



Resources for Caregiving in Rural Communities

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Introduction

Estimates suggest that informal caregivers provide the vast majority of all long-term care (80-90%) to family members or close friends who are in need of personal care assistance.¹ This unpaid caregiving has been associated with poor health outcomes, like stress, depression, and a decrease in physical health, particularly for caregivers who lack proper support.² Fortunately, these impacts on health can be mitigated by the use of supportive services,³⁻⁵ and services like respite care, education, training, and support groups have been shown to alleviate burden and increase the positive aspects of caregiving.^{6,7} Locating available services and supports for caregivers can be difficult, particularly in rural areas where service providers are often more scarce. However, rural areas have older populations and higher disability rates, leading to greater need for caregiving, which makes it urgently important to ensure that rural caregivers are supported.

Purpose

This policy brief describes resources that are being used across the country to support caregivers in rural communities. A [corresponding policy brief](#), “Perspectives on Caregiving Challenges and Interventions,” found that there are many challenges related to caregiving in rural areas, including access to resources like caregiving supports.

Approach

We reviewed relevant peer-reviewed journal articles; national, state, and local government websites; national, state, and local organizations’ websites; and known caregiver resource websites to identify programs providing various forms of support to caregivers in rural areas through local, state, and national initiatives. We also conducted 34 qualitative interviews with 41 key informants representing service providers, academics, advocacy organizations, and many other groups involved with issues related to caregiving and caregiver services. In these interviews, we gathered additional information about specific programs across the country that are available to rural caregivers.

We included resources that offer any benefit to caregivers and those interested in supporting caregivers in rural areas. These resources can include programs that impact caregivers directly through training, programs for care recipients (like respite care) that improve daily life for caregivers, or programs that are broader that may be targeted at various organizations who want to improve or expand the services they provide to support caregivers in their rural communities. We also attempted to select resources that are not cost prohibitive to implement.

In selecting resources to feature in this policy brief, we focused on those that provide services targeted to caregivers of adults with long-term care needs, particularly those programs available to caregivers in rural areas. While many programs are national in scope, the resources featured here include many that have been implemented in rural communities and states with large rural populations, as well as resources that are available remotely (online or via telephone), thus increasing the accessibility to rural caregivers.

This resource guide is not an exhaustive list of available programs and focuses on resources for caregivers of older adults and adults with functional impairments. There are many other organizations that focus on supporting caregivers of other groups of individuals (i.e., children); those resources are not included here.

Resources for Caregivers

Providing caregivers with proper training, knowledge of resources available to them in their areas, and tools for managing difficult behaviors or their own stress are critical to their success as caregivers and their personal mental and physical health. Programs providing support to caregivers can be run at the state or local governmental level or operated by non-profit, corporate, or faith-based organizations. Supportive services range from providing much-needed respite care to educating caregivers on how to safely provide care. Caregiving support programs are beneficial for caregivers and care recipients alike. Table 1 includes a list of resources complete with a general program description, listed key components of each program, and a link to access additional information.

National Resources

These represent national organizations or programs that provide services across the country. Many provide grants to several states or rural communities and organizations, or are resources provided by national organizations that have representation in various states in the U.S.

Program Name	Description	Key Components
AAA (Area Agencies on Aging) Programs	AAAs were established in the 1973 Older Americans Act (OAA) legislation as the "on-the-ground" organizations charged with helping vulnerable older adults live with independence and dignity in their homes and communities. AAAs plan, develop, coordinate and deliver a wide variety of long-term services and supports for caregivers and in other areas related to older adults. Caregiver-related services include respite care, emergency assistance, counseling and support groups, education classes and training, and referrals to local providers for additional assistance. • https://www.n4a.org/	<ul style="list-style-type: none"> • Caregiver Training • Counseling Services • Educational Program(s) • Government Funded • Link to Resources • Respite Services • Support Groups
Alzheimer's Association resources	The Alzheimer's Association is a nonprofit organization that works on a global level to provide care and support for all those affected by Alzheimer's and other dementias. They have local chapters across the nation that provide services within each community, such as a 24/7 helpline, care consultations, support groups, educational sessions, and other online resources. • https://www.alz.org/	<ul style="list-style-type: none"> • Alzheimer's/Dementia Services • Care Consultations • Educational Program(s) • Helpline • Link to Resources • Online Resources • Support Groups
BRI (Benjamin Rose Institute) Care Consultation	BRI Care Consultation is an evidence-based care-coaching program that helps professionals deliver cost-effective assistance and support to individuals with chronic conditions and family caregivers by telephone and email. The program includes an assessment, action planning, and ongoing support. • http://www.benrose.org/bricareconsultation/	<ul style="list-style-type: none"> • Action Planning • Care Consultations • Online Program • Telephone Program • Train the Trainer
Community-Based Approaches to Caring for Older Adults	There are many approaches to improving communities to make them more welcoming and supportive of older adults. In these approaches, communities work together to provide information to citizens, businesses, local government and law enforcement, and others in order to create a knowledgeable, safer, and more understanding community. These types may include techniques like Age-Friendly Communities, Dementia-Friendly Communities, and Dementia Capable Communities. • https://www.ruralhealthinfo.org/toolkits/aging • http://www.dfamerica.org/	<ul style="list-style-type: none"> • Alzheimer's/Dementia Services • Educational Program(s) • Online Resources
Dealing with Dementia	Originally implemented in Georgia, this Rosalynn Carter Institute for Caregiving initiative is beginning phase 2 expansion to the rest of the country. The program includes training for trainers, which is followed by those facilitators holding workshops for family and professional caregivers in their communities. These workshops provide information and solutions to problems caregivers face daily, including a guide and training on best practices for caring for loved ones and themselves. • http://www.rosalynncarter.org/Dealing_with_Dementia_copy/	<ul style="list-style-type: none"> • Action Planning • Caregiver Training • Educational Program(s) • Workshops

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National Resources (continued)

Program Name	Description	Key Components
Family Caregiver Alliance	Community-based nonprofit that addresses the needs of families and friends providing long-term care for loved ones at home. They have several services and programs regionally and nationally, including online support and resources, caregiver education, and other classes and events. The website also includes a Family Care Navigator that provides resource by state. • https://www.caregiver.org	<ul style="list-style-type: none"> • Caregiver Training • Educational Program(s) • Online Resources • Online Program
Lifespan Respite	Funded by the Administration for Community Living at the US Department of Health and Human Services, state Lifespan Respite programs implement statewide systems of coordinated, community-based respite care for family caregivers. • https://archrespite.org/lifespan-programs	<ul style="list-style-type: none"> • Government Funded • Respite Services
National Network of Caregiver Coalitions	The National Network of Caregiving Coalitions is a virtual network of 80+ state and local caregiving coalitions across the U.S. The Family Caregiver Alliance provides webinars, a guidebook and an annual conference to assist these coalitions in their work with family caregivers. • http://www.caregiving.org/coalitions/natlnetwork/	<ul style="list-style-type: none"> • Guidebook • Online Program • Support Groups
No Wrong Door	Funded by the Administration for Community Living at the US Department of Health and Human Services, several grants were awarded to states to develop "no wrong door" systems that ensure that regardless of which agency people contact for help, they can access information and counseling about the options available across all agencies in their communities - specifically for older adults and people with disabilities. • http://nwd.acl.gov/	<ul style="list-style-type: none"> • Counseling Services • Government Funded • Link to Resources
Operation Family Caregiver	Coaches families and friends of newly returning service members and veterans to manage difficult transitions for those with psychological and physical injuries. Through in-person or skype access, caregivers can receive the benefits of this 16 to 24 week program, which is operated by the Rosalynn Carter Institute for Caregiving. Caregivers work with coaches to develop strategies to help them with challenges they face and to plan for managing those in the long term. • http://www.operationfamilycaregiver.org/	<ul style="list-style-type: none"> • Action Planning • Assessments/Evaluations • Behavior Management • Caregiver Training • Link to Resources • Stress Management • Veterans Services
PsychArmor Institute	PsychArmor Institute is a program to bridge civilian-military divide by ensuring that every American has the knowledge, tools, and resources needed to engage effectively with service members and Veterans. The institute provides free courses on a variety of subjects, including for Military Veteran Caregivers and Families. Some available courses include information on respite care, caregiver support, advocacy, dealing with PTSD and other behaviors, and how to deal with stress. • https://psycharmor.org/	<ul style="list-style-type: none"> • Behavior Management • Educational Program(s) • Link to Resources • Stress Management

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National Resources (continued)

Program Name	Description	Key Components
REACH (Resources for Enhancing Alzheimer's Caregiver Health)	REACH is a program for people caring for a loved one with Alzheimer's or other dementias at home. Program counselors provide clients with in-home assessments and individualized solutions to problems such as caregiver stress, challenging behaviors, home safety, depression, self-care, and social support. • http://www.rosalyncarter.org/rci_reach/	<ul style="list-style-type: none"> • Alzheimer's/Dementia Services • Assessments/Evaluations • Behavior Management • Counseling Services • In-Home Program • Stress Management
SHARE for Dementia	The SHARE for Dementia program incorporates: Support, Health, Activities, Resources, and Education, and is offered through the Benjamin Rose Institute on Aging. It is an evidence-based care-planning program that helps professionals to assist families facing early-stage dementia diagnoses by supporting care partners, promoting health and decreasing stress, encouraging participating in fulfilling activities, teaching about available resources, and providing education about dementia. • http://www.benrose.org/SHARE/INDEX.cfm	<ul style="list-style-type: none"> • Alzheimer's/Dementia Services • Educational Program(s) • Link to Resources • Stress Management • Train the Trainer
TCARE (Tailored Caregiver Assessment and Referral) System	TCARE is designed to support family members who are providing care for relatives who need assistance due to illness or disabilities. Includes web-based software, standardized assessment tools, decision algorithms, and a training program for professionals who work with family caregivers. • https://www.tailoredcare.com/#	<ul style="list-style-type: none"> • Assessments/Evaluations • Caregiver Training • Educational Program(s) • Formal Caregiver Training • Online Program
Tele-Savvy	Tele-Savvy Education Program for Dementia Caregivers is a current clinical trial going through Nov 2020 and based on an earlier pilot from 2014-2015 of the Savvy Caregiver Program. Tele-Savvy is testing an Internet-based education program for caregivers of people with Alzheimer's or other dementia that will provide caregivers with skills and knowledge to be able to handle caregiving challenges, and manage stress. • https://www.nia.nih.gov/alzheimers/clinical-trials/tele-savvy-education-program-dementia-caregivers	<ul style="list-style-type: none"> • Alzheimer's/Dementia Services • Behavior Management • Caregiver Training • Educational Program(s) • Online Program • Stress Management
U.S. Department of Veterans Affairs Care for Caregivers Program	This program offers a VA Caregiver Support Line, as well as monthly calls on a variety of topics where caregivers can discuss self-care tips and ask questions. They also offer peer support mentoring, an online workshop on how to become a better caregiver, and other support programs for caregivers of certain groups of veterans. • https://www.caregiver.va.gov/Care_Caregivers.asp	<ul style="list-style-type: none"> • Action Planning • Assessments/Evaluations • Behavior Management • Caregiver Training • Link to Resources • Stress Management • Veterans Services
WeCareAdvisor	A web-based tool created through an NIH-funded grant to help caregivers assess and manage the behavioral and psychological symptoms of dementia. Leads the caregiver through the assessment, management and monitoring. This tool is built upon the DICE Approach that aims to help caregivers manage the behavioral and psychological symptoms of dementia. • http://www.programforpositiveaging.org/wecareadvisor/	<ul style="list-style-type: none"> • Alzheimer's/Dementia Services • Assessments/Evaluations • Behavior Management • Government Funded • Online Program

Resources by State

These represent organizations that exist at the state or local level and provide services to support caregivers. This resource list is not exhaustive of all programs, but provides a look at resources for caregivers of older adults in rural communities in several places across the country.

Program Name	Location	Description	Key Components
Bridges - Pathways to Abundant Living	Montana	Bridges is a community outreach program of the Helena United Methodist Ministries, hosted by Covenant United Methodist Church in collaboration with AARP Montana that offers specialized educational programs and workshops that focus on challenges and opportunities of aging. • http://covenanthelelena.org/bridges/	<ul style="list-style-type: none"> • Educational Program(s) • Faith-based • Workshops
Camarillo Health Care District (CA) (Health Care Districts generally)	California	Camarillo Health Care District is a public agency providing a broad range of community-based health and wellness services including adult day center and support services; care management services; chronic disease care management services; caregiver respite, education and training; nutrition, advocacy and exercise; transportation; evidence-based health promotion services; support groups and many other services. • https://www.camhealth.com/	<ul style="list-style-type: none"> • Adult Day Services • Assessments/Evaluations • Caregiver Training • Counseling Services • Educational Program(s) • Respite Services • Support Groups • Transportation
Caregiver Champions	Pennsylvania	Caregiver Champions is a program designed to help informal caregivers gain confidence and control they need to better balance their lives. Champions are experienced family and informal caregivers who serve as resources of information and support within their communities. They host Caregiver Learning Circles and help attendees learn to navigate systems, advocate for loved ones, and access resources. • http://www.caregiverchampions.org/	<ul style="list-style-type: none"> • Advocacy Training • Link to Resources • Peer Mentoring • Support Groups
Caregiver Tele-Connection Collaboration	Texas	The Caregiver Teleconnection is a free, bilingual program that connects caregivers and family members to information and support through tele-learning. They provide learning sessions on a variety of topics hosted by experts. Caregivers can also connect and share with others in their situation during the sessions. • http://caregiversos.org/caregiver-teleconnection	<ul style="list-style-type: none"> • Bilingual • Educational Program(s) • Support Groups • Telephone Program
Creating Confident Caregivers	Michigan	Creating Confident Caregivers is an educational training program for family caregivers of a person with a dementia related illness, such as Alzheimer's Disease. Trainings are held for six weeks and provide information to reduce caregiver stress, improve confidence and caregiving skills, and manage behaviors caused by dementia. The training program utilizes training methods from the Savvy Caregiver Program. • http://www.areaagencyonaging.org/news-events/education-trainings/1486-creating-confident-caregivers • http://www.valleyareaaging.org/programs-and-services/creating-confident-caregivers/ • https://www.detroit seniorsolution.org/creating-confident-caregivers • http://www.aaanm.org/caregiver-workshops/	<ul style="list-style-type: none"> • Alzheimer's/Dementia Services • Behavior Management • Caregiver Training • Educational Program(s) • Stress Management

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Resources by State (continued)

Program Name	Location	Description	Key Components
Elder Network	Minnesota	Elder Network is a non-profit in southeastern Minnesota that provides education and support for seniors and their caregivers. They provide respite care, educational programming, support groups, peer mentoring; household assistance; and other non-medical support programs. They also offer referrals to other organizations for additional required services for caregivers. • http://www.elder-network.org/what-we-do.php	<ul style="list-style-type: none"> • Educational Program(s) • Faith-based • Workshops
FAIR (Family Alzheimer In-home Respite) Program	West Virginia	FAIR is a state-funded program that assists family caregivers who provide care for adults with Alzheimer's disease by providing relief to caregivers and one-on-one attention for persons with a diagnosis of Alzheimer's Disease or a related dementia. These respite services are delivered in-home to allow for caregivers to take needed time away from their loved ones and not have to worry about trained care being provided in their absence. • http://www.wvseniorservices.gov/HelpatHome/FAIRFamilyAlzheimersInHomeRespite/tabid/75/Default.aspx	<ul style="list-style-type: none"> • Adult Day Services • Assessments/Evaluations • Caregiver Training • Counseling Services • Educational Program(s) • Respite Services • Support Groups • Transportation
North Dakota Dementia Care Services Program	North Dakota	The North Dakota Dementia Care Services Program provides in-person, phone, and online services and supports to individuals with dementia and their families. The program includes care consultation, training, education, and support services and is provided by the Alzheimer's Association of Minnesota-North Dakota Chapter through funding from the state. • https://www.alz.org/mnnd/	<ul style="list-style-type: none"> • Advocacy Training • Link to Resources • Peer Mentoring • Support Groups
Project C.A.R.E. (Caregiver Alternatives to Running on Empty)	North Carolina	Project C.A.R.E. is a state funded program supporting family caregivers of persons living with Alzheimer's disease or related dementia(s). The program utilizes a care consultation model providing information and referral services, dementia and caregiving specific education, caregiver assessment and care planning, and limited respite dependent upon funding. The family consultants are regionally located across the state working collaboratively with local community-based services and networks to connect supports for caregivers. • https://www.ncdhhs.gov/assistance/adult-services/project-care	<ul style="list-style-type: none"> • Bilingual • Educational Program(s) • Support Groups • Telephone Program
Take Time Texas	Texas	Take Time Texas is Texas' Lifespan Respite Care Program that provides respite services in the state and encourages caregivers to take time for themselves in order to be a better family caregiver. • https://www.dads.state.tx.us/taketimetexas/index.cfm	<ul style="list-style-type: none"> • Action Planning • Caregiver Training • Educational Program(s) • Health Care Training • In-Home Program • Telephone Program

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Resources by State (continued)

Program Name	Location	Description	Key Components
The Care Transitions Program	Colorado	The Care Transitions Intervention includes a four-week program where patients with complex care needs and family caregivers receive specific tools and work with a Transitions coach to learn self-management skills to assist with their transition from hospital to home. The evidence-based intervention is comprised of a home visit and three phone calls. • https://caretransitions.org/ • https://caretransitions.org/about-the-care-transitions-intervention/	<ul style="list-style-type: none"> • Action Planning • Caregiver Training • Educational Program(s) • Health Care Training • In-Home Program • Telephone Program
University of Arkansas for Medical Sciences Schmieding Home Caregiver Training	Arkansas	This program offers a variety of programs to the community including Certified Nursing Assistant training, as well as free workshops for family caregivers providing unpaid care to older adults in the home and additional educational programs to promote healthy living for seniors. Workshop topics include training for caregiving of individuals with Alzheimer's or other dementias, caregiver stress and burnout, and physical skills of caring for an older adult. • http://uamscaregiving.org/ • https://agec.uams.edu/	<ul style="list-style-type: none"> • Alzheimer's/Dementia Services • Behavior Management • Caregiver Training • Educational Program(s) • Formal Caregiver Training • Link to Resources • Stress Management • Workshops

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