

Education, Counseling, and Peer Supports for Family Caregivers

Introduction

An estimated 53 million Americans provide care for an older adult or someone living with illness or disability.¹ Family caregivers provide a wide range of services, such as transportation, food preparation, housekeeping and personal care, enabling care recipients to live at home or in the setting of their choice with dignity and independence. Without supportive services, nearly 62 percent of caregivers have suggested that the individual they care for would be living in a nursing home.² Additionally, there are at least 2.4 million children being raised by grandparents or other relative caregivers, serving as a safety net and providing care when children's parents are unable.³

This Action Guide is part of a series to help Aging Network organizations develop innovative caregiver services and supports that meet the needs of a growing population of caregivers.

A **family caregiver** is an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation. This includes any grandparent or relative adult who has primary responsibility for grandchildren or other children who cannot remain with their parents.⁴

Caregiver Needs for Education, Counseling and Peer Support

Caregivers' needs vary by caregiver, intensity of caregiving and length of their caregiving journey. Caregivers commonly request information about keeping the care recipient safe at home and about managing their own stress (26 percent), as well as assistance with figuring out forms, paperwork and eligibility for services (25 percent).⁵

Family caregivers make vital decisions about finances and overall care of the care recipient as well. About one in eight caregivers need help with critical care decisions for their care recipient, such as making end-of-life decisions or choosing home care, assisted living or a nursing home (13 percent). Some caregivers also want help managing their own finances (13 percent), using technology for care support (12 percent) and managing challenging behaviors of their recipient (11 percent).⁶

The Administration for Community Living (ACL) defines **counseling** as a service to support caregivers and assist them in their decision-making and problem solving. Counselors are service providers that are degreed and/or credentialed as required by state/territory policy; trained to work with older adults and families; and specifically to understand and address the complex physical, behavioral and emotional problems related to their caregiver roles, such as maintaining their own health and practicing self-care activities. This includes counseling to individuals or group sessions.⁷ While ACL does not provide definitions of “education” or “peer support,” [ACL’s Peer Providers](#) page is a helpful resource.

To better support family caregivers and address their array of needs, the [National Family Caregiver Support Program](#) (NFCSP) provides grants to states and territories to fund support at the local level for family caregivers of older adults and adults with disabilities, as well as kinship caregivers. The NFCSP is a key component of the nation’s long-term services and supports to meet the needs of family or other informal caregivers. In 2020, NFCSP providers delivered more than 530,000 counseling/support groups/caregiver training sessions to caregivers of older adults.⁸ Eighty-eight percent of caregivers said the NFCSP services they received have helped them be a better caregiver.⁹ The next section includes examples of innovative education, counseling and peer support programs and resources from across the country that support family caregivers.

Action Steps

1. Explore innovative models for caregiver education, counseling and peer support.

Studies have shown that caregiver education, training and peer support can help reduce caregiver stress, anxiety and help the caregiver develop a better relationship with the care recipient.^{10,11,12} The programs listed below provide examples of innovative programs in action supporting caregivers through education, training and peer support models.

Program Name: C.U.P of T.E.A

Organization: Appalachian Council of Governments Area Agency on Aging (Greenville, SC)

Program Description: The C.U.P of T.E.A program was created during the COVID-19 pandemic to bring one-on-one education and training to caregivers in their home settings. The program acronym stands for Compassion, Understanding, Providing Training, Education and Assistance. Training is offered in areas caregivers struggle with, including knowing how to care for loved ones and themselves to reduce burnout.

Learn More: www.scacog.org/aging-services

Program Name: African American Alzheimer’s Caregiver Training and Support Project 2 (ACTS2)

Organization: Florida State University College of Medicine

Program Description: The ACTS2 Project offers free skills-building and support services for African American caregivers of loved ones with dementia. The program includes 12 telephone sessions, focusing on skills building, spiritual support and improving self-care and the relationship with the person living with dementia.

Learn More: acts2project.org/Service.html

Program Name: elderCONNECT

Organization: Area Agency on Aging, Region One (Phoenix, AZ)

Program Description: This program provides internet-connected tablets and basic tutorials to help isolated caregivers stay connected with family and friends through video calls, social media and messaging apps. This connectivity helps reduce feelings of isolation and loneliness while caring for their loved ones. Caregivers can access Trualta, an online platform that provides relevant educational content; practical tutorials; and a dependable online community where they can join discussion forums, gain insight from support groups and ask questions of industry professionals. Caregivers can also use the tablet to

access health information, manage their finances and stay updated with news and events. The tablet provides various entertainment options, including movies, music, games and e-books, helping caregivers stay engaged and mentally stimulated.

Learn More: www.aaaphx.org

Program Name: Finding Meaning and Hope

Program Description: *Finding Meaning and Hope* is a 10-session discussion series for family caregivers based on the book, *Loving Someone Who Has Dementia: How to Find Hope While Coping With Stress and Grief* by Pauline Boss, Ph.D. Each session is 90 minutes and features videos with Dr. Boss in conversation with family caregivers and includes guided discussions, led by trained volunteer facilitators, that help caregivers build resilience while they unpack the complex grief of ambiguous loss—caring for someone who is physically present but psychologically absent or no longer who they used to be. The program is offered free to caregivers and is available in English, Spanish and Diné.

Learn More: www.meaningandhope.org

Program Name: RCI REACH

Organization: Rosalynn Carter Institute for Caregivers

Program Description: REACH, or Resources for Enhancing Alzheimer's Caregiver Health, offers one-on-one care-related education and skills training for caregivers of persons living with dementia. The program focuses on performing daily activities safely and increasing support for caregivers. Services are tailored to individual caregiver needs and delivered over a six-month period via nine home visits and three telephone sessions.

Learn More: rosalynncarter.org

2. Reach out to organizations with innovative caregiver education, training and peer support programs to inquire about implementation efforts.

Have a list of questions related to implementation that can be used when reaching out. This material on [Starting a Kin Caregiver Respite Program](#) provides key tips on launching a program. Some examples of questions to ask are:

- What is the level of effort needed for implementation?
- What staffing is needed, and what is their expected time commitment?
- What recruitment and outreach efforts are most effective to reach potential participants?
- Is the program designed to reflect the community (e.g., health literacy level, age, etc.)?
- Does the program rely on any fee-based technology or other “hard costs” in addition to staffing?
- Does the program use validated assessments for pre- and post-intervention?

3. Include caregiver training, counseling and peer support questions in community needs assessments to identify prominent caregiver needs in the community.

Understanding the needs and preferences of caregivers in your community is a critical component of [community needs assessments](#).

- Select data collection categories with input from caregivers and others with lived experience. Prioritize identifying the needs of caregivers by using a variety of methods such as caregiver interviews, focus groups or existing data sources on caregiver needs.
- To administer the needs assessment, remember that many caregivers may not self-identify as caregivers. To address this issue, consider prefacing questions by describing what a caregiver is or providing a definition.
- Create and implement an action plan based on recommendations from the community needs assessment report. Start with three to five priority areas to implement. Broadly advertise the action plan and related services to caregivers in your community.

- Also remember that there are opportunities to be creative. The Illinois Family Caregiver Coalition released [a collection of caregiver stories](#) highlighting caregiver needs and preferences through their unique experiences.

4. Tap into information from caregiver assessments to guide referrals and shape new or enhanced services.

- Review commonly used caregiver assessment measures, such as [Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners](#).
- Monitor the National Caregiver Support Collaborative website for additional [information on caregiver assessment best practices](#).

Conclusion

Finding and implementing innovative caregiver education, counseling and peer support programs require thoughtful and intentional planning. It is important that your organization takes the needs and wants of caregivers into consideration when developing a program that can make a difference in the outcomes for the caregiver.

Additional Resources

- [AARP Caregiving in the United States 2020 report](#)
- [Administration for Community Living \(ACL\)–National Strategy to Support Family Caregivers](#)
- [ACL–Peer Providers](#)
- [ARCH National Respite Network & Resource Center](#)
- [Benjamin Rose Institute on Aging](#)
- [Best Programs for Caregiving](#)
- [Eldercare Locator](#)
- [Family Caregiver Alliance–State by State Services Guide](#)
- [Georgia Mental Health Consumer Network](#)
- [National Association for State Health Policy–Supporting Family Caregivers: A Roadmap for States](#)
- [Powerful Tools for Caregivers](#)
- [Rosalynn Carter Institute for Caregivers](#)
- [Savvy Caregiver](#)
- [Scripps Gerontology Center–Enhancing Caring Communities Toolkit](#)
- [Veteran Administration's Caregiver Support Program–Peer Support](#)

Acknowledgements

USAging would like to thank the Caregiving Action Guide Workgroup comprised of Abby Holm, ADvancing States; Yadira Montoya and Lauren Tokarewich, National Alliance for Caregiving; Lesly Katz, Loudoun County Area Agency on Aging; Christina Irving, Family Caregiver Alliance, with support from Rosalynn Carter Institute for Caregivers staff Lezlie Poole and Karen Kavanaugh, for their major contributions that helped shape this Action Guide.

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- ¹² Chen, Y.-M., et al. (2010). [A Pilot Evaluation of the Family Caregiver Support Program–ScienceDirect](#)

This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$4,400,000 with 75 percentage funded by ACL/HHS and \$1,476,288 and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, ACL/HHS, or the U.S. Government.