens living with serious illnesses.

The National Cancer Institute’s (NCI): NCI’s [*Resources for Caregivers*](https://www.cancer.gov/resources-for/caregivers) webpage includes information about caring for the “cancer patient” and coping tips for caregivers, which can be found at: [*Support for Caregivers of Cancer Patients*](https://www.cancer.gov/about-cancer/coping/caregiver-support).

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD): NICHD’s Health Information webpages offer brochures, booklets, reports, and other materials on topics within its research portfolio for different audiences, and the [*Grandparent Videos*](https://safetosleep.nichd.nih.gov/resources/caregivers/grandparents) section features [*Safe Infant Sleep for Grandparents and Other Trusted Caregivers*](https://safetosleep.nichd.nih.gov/resources/caregivers/grandparents).

National Library of Medicine (NLM): [*MedlinePlus*](https://medlineplus.gov/) is a free online health information resource for patients and their families and friends. It is a service that NLM provides in its mission to present high-quality, relevant health and wellness information that is trusted, easy to understand, and free of advertising, in both English and Spanish. Included among the hundreds of Health Topicscovered in MedlinePlus are three separate pages devoted to caregivers, which provide a comprehensive list of caregiver consumer health materials, consisting of basic information about how caregiving affects health as well as links to tips for stress management and treatments and therapies, journal articles, and caregiver clinical trials, as well as patient handouts for caregivers of children and adults: [*Caregivers*](https://medlineplus.gov/caregivers.html); [*Caregiver Health*](https://medlineplus.gov/caregiverhealth.html); and [*Caregivers for Alzheimer's Disease*](https://medlineplus.gov/alzheimerscaregivers.html). In addition, while the [*NLM Resources for Caregivers*](https://sis.nlm.nih.gov/outreach/caregivers.html) webpage was sunset on September 30, 2020, the information and links presented remain current.

NIH Funding Opportunity Announcements for Research on Caregiving*:* [NIH Guide for Grants and Contracts](https://grants.nih.gov/funding/searchguide/index.html#/?query= caregiver, caregiving, caregivers&type=active,nosis&foa=all&parent_orgs=NIH&orgs=all&ac=all&ct=all&pfoa=all&date=01021991-11122020&fields=all&spons=true): NIH's official publication of current notices of funding opportunity announcements (FOAs) calling for research applications focused on caregiving.

NIH Clinical Trials on Caregiving*:* [The NIH Clinical Trials and You](https://www.nih.gov/health-information/nih-clinical-research-trials-you) website is a resource for people who want to learn more about clinical trials.

### Substance Abuse and Mental Health Services Administration (SAMHSA)

#### PROGRAM NAME: The Family Support Technical Assistance Center

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies. (The Family Support Technical Assistance Center (FAM-CoE) provides information to persons and communities across the country who are caring for family members with serious mental illness (SMI).

Statewide Family Network (SFN) program grants provide support to families who are raising children with serious emotional disturbance (SED). “Family” is defined by the family, and includes grandparents.

**URL(s):** <https://www.samhsa.gov/grants/grant-announcements/fg-20-002>

**AUTHORITY:** Funded by SAMHSA.

**SUMMARY:** SAMHSA recognizes the critical role families play in addressing mental health and substance use disorders and the toll such disorders take on families across the country. Each one of the SFN grantees is required to have the availability of relevant information to the public such as toll-free phone lines, newsletters, and the like. Virtually all grantees now offer an electronic newsletter.

The Fam-CoE will focus on training and education of the general public and health care practitioners on the importance of family supports and services and the integration of these services into mental and substance use disorder treatment programs. The Fam-CoE will also provide much needed resources and education directly for families.

Statewide Family Network program grants. The purpose of this program is to enhance state capacity and infrastructure to better respond to the needs of children and adolescents with serious emotional disturbances and their families by providing information, referrals, and support to families who have a child with a mental health challenge, and to create a mechanism for families to participate in state and local mental health services planning and policy development. This grant program is the CMHS primary initiative that responds to the needs of grandparents as caregivers to children and youth with SED.

The Statewide Family Network program builds on the work of SAMHSA’s Center for Mental Health Services, which helped to establish a child and family focus in programs serving children and adolescents with mental health challenges around the country. Today, nearly every state has active family organizations dedicated to promoting systems of care that are responsive to the needs of children and adolescents with mental health challenges and their families. Although significant progress has been made, further support will ensure self-sufficient, empowered networks that will effectively participate in state and local mental health services planning and health care reform activities related to improving community-based services for children and adolescents with mental health challenges and their families.

##### Child, Adolescent, and Family Branch

#### PROGRAM NAME: Statewide Family Network Program Grants

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (Persons and communities across the country caring for family members with severe mental illness).

**URL(s):** <https://www.samhsa.gov/grants/grant-announcements/sm-15-001> Programs have toll free lines and newsletters.

**AUTHORITY:** Funded by SAMHSA.

**SUMMARY:** The purpose of this program is to enhance state capacity and infrastructure to better respond to the needs of children and adolescents with serious emotional disturbances (and their families) by providing information, referrals, and support to families who have a child with a mental health challenge, and to create a mechanism for families to participate in state and local mental health services planning and policy development. This grant program is the primary initiative that responds to the needs of grandparents and caregivers to children and youth with SED. Statewide Family Network Program builds on the work of SAMHSA’s Center for Mental Health Services, which helped to establish a child and family focus in programs serving children and adolescents with mental health challenges. Today, nearly every state has active family organizations dedicated to promoting systems of care that are responsive to the needs of children and adolescents with mental health challenges and their families. Although significant progress has been made, further support will ensure self-sufficient, empowered networks that will effectively participate in state and local mental health services planning and health care reform activities related to improving community-based services for children and adolescents (and their families).

The Statewide Family Network grants provide for infrastructure development as well as information and communication.

### HHS Office of the Secretary (OS)

#### PROGRAM NAME: Office of the Assistant Secretary for Planning and Evaluation (ASPE)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies (ASPE’s Primary audience is the Secretary and other policy makers making decisions about the health and well-being of the American population).

**URL(s):** <http://aspe.hhs.gov>

**AUTHORITY:** N/A.

**SUMMARY:** The Office of the **Assistant Secretary for Planning and Evaluation (ASPE)** advises the Secretary of the Department of Health and Human Services on policy development in health, disability, human services, data, and science, and provides advice and analysis on economic policy. ASPE leads special initiatives; coordinates the Department's evaluation, research, and demonstration activities; and manages cross-Department planning activities such as strategic planning, legislative planning, and review of regulations. Integral to this role, ASPE conducts research and evaluation studies; develops policy analyses; and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress.

Within ASPE, the Office of Behavioral Health, Disability, and Aging Policy (BHDAP) focuses on policies and programs that support the independence, productivity, health, and well-being of people with disabilities, people with mental and substance use disorders (behavioral health), and older adults.

BHDAP’s portfolio includes, but is not limited to, behavioral health treatment and coverage issues; issues related to the need for and use of long-term services and supports; Alzheimer’s disease and related dementias; and issues related to behavioral health and long-term care quality and financing through Medicare, Medicaid, and private insurance. BHDAP works closely with the ACL, SAMHSA, the CMS, and the NIH, among other HHS and federal agencies focused on aging, disability, and behavioral health.

The Division of Long-Term Care Policy focuses on the long-term care and personal assistance needs of people of all ages with chronic disabilities. Areas of focus include informal caregiving; assessing the interaction between health care, chronic care, long-term care, and supportive services needs of persons with disabilities across the age spectrum; determining service use and program participation patterns; and coordinating the development of long-term care data and policies that affect the characteristics, circumstances, and needs of people with long-term care needs, including older adults and people with disabilities.

The Division of Disability and Aging Policy is responsible for policy development, coordination, research and evaluation of policies and programs focusing on persons with disabilities and older Americans. This includes measuring and evaluating the impact of all programs authorized by the Older Americans Act. Aging activities related to older Americans are carried out in coordination with other HHS agencies and organizations. The Division is also responsible for supporting the development and analysis of crosscutting disability and aging data and policies within HHS and in other federal agencies.

The Division of Behavioral Health and Intellectual Disabilities Policy focuses on financing, delivery, and quality of services and supports for individuals with mental illnesses, substance use disorders, or intellectual disabilities. Areas of focus include coverage and payment issues in private insurance, programs and policies of Medicare and Medicaid, quality and consumer protection issues, and programs and policies of HHS agencies as they affect adults, children, and youth with mental health conditions, substance abuse, or intellectual disabilities.

Family caregiving has been a focus of many BHDAP research and reports. Some examples include:

**Economic Impacts of Programs to Support Caregivers**

<https://aspe.hhs.gov/basic-report/economic-impacts-programs-support-caregivers-final-report>

**Assessing the Out-of-Pocket Affordability of Long-Term Services and Supports**

<https://aspe.hhs.gov/basic-report/assessing-out-pocket-affordability-long-term-services-and-supports-research-brief>

**How Many Older Adults Can Afford To Purchase Home Care?** <https://aspe.hhs.gov/basic-report/how-many-older-adults-can-afford-purchase-home-care>

**What Is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports?**

<https://aspe.hhs.gov/basic-report/what-lifetime-risk-needing-and-receiving-long-term-services-and-supports>

**Community-Dwelling Older Adults with Dementia and Their Caregivers: Key Indicators from the National Health and Aging Trends Study**

<https://aspe.hhs.gov/basic-report/community-dwelling-older-adults-dementia-and-their-caregivers-key-indicators-national-health-and-aging-trends-study>

#### PROGRAM NAME: Office of the National Coordinator (ONC) For Health Information Technology

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies.

**URL(s):** <https://www.healthit.gov/>

**AUTHORITY:** The position of National Coordinator was created in 2004, through an executive order, and legislatively mandated in the Health Information Technology for Economic and Clinical Health Act ([HITECH Act](https://www.healthit.gov/policy-researchers-implementers/health-it-legislation)) of 2009.

**SUMMARY:** One of the big challenges for caregivers is the ability to coordinate care for their care recipient. This is particularly difficult when utilizing health care and human/social/community services from a variety of providers, most of whom are not connected to one another. Furthermore, it is very difficult to collect and track all the information and medical records, and consolidate them in one place, not to mention the challenge of permissions needed to access records by a caregiver.

While many patients can access their medical information through multiple provider portals, the current ecosystem is frustrating and cumbersome. The more providers they have, the more portals they need to visit, the more usernames and passwords they need to remember. In the end, these steps make it hard for patients and their caregivers to aggregate their information across care settings and prevent them from being empowered consumers.

Interoperable health information exchange can improve care coordination including; a historical and current view of the patients health record and the care they have received; Access to longitudinal health information that enables improved efficiencies, improved quality of care, and improved health outcomes; patient and caregiver communications with providers; transitions between health care settings [inpatient, ambulatory, acute care, long-term and post-acute care (LTPAC), and home and community-based services].

Data should be usable across the continuum of care and beyond the traditional health care system, including community-based services. As we move forward, we expect to include more information about a person’s health (SDOH, Community-based care, etc.) within the core information that is shared.

In 2016, the 21st Century Cures Act was passed with near unanimous bipartisan support and signed into law with two major provisions including: patient access to, and the ability to control their health information; and interoperability of health information. This will require all health care providers to share a patient’s health data with one another to better enable care coordination, view health history, lab results, medication information, etc.

In ONC’s role in coordinating health information technology (health IT) innovators are working to develop strategies to support the use of mobile apps to help individuals manage their own health or the health and care of a loved one. A robust health app ecosystem can also lead to disease-specific apps and allow patients to share their health information with researchers working on clinical trials to test a drug or treatment’s efficacy or monitoring outcomes like those in the NIH’s All of Us Research Program.

Final Rule released in March 2020:

<https://www.hhs.gov/about/news/2020/03/09/hhs-finalizes-historic-rules-to-provide-patients-more-control-of-their-health-data.html#:~:text=The%20ONC%20Final%20Rule%20identifies,certified%20health%20IT%2C%20health%20information>

HHS finalized two transformative rules that will give patients unprecedented safe, secure access to their health data. Multiple administrations and numerous laws have pursued interoperability, and today, these rules finally deliver on giving patients true access to their healthcare data to make informed healthcare decisions and better manage their care. Putting patients in charge of their health records is a key piece of giving patients more control in healthcare, and patient control is at the center of the Trump administration’s work toward a value-based healthcare system.

ONC’s final rule establishes secure, standards-based application programming interface (API) requirements to support a patient’s access and control of their electronic health information. APIs are the foundation of smartphone applications (apps). As a result of this rule, patients will be able to securely and easily obtain and use their electronic health information from their provider’s medical record for free, using the smartphone app of their choice.

## U.S. Department of Education

#### PROGRAM NAME: Rehabilitative Services Administration Programs

**TARGET CAREGIVER POPULATION(S):** Kinship Families and Grandfamilies (including Parents, Guardians, State Vocational Rehabilitation)

**URL(s):** <https://www.raisecenter.org/>

**AUTHORITY:** Rehabilitation Act of 1973, as amended (29 U.S.C. §773(c)(2)) establishes a parent information and training program (RSA PTIs), administered by the Rehabilitation Service Administration (RSA) under the Office of Special Education and Rehabilitative Services (OSERS).

**SUMMARY:** The purpose of the program is to provide information, training, and resources on Youth Transition, the period between adolescence and adulthood, and the transition between IDEA services and postsecondary, rehabilitative, and adult services. There are currently eight RSA PTIs throughout the US that provide various training and programming to youth and young adults with disabilities and their families, professionals, and parent training and information centers funded under IDEA. The current RSA PTIs support various entities within their region, to include national coverage. In addition, the National Resources for Advocacy, Independence, Self-determination, and Employment (RAISE) Technical Assistance Center, also funded under the program, provides technical assistance and support to the eight RSA PTIs and has a website with useful resources for families and others.

#### PROGRAM NAME: Elementary and Secondary Education Act (ESEA) Programs

**TARGET CAREGIVER POPULATION(S):** Kinship Families and Grandfamilies (including parents, guardians, and schools).

**URL(s):** <https://oese.ed.gov/families/>

**AUTHORITY:** The SFEC program is authorized under title IV, part E of the Elementary and Secondary Education Act of 1965, as amended (ESEA).

**SUMMARY:** The purpose of the Statewide Family Engagement Centers (SFEC) program is to provide financial support to organizations that provide technical assistance and training to State Educational Agencies (SEAs) and Local Educational Agencies (LEAs) in the implementation and enhancement of systemic and effective family engagement policies, programs, and activities that lead to improvements in student development and academic achievement. The eligible entities for this grant are statewide organizations (or consortia of such organizations) in partnership with an SEA to establish SFECs that (1) carry out parent education and family engagement in education programs, and (2) provide comprehensive training and technical assistance to SEAs, LEAs, schools identified by SEAs and LEAs, organizations that support family-school partnerships, and other such programs.

The SFEC program seeks to promote high-impact cradle-to-career family, school, and community engagement by funding centers that build the capacity of all stakeholders—including families, SEAs, LEAs, school-level staff and personnel, and community based organizations—to engage in effective partnerships that support student achievement and school improvement and increase the number of high-quality educational options available to families.

A few grantees are conducting work directly targeting grandparents. The West Virginia Center co-hosted professional development for grandparents and great-grandparents raising grandchildren. The Ohio Center has recently begun a project to strengthen the support and engagement of grandparents raising school-age kids. They are completing a review of the research in this area and will be releasing a brief on the results. They will also begin developing a training to pilot with schools and a program for grandparents.

#### PROGRAM NAME: Office of English Language Acquisition (OELA)

**TARGET CAREGIVER POPULATION(S):** Kinship Families and Grandfamilies.OELA provides guidance to families to help them choose educational services and supports that best fit their child’s needs.

**URL(S):** <https://www2.ed.gov/about/offices/list/oela/index.html>

**AUTHORITY:** OELA’s appropriations, programs and services are authorized under Title III of the Elementary and Secondary Education Act (ESEA) and reauthorized under Title III of the Every Student Succeeds Act (ESSA).

**SUMMARY:** The U.S. Department of Education's Office of English Language Acquisition (OELA) provides national leadership to help ensure that English Learners (ELs) and immigrant students attain English proficiency and achieve academic success. In addition to preserving heritage languages and cultures, OELA is committed to prompting opportunities for biliteracy or multiliteracy skills for all students.

OELA also funds research and evaluation studies regarding ELs as well as the National Clearinghouse for English Language Acquisition (NCELA). NCELA’s mission is to collect, coordinate, and convey a broad range of research and resources in support of an inclusive approach to high quality education for ELs. To fulfill its mission, NCELA supports OELA in a variety of activities in addition to serving other stakeholders involved in EL education including State Educational Agencies (SEAs), teachers and other practitioners, parents, university faculty, administrators, and federal policymakers.

### Office of Special Education and Rehabilitative Services (OSERS), Office of Special Education Programs (OSEP)

#### PROGRAM NAME: Individuals with Disabilities Education Act (IDEA) Programs

**TARGET CAREGIVER POPULATION(S):** Kinship Families and Grandfamilies.

**URL(s):** <https://sites.ed.gov/idea/parents-families/>

**AUTHORITY:** P.L. 101-476 (IDEA includes “an individual acting in the place of a natural or adoptive parent (including a grandparent, stepparent, or other relative) with whom the child lives, or an individual who is legally responsible for the child’s welfare” (20 U.S.C. § 1401) in its definition of parent).

**SUMMARY**: Part C of IDEA: Congress established the Program for Infants and Toddlers with Disabilities in IDEA in 1986. Part C of the current IDEA legislation (20 U.S.C. §§ 1431-1444) authorizes a grant program to states to maintain and implement a statewide, comprehensive, coordinated, multidisciplinary interagency system to provide early intervention services for infants and toddlers with disabilities and their families. In order for a state to participate in the program, it must assure that early intervention services will be available to all infants and toddlers with disabilities and their families.

Part C early intervention services are designed to ensure that infants or toddlers with disabilities are identified and evaluated. An infant or toddler with a disability means an individual under three years of age who needs early intervention services because they are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more areas, or has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. The areas under consideration are cognitive, physical, communication, social or emotional, and adaptive development. States have discretion in terms of defining developmental delay and diagnosed conditions; therefore, the percent of infants and toddlers served under Part C varies from state to state. At the discretion of the state, at-risk infants or toddlers may also be served under Part C. Services are detailed for each child and their family in an Individualized Family Service Plan (IFSP), and parents are an integral member of the team developing the IFSP. To the maximum extent feasible, services are to be provided in “natural environments,” including the home or with other infants and toddlers without disabilities.

Part B of IDEA: Part B of IDEA (20 U.S.C. §§ 1411-1419) ensures that all children with disabilities ages 3 through 21 have available to them a Free and Appropriate Education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.

Special education is the provision of specially designed instruction that meets the unique needs of a child with a disability. IDEA Part B lists 13 different disability categories under which a child may be found eligible for special education and related services. These categories are autism, deafness, deaf-blindness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment including blindness. States may also adopt developmental delay as a disability category for children ages three through nine or for a subset of that age range.

Special education and related services must be provided, to the maximum extent appropriate, in the least restrictive environment (LRE) based on the child’s unique needs. The LRE Requirements indicate a strong preference for educating children with disabilities in general education settings with appropriate aids and supports alongside their peers without disabilities to the maximum extent appropriate. Each child’s Individualized Education Program (IEP) states the services and accommodations the child will receive. Parents are important members of the team that develops the IEP. States are also required to have a system to ensure that all children with disabilities residing in the state, regardless of the severity of their disability, and who are in need of special education and related services, are identified, located, and evaluated.

Part D of IDEA: Part D of IDEA (20 U.S.C. §§ 1450-1482) funds national activities that support the provision of early intervention and special education services to infants, toddlers, children, and youth with disabilities. These activities include state personnel development grants to support current personnel; grants to institutions of higher education to prepare early intervention and special education personnel, including related services; grants to fund technical assistance and dissemination centers, and model demonstration centers, that promote best practices in supporting children with disabilities; and grants for technology projects that disseminate accessible materials and media and promote children with disabilities’ effective use of technology.

Part D also funds the parent training and information center program (20 U.S.C. §§ 1470-1473), which provides direct services to families of children with disabilities, including children who may not yet be identified as having a disability or may be inappropriately identified. The purpose of the program is to ensure that children with disabilities and their parents receive training and information on their rights, responsibilities, and protections under IDEA; that the training and information is designed to assist the children in meeting developmental and functional goals and challenging academic achievement goals that prepare them to lead as productive and independent adult lives as possible; and that parents and youth develop the skills necessary to cooperatively and effectively participate in planning and decision making relating to early intervention, educational, and transitional services.

The program consists of 99 grants of three types: Parent Training and Information Centers (PTIs) in every state and territory; Community Parent Resource Centers (CPRCs) in underserved communities; Regional Parent Technical Assistance Centers (PTACs) and a national technical assistance center, the Center for Parent Information and Resources (CPIR).

PTIs and CPRCs provide direct services to all families of children with disabilities and youth with disabilities, including families of children who are suspected of having a disability, in the form of in-person, telephone, and electronic consultations, in-person and web-based trainings, support groups, and leadership development activities.

While PTIs and CPRCs primarily focus on educational issues, they also connect families with relevant local and state resources applicable to kinship families. The national Center for Parent Information and Resources’ website contains a list of all the PTIs and CPRCs throughout the country and a curated list of informational resources for families and professionals.

## U.S. Department of Labor

### Wage and Hour Division

#### PROGRAM NAME: The Family and Medical Leave Act of 1993 (FMLA)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies (e.g., employees of private sector employers with 50 or more employees and public agencies regardless of the number of employees they employ).

**URL(s):** [www.dol.gov/agencies/whd/fmla](http://www.dol.gov/agencies/whd/fmla)

**AUTHORITY:** (29 U.S.C. 2601), signed into law on February 5, 1993, and effective August 5, 1993.

**SUMMARY:** The FMLA is a federal law that provides eligible employees of covered employers with unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance under the same terms and conditions as if the employee had not taken leave. The U.S. Department of Labor’s Wage and Hour Division (WHD) is responsible for administering and enforcing the FMLA for most employees. Additionally, WHD offers a wide variety of materials to help the public understand the law. WHD’s FMLA website, [www.dol.gov/agencies/whd/fmla](http://www.dol.gov/agencies/whd/fmla), is consistently one of the Department’s most frequently visited web pages. In 1995, 2000, 2012, and 2018, the Department surveyed employees and employers to gain knowledge about how individuals understand and experience FMLA (<https://www.dol.gov/agencies/oasp/evaluation/fmla2018>).

WHD does not enforce the FMLA for most federal employees. Most employees of the U.S. government, if they are covered by the FMLA, are covered under Title II of the FMLA, which is administered by the U.S. Office of Personnel Management (OPM).

The FMLA generally applies to private sector employers with 50 or more employees. Public agencies are covered employers under the FMLA, regardless of the number of employees they employ. Local educational agencies are also covered regardless of the number of employees they employ. Such educational agencies include public school boards, public elementary and secondary schools, and private elementary and secondary schools. An eligible employee is one who works for a covered employer, has worked for the employer for at least 12 months as of the date the FMLA leave is to start, has at least 1,250 hours of service for the employer during the 12-month period immediately before the date the FMLA leave is to start (a different hours of service requirement applies to airline flight crew employees), and works at a location where the employer employs at least 50 employees within 75 miles of that worksite as of the date when the employee gives notice of the need for leave. Among other qualifying reasons for leave, eligible employees may take up to 12 workweeks of leave in a 12-month period to care for a spouse, son, daughter, or parent who has a serious health condition, including incapacity due to pregnancy and for prenatal medical care; and up to 26 workweeks of leave during a single 12-month period to care for a covered service member with a serious injury or illness when the employee is the spouse, son, daughter, parent, or next of kin of the service member.

WHD has issued Administrator Interpretations ([FMLA 2013-1 and 2010-3](https://www.dol.gov/agencies/whd/opinion-letters/administrator-interpretation/flma)) and plain language fact sheets regarding the availability of leave to employees who have or have had an “in loco parentis” relationship to a child or parent, and providing guidance on the FMLA definition of a son or daughter who is 18 or older and incapable of self-care because of a disability. WHD has also provided examples and guidance on grandparent and sibling relationships that may qualify, in certain circumstances, as covered “in loco parentis” caregiving relationships.

Every employer covered by the FMLA must provide a general notice to their employees regarding the FMLA. To satisfy the general notice requirement, employers must display or post a general notice (a poster). If a significant portion of an employer’s employees do not read and write English, the employer must provide the general notice in a language in which they can read and write. When providing FMLA notices to sensory-impaired individuals, employers must also comply with all applicable requirements under federal and state law. Employers may make the poster available electronically, create their own poster, or use another format. In addition to displaying a poster, if a covered employer has any FMLA eligible employees, it must also provide each employee with a general notice about the FMLA in the employer’s employee handbook or other written materials about leave and benefits. If no handbook or written leave materials exist, the employee must distribute this general notice to each new employee upon hire. When an employee requests FMLA leave, or when the employer acquires knowledge that an employee’s leave may be for a FMLA-qualifying reason, the employer must notify the employee of his or her eligibility to take FMLA leave and provide a rights and responsibilities notice. WHD makes available posters and optional-use forms for notifying employees of their FMLA eligibility, rights, and responsibilities, and leave designation on its website at <https://www.dol.gov/agencies/whd/fmla/forms>.

### Division of Strategic Investments, Office of Workforce Investment

#### PROGRAM NAME: Strengthening Working Families Initiative (SWFI) grant program

**TARGET CAREGIVER POPULATION(S):** Family caregivers

**URL(s):** <https://www.dol.gov/agencies/eta/skills-grants/h1-b-skills-training>

**AUTHORITY:** Section 414(c) of the American Competitiveness and Workforce Improvement Act of 1998 (ACWIA), as amended (codified at 29 USC 3224a).

**SUMMARY:** SWFI grants assist low- to middle-skilled parents in accessing the affordable, quality child care they need to earn an education, participate in training programs, and ultimately compete for better-paying jobs in emerging industries. These projects are also connecting workforce and child care systems to address the needs of working parents beyond the grant period. DOL awarded approximately $54 million in SWFI grants to 14 partnerships providing services to 13 states in June 2016. The grant period of performance was four years, and some grantees received up to one-year extensions. All grantees will complete their period of performance by June 30, 2021. No further rounds are anticipated.

The SWFI grant program is one of several H-1B Skills Training Grants fund projects that provide training and related activities to workers to assist them in gaining the skills and competencies needed to obtain or upgrade employment in high-growth industries or economic sectors. These grants are supported by user fees paid by employers seeking high skilled foreign workers under the H-1B visa program. The goal of the training grants is to prepare Americans for high skill jobs, reducing the dependence on foreign labor. Funds are authorized by Section 414(c) of the American Competitiveness and Improvement Act of 1998 (ACWIA), as amended (29 USC 3224a).

### Employment and Training Administration, Office of Workforce Investment, Division of Youth Services

#### PROGRAM NAME: Workforce Innovation and Opportunity Act (WIOA) Youth Formula Funded

**TARGET CAREGIVER POPULATION(S):** Family Caregivers; Kinship Families and Grandfamilies (e.g., youth facing barriers to education, training, and employment)

**URL(s):** <https://www.dol.gov/agencies/eta/youth/wioa-formula>

**AUTHORITY:** 29 U.S.C. 3101, Title I, Chapter 2, July 2015

**SUMMARY:** Out-of-school youth (i.e., not attending school), ages 16-24 and with one or more barriers to employment including school dropout, high school graduate and basic skills deficient or English language learner, offender, homeless or runaway, foster care, pregnant or parenting, disability, and low income who requires additional assistance for education or employment.

In-school youth who is attending school, ages 14-21, low income and has one or more barriers to employment including basic skills deficient, English language learner, offender, homeless or runaway, foster care, pregnant or parenting, disability, and requires additional assistance.

WIOA Youth Formula Funded activities include 14 program elements: tutoring; alternative secondary school services; paid and unpaid work experiences, which include summer and year round employment opportunities, pre-apprenticeship programs, internships and job shadowing, and on-the-job training; occupational skill training; education offered concurrently with workforce preparation and training; leadership development opportunities; supportive services; mentoring; follow-up services; comprehensive guidance and counseling; financial literacy education; entrepreneurial skills training; services that provide labor market and employment information; and postsecondary education and training preparation activities.

A minimum of 75% of the Youth funds allocated to states and local areas must be used to provide services to out-of-school youth**.**

## U.S. Department of Veterans Affairs

### Office of Community Engagement (OCE)

#### PROGRAM NAME: Varies

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (i.e., Veterans, their families, caregivers, and survivors).

**AUTHORITY:** 38 U.C. § 8301; 38 U.S.C. § 523; The Economy Act, 31 U.S.C. 1535; 38 U.S.C. 1710B and 1720B; The Economy Act, 31 U.S.C. 1535; The Domestic Volunteer Service Act of 1973, as amended (DVSA) (42 U.S.C. 5028). The National and Community Service Act of 1990, as amended (NCSA), 42 U.S.C. 12511(34), 1265lb(g)(10)(B) and 12657.

**SUMMARY:** OCE serves as a trusted resource and a catalyst for the growth of effective partnerships at the national, state, and community level and as a facilitator/access point for public and private entities interested in partnering with VA’s Veterans Health Administration (VHA) to benefit Veterans, their families, caregivers, and survivors. Nine partnerships that directly impact caregivers include:

CancerCare (in development): The goal of this partnership is to improve care and outcomes of Veterans, their families, caregivers, and survivors diagnosed with any type of cancer. <https://www.cancercare.org/>

Cancer Support Community: The purpose of this partnership is to provide cancer related resources and support services to Veterans, VHA health care professionals, and Veterans’ family members and caregivers; provide specific resources that focus on reducing social isolation and hopelessness to Veterans with cancer; and increase Veterans’ awareness of an opportunity to participate in the voluntary CSC Cancer Experience Registry (CER) to document the Veteran cancer patient experience. <https://www.cancersupportcommunity.org/>

American Lung Association: The goal of this partnership is to enhance services to Veterans, their families, and caregivers through collaborative education and services for Veterans living with lung disease. <https://www.lung.org>

VHA/AmeriCorps Choose Home Partnership: The purpose of this partnership is to provide homemaker services and in-home respite care services to eligible Veterans so that those Veterans can continue to remain in their own homes and live more independently. <https://www.va.gov/opa/pressrel/pressrelease.cfm?id=5277> or https://www.americorps.gov/about/what-we-do/veterans

Imerman Angels (in development): The partnership with Imerman Angels will provide increased outreach to Veterans and their families and caregivers in and out of the VA system, with the specific aim of improving access to a cancer patient support network, educational material, and cancer survivor mentor training for Veterans and caregivers. <https://imermanangels.org/>

American Kidney Fund (AKF): The partnership will provide support for Veterans, family members, caregivers, and survivors diagnosed with kidney disease by helping them to live healthier lives through awareness, education, and sharing resources about prescreening and receiving appropriate treatment. <https://www.kidney.org/>

Arthritis Foundation (AF) (in development): The partnership will provide education and support for Veterans, family members, caregivers, and survivors diagnosed with arthritis. <https://www.arthritis.org/>

American Cancer Society (ACS) (in renewal development): This partnership provides the advancement and improvement of quality of life for Veterans, family members, and caregivers who are at-risk, living with, or surviving cancer. <https://www.cancer.org/>

American Diabetes Association (ADA) (in development): This partnership will provide awareness and education for Veterans, family members, caregivers, and survivors who are at-risk or diagnosed with diabetes. <https://www.diabetes.org/>

##### Office of Research & Development

#### PROGRAM NAME: Elizabeth Dole Center of Excellence for Veteran and Caregiver Research

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (i.e., Veterans, Caregivers of Veterans as well as Children and Youth living in caregiving households).

**URL(s):** <https://www.hsrd.research.va.gov/centers/dole/default.cfm/>

**AUTHORITY:** 38 U.S. Code § 7303.

**SUMMARY:** The Elizabeth Dole Center of Excellence for Veteran and Caregiver Research was created as part of the VA Choose Home Initiative. The goal of Choose Home is to allow Veterans to remain in their homes rather than institutional care. The purpose of the Center is to expand VA capacity to deliver integrated, Veteran and caregiver-partnered, data-driven approaches to care. The center is conducting complimentary projects whose results will inform VA operational leaders in expanding VA caregiver programs. The Center is multi-site, with locations in San Antonio, Palo Alto, Salt Lake City, Miami, and Canandaigua. These programs have 4 key components:(1) pilot projects related to caregiver support; (2) interviews of Veterans, caregivers, and other stakeholders to assess measures that are most meaningful to caregivers; (3) data analytics to assess the types of home-based care services that are most effective for different Veteran populations, and (4) an assessment of the lived experiences of youth in caregiving households.

##### Veterans Health Administration (VHA)

#### PROGRAM NAME: VA Voluntary Services (VA Volunteer In-Home Visitor Program and Compassionate Contact Corps Program)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (i.e., Any Veteran referred by their clinician is eligible for these programs).

**URL(s):** Volunteers and community partners can learn more about these programs by contacting their local VA medical center. To locate the nearest facility, visit: [www.volunteer.va.gov](http://www.volunteer.va.gov). Toolkits and the Program Implementation Guide will be accessible to Voluntary Service Officers at local facilities executing the program.

**AUTHORITY:** N/A.

**SUMMARY:** Volunteer In-Home Visitor Program: This friendly visitor program pairs VA trained and vetted volunteers with Veterans for non-clinical companionship. Veteran participants, many of whom suffer from loneliness and/or social isolation, are clinician-referred. The visits also provide caregivers regular respite (2–4 hours/week) during the visits. Volunteers are fingerprinted, background checked, given orientation, and initial and ongoing training. Volunteers often serve as an extra set of eyes and are among the first to know and report changes in the Veteran’s condition and/or their environment. We are currently working to develop an evaluation tool to help measure the impact of the program.

Compassionate Contact Corps: This program was borne out of COVID-19. In March 2020, VA suspended its Volunteer In-Home Visitor Program, due to the high-risk demographics of the Veterans, caregivers, and many of our volunteers. What was created and implemented using the foundation of the in-home visitor program, was a non-clinical tele-support program. This allowed volunteers to continue filling an even more crucial need for Veterans and their caregivers, while expanding access to this service to Veterans from across VHA.

The Office of Voluntary Service is working to create a series of marketing and communication materials, as well as develop an evaluation tool to measure the impact of the program on Veterans, caregivers, and the volunteers who serve.

#### PROGRAM NAME: Caregiver Support Program (CSP)

**TARGET CAREGIVER POPULATION(S):** Caregivers participating in VA’s Program of Comprehensive Assistance for Family Caregivers (PCAFC) or the Program of General Caregiver Support Services (PGCSS)

**URL(s):** <https://www.caregiver.va.gov/>

National Caregiver Support Line: 855.260.3274.

[Caregiver Support Program Staff](https://www.caregiver.va.gov/support/New_CSC_Page.asp) (State Directory).

[Peer Support Mentoring](https://www.caregiver.va.gov/support/Peer_Support_Mentoring_Program.asp): Peer based learning network contributing to skill building and peer-based support and guidance.

[Spanish-Speaking Telephone Support Groups](https://www.caregiver.va.gov/pdfs/Spanish-Language-call-Flyer-Final.pdf): Caregivers participating in VA’s Program of Comprehensive Assistance for Family Caregivers (PCAFC) or the Program of General Caregiver Support Services (PGCSS)

[Publications and Resources by Topic](https://www.caregiver.va.gov/publications_resources_topic.asp) (listed by Diagnosis, concern, or topic)

Train the Trainer Caregiver Self-Care Classes.

[Building Better Caregivers](https://va.buildingbettercaregivers.org/): Facilitated, self-paced, six-week self-care course for caregivers.

[REACH VA](https://www.caregiver.va.gov/REACH_VA_Program.asp): Resources for Enhancing All Caregivers Health. Education, Skill Building and Support for caregivers of Veterans with ALS, Dementia, MS, PTSD, or Spinal Cord Injury. Emphasis on Rural Caregivers.

[Elizabeth Dole Foundation, the Campaign for Inclusive Care](https://www.elizabethdolefoundation.org/): In partnership with VA’s Caregiver Support Program, trains providers about Veteran caregivers, the role of caregivers, impact on caregiving and how to include caregivers in the care team. The goal is to improve outcomes for Veterans, their caregivers, and their health care providers.

AmeriCorps: Volunteer based, non-institutional care effort to enable older Veterans and their caregivers to receive homemaker and other living supports and respite in their home.

[Veteran Services Organizations](https://www.dav.org/): Chartered organizations recognized by the Secretary of Veterans Affairs work to support Veterans and caregivers.

[Rosalynn Carter Institute for Caregiving](http://rosalynncarter.org/): The institute’s overall goal is to support caregivers through advocacy, research, and service. In partnership with VA’s Caregiver Support Program, it implements [The Operation Family Caregiver Program](https://www.operationfamilycaregiver.org/) at some VA medical centers. This free program, available to those caring for a family member or friend who has a visible and/or invisible injury due to military service, provides certified coaches to problem solve issues related to caregiving.

VHA Office of Mental Health: [Suicide Prevention Toolkit for Caregivers](https://www.caregiver.va.gov/pdfs/VA-Suicide-Prevention-Toolkit-for-Caregivers.pdf)

Geriatrics and Extended Care: [Home and Community-Based Services](https://www.caregiver.va.gov/Care_Veterans.asp) Adult Day Health Care, Home Based Primary Care, Home Hospice, Home Telehealth, Remote Monitoring, Respite, Skilled Home Care.

[Office of Connected Care](https://connectedcare.va.gov/): “Annie App” Caregiver Self Care and Stress Management via Text Messaging: <https://mobile.va.gov/app/annie-app-veterans>

[Office of Rural Health](https://www.ruralhealth.va.gov/vets/index.asp): Promising practices, educational videos, and other resources.

[Office of Mental Health and Suicide Prevention](https://www.mentalhealth.va.gov/)

[Social Work Fisher House](https://www.socialwork.va.gov/fisher.asp)

[Resources and Education for Stroke Caregivers’ Understanding and Empowerment (RESCUE)](https://www.cidrr8.research.va.gov/rescue/)

[Veterans and Community Partnerships](https://www.va.gov/healthpartnerships/vcp.asp)

[Veterans Transportation Programs](https://www.va.gov/HEALTHBENEFITS/vtp/)

[National Resource Directory](https://nrd.gov/)

**AUTHORITY:** P.L. 111–163 – Caregivers and Veterans Omnibus Health Services Act of 2010; P.L.115–182, VA Maintaining Internal Systems and Strengthening Integrated Outside Networks (VA MISSION Act).

**SUMMARY:** The Department of Veterans Affairs established a Program of Comprehensive Assistance for Family Caregivers (PCAFC) and a Program of General Caregiver Support Services (PGCSS), collectively referred to as the Caregiver Support Program (CSP). The CSP implemented a national caregiver staffing infrastructure and develops, implements, and supports critical programming, tools, and services. The CSP works alongside external partners and other VA program offices to contribute to a larger system of services intended to improve both Veteran and caregiver health, safety, and well-being.

In 2010, *P.L. 111–163 – Caregivers and Veterans Omnibus Health Services Act of 2010* expanded upon existing VA caregiver services and supports available through the Program of General Caregiver Support Services (PGCSS) (without application) for enrolled Veterans and their caregivers. The legislation also supported the development of the Program of Comprehensive Assistance for Family Caregivers (PCAFC) with services and supports intended to help caregivers address the needs of the eligible Veterans and Service members who were seriously injured in the line of duty on or after September 11, 2001.

On June 6, 2018, *Pub L.115–182, VA Maintaining Internal Systems and Strengthening Integrated Outside Networks (VA MISSION Act)* was signed into law expanding the Program of Comprehensive Assistance for Family Caregivers to include eligible Veterans of all eras, in a phased approach. The MISSION Act authorizes additional services and supports and revises terms and eligibility requirements for the CSP for eligible Veterans. The MISSION Act provides Veterans greater access to health care in VA medical facilities and the community, and expands support for caregivers of eligible Veterans.

#### PROGRAM NAME: Veterans Experience Office - Veterans Signals (V-Signals)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (Note: The target population consists of Veterans that had one of the following interactions with VHA Outpatient services within the prior week: (1) scheduling an appointment, (2) visiting a health care provider, (3) labs/imaging services, (4) pharmacy services received by mail or (5) pharmacy services received in-person. These interactions make up the five survey types).

**URL(s):** Only approved/authorized VHA staff can access this data.

**AUTHORITY:** N/A.

**SUMMARY:** VSignals surveys such as Outpatient Services surveys and the Board of Veterans Appeals Surveys contain a “free text capability” that allows for Veterans to provide compliments, concerns, or recommendations related to their own experience with VA products and services, including their sentiment and perspective on opportunities, successes, and challenges associated with Veteran Caregivers. Using artificial intelligence that applies keyword searches to our Medallia-based Vsignals platform, insights can be extracted that specifically reference caregivers or words associated with the caregiver experience.

#### PROGRAM NAME: Office of Patient Centered Care & Cultural Transformation (PCCCT)

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (i.e., Virtual seminars target caregivers, Veterans, families, and the public).

**URL(s):** <https://www.va.gov/WHOLEHEALTH>

<https://www.blogs.va.gov/VAntage/tag/livewholehealth/>

**AUTHORITY:** In accordance with the requirements of section 933 of the Comprehensive Addiction and Recovery Act (CARA), a VA pilot program on the integration of Complementary and Integrative Health (CIH) and Well-Being Programs launched the Whole Health System in 18 Flagship Facilities in FY18. No appropriations specific to caregivers.

**SUMMARY:** OPCC&CT staff provides consultation at VA facilities. The Portland VAMC Care Giver Support (CGS) program has embraced the integration of Whole Health in many aspects of their program, including: Use of Complementary & Integrative Health (CIH) services; integration of the Personal Health Inventory and Personal Health Plan process; new employee onboarding recommendations that include Whole Health; staff participation in Whole Health education; contributions to a video collaboration with the Elizabeth Dole Foundation and Portland with a goal to bring the caregiver into the care team; and additional consultation regarding resources and program alignment to support caregivers.

The Office of Patient Centered Care & Cultural Transformation was established by VHA in 2011 to radically redesign health care to create a health system, rather than a disease care system, that partners with the Veteran throughout his or her life.

Whole Health is an approach to health care that empowers and equips Veterans to take charge of their health and well-being, and to live their life to the fullest. The Whole Health delivery system includes three components:

Empower: The Pathway: In partnership with peers, Veterans explore their mission, aspiration, and purpose, and begin their overarching personal health plan.

Equip: Self-care through Well-being Programs: With a focus on self-care, skill building, and support, these programs are not diagnosis or disease based but support the personal health plan of each individual. Services include proactive, complementary, and integrative health (CIH) approaches such as stress reduction, yoga, tai chi, mindfulness, nutrition, acupuncture, and health coaching.

Treat: Whole Health Clinical Care: In the VA, community, or both, clinicians are trained in Whole Health and align the Veteran’s clinical care with their mission and personal health plan, the foundation of which is the Veteran’s self-care.

##### VHA Office of Geriatrics & Extended Care

#### PROGRAM NAME: Geriatric and Extended Care (GEC) Purchased Long-Term Services and Supports

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (i.e., Veterans enrolled in VA for health care and are eligible for VA’s Community Care Programs. Veterans who are dependent in 3 or more activities of daily living or have cognitive impairments).

**URL(s):** <https://www.va.gov/geriatrics/>

<https://www.va.gov/GERIATRICS/Long_Term_Services_and_Supports_Overview.asp>

**AUTHORITY:** 38 U.S.C. 1720, 1720B, 1720C. (Personal Care Services includes Homemaker/Home Health Aide and Respite Care (1993), Veteran Directed Care (2009), and Community Adult Day Health Care (1989)).

**SUMMARY:** Caregivers are the backbone of all VA long-term services and supports. VA coordinates its efforts in providing long-term services and supports to Veterans with CMS, and the ACL on an ongoing basis.

##### Office of Connected Care

#### PROGRAM NAME: Office of Connected Care and Telehealth Services

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (i.e., Eligible Veterans, Service members and their Caregivers).

**URL(s):** <https://telehealth.va.gov/>

**AUTHORITY:** No specific appropriations for caregiver support. Technologies are provided under prosthetics support.

**SUMMARY:** Remote Patient Monitoring - Home Telehealth (RPM-HT) is a program into which Veterans are enrolled that applies care and case management principles to coordinate care using health informatics, disease management, and technologies such as in-home and mobile monitoring, messaging and/or video technologies. The goal of Home Telehealth is to improve clinical outcomes and access to care while reducing complications, hospitalizations, and clinic or emergency room visits for Veterans in post-acute care settings, high-risk Veterans with chronic disease or Veterans at risk for placement in long-term care. Utilization data is reported each quarter to determine improvements with health. Veteran satisfaction is approximately 88%.

Disease Management Protocols (DMPs) are the sessions that Veterans complete daily (for chronic care) or weekly (Low Acuity / Low Intensity). The results are securely transmitted via the technology assigned/provided to the Veteran. There are 20 DMPs developed by subject matter experts in VHA. In addition, each of the two contracted RPM-HT vendors provide their own vendor DMPs.

Annie Caregiver Text Support: Annie is a text messaging service that promotes self-care for Veterans enrolled in VA health care, as well as for caregivers, with approximately 1900 individuals enrolled in FY20. Annie sends stress management tips via text messaging to caregivers, three times per week. Messages may be educational, motivational, or an activity to manage stress. Caregivers may pause or stop the service at any time.

My HealtheVet: VA’s Personal Health Record, My HealtheVet (MHV) deployed a caregiver checkbox on the registration page in June of 2020. The program plans to implement Delegation (caregivers, family, anyone the Veteran chooses) to allow a Veteran to choose someone to act on their behalf or have access to their electronic health information in FY21/22.

##### VHA Office of Mental Health and Suicide Prevention

#### PROGRAM NAME: Suicide Prevention Program (SPP)/Partnerships

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (i.e., The Suicide Prevention Caregiver Toolkit and PsychArmor S.A.V.E. training is available to all era Veterans, their caregivers and anyone seeking suicide prevention knowledge and training).

**URL(s):** <https://www.mentalhealth.va.gov/suicide_prevention/docs/Office-of-Mental-Health-and-Suicide-Prevention-National-Strategy-for-Preventing-Veterans-Suicide.pdf>

**AUTHORITY:** N/A.

**SUMMARY:** In March of 2020, SPP released a Suicide Prevention Toolkit for Caregivers. This toolkit is a comprehensive guide aimed at providing caregivers with the resources needed to help them care for Veterans, as well as themselves. The toolkit includes important information about suicide prevention, evidence-based mental health and substance use disorder treatments, and resources available to help Veterans recover, as well as meet their goals.

Suicide is a national issue, with rising rates of suicide in the general population. In addition, suicide rates are higher and are rising faster among Veterans than non-Veteran adults. There were 46,510 American adults who died from suicide in 2018, including 6,435 U.S. Veterans. Every death by suicide is a tragedy that affects individuals, families, and communities. Unfortunately, no one strategy in isolation has been shown to be effective in ending suicide. We must come together to systematically address the larger societal issues fueling the increased rates of suicide in our nation, keeping at the forefront of our minds that we prevent suicide through meaningful connection, one person at a time. Suicide prevention is everyone’s business. Caregivers play an important role in a Veteran’s life; sometimes a lifesaving one. Whether they are a spouse of a Veteran, a family member of a Veteran, or a friend, they may be the first to recognize changes in mood and behavior, such as expressions of anger or emotional pain, or increasing use of alcohol or drugs. Caregivers have a vital role in supporting the Veteran and preventing crisis. VHA, Office of Mental Health and Suicide Prevention - Suicide Prevention Program (SPP) provides several outreach and educational materials to support caregivers and their role in preventing Veteran suicide.

The VA has continued to work actively in partnership with the White House, Congress, VHA networks, and federal and community partners to address the issue of Veteran suicide.VA is actively working to reach not only Veterans receiving VHA health services but also other Veterans in the community. A key goal for VA was the expansion of the public health approach to save lives by reaching Veterans, their loved ones, their caregivers, their communities, and the greater population. VA's public health strategy combines partnerships with communities to implement tailored, local prevention plans while also focusing on evidence based clinical strategies for intervention. The approach focuses on both what we can do now in the short term and over the long term to implement VA’s National Strategy for Preventing Veteran Suicide.

##### VHA Office of Rural Health (ORH)

#### PROGRAM NAME: Office of Rural Health: Decisions about care: Bringing serious illness care conversations to Veterans and their families

**TARGET CAREGIVER POPULATION(S):** Family Caregivers (i.e., Caregivers of any Veterans enrolled in the Program of Comprehensive Assistance for Family Caregivers and the Program of General Caregiver Support Services).

**URL(s):** This program is currently in development. Once developed, potential caregivers and veterans will be approached during treatment at their VHA facility. Any toolkits developed based on this work will be available by contacting the project lead, Dr. Berry-Stoelzle.

**AUTHORITY:** N/A.

**SUMMARY:** The goal of this project is to develop a protocol for a VA telemedicine platform for advanced care discussions with rural Veterans and their families in their homes. It aims to improve access to care by facilitating serious illness care discussions for rural and remote Veterans. By allowing Veterans and their families to participate in ongoing and directed discussions about their preferences, we expect Veterans and their families to be better informed in making decisions for specific medical therapies.

# Works Cited

Administration for Community Living. (2017, December 1). History of the DD Act. Retrieved October 14, 2020, from ACL.gov: https://acl.gov/about-acl/history-dd-act

Centers for Medicare & Medicaid Services. (2020). Long-Term Services and Supports Rebalancing Toolkit. Retrieved from https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-toolkit.pdf

National Academies of Sciences, Engineering, and Medicine. (2016). Families Caring for an Aging America. National Academies of Sciences, Engineering, and Medicine, Health and Medicine Division, Board on Health Care Sciences. Washington (DC): National Academies Press. Retrieved June 30, 2020, from http://www.nap.edu/23606

Reinhard, S. C., Young, H. M., Ryan, E., & Choula, R. B. (March 2019). The CARE Act Implementation: Progress and Promise. Washington (DC): AARP Public Policy Institute. Retrieved October 9, 2020, from https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf