

# Advancing the Availability of Flexible and Accessible Respite Care for Family Caregivers

## Introduction

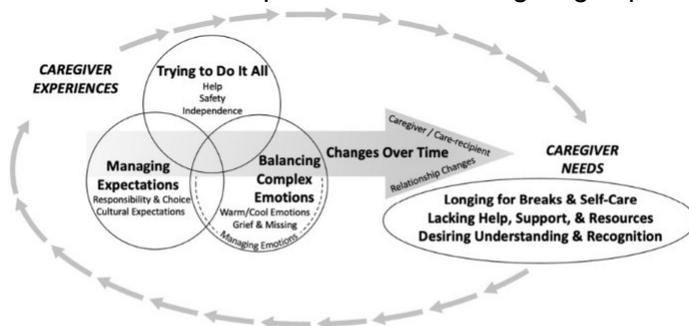
An estimated 63 million Americans provide care for an older adult or someone living with illness or disability.<sup>1</sup> Family caregivers provide a wide range of services, such as transportation, food preparation, housekeeping and personal care, enabling care recipients to live at home or in the 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.<sup>2</sup> 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.<sup>3</sup>

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.<sup>4</sup>

## Respite and Family Caregivers

While caregiving can be profoundly rewarding, the role is demanding and can lead to chronic strain, illness and a decline in health and financial security.<sup>5</sup> Self-care and the need for a break or respite from caregiving responsibilities are critical components of the caregiving experience (see Figure 1).<sup>6</sup>



**Figure 1.** Caregiver experiences and needs across conditions, relationships, and the lifespan. Caregiver experiences include *Trying to Do It All*, *Managing Expectations*, and *Balancing Complex Emotions*—which all overlap and interact with one another, as displayed in a Venn diagram. These experiences are also depicted with an arrow indicating *Adjusting to Changes Over Time*—specifically, changes in the care-recipient, caregiver, and/or the caregiving relationship. All of these experiences inform and are informed by substantial caregiver needs including the need for: *Longing for Breaks and Self-Care*; *Lacking Help, Support, and Resources*; and *Desiring Understanding and Recognition* for the caregiver.

## *What Is Respite?*

According to the Administration for Community Living, respite is any activity that provides the caregiver with a meaningful break. The [2022 National Strategy to Support Family Caregivers: Actions for States, Communities and Others](#) uses “the widest possible definition of respite” in program and service delivery. Respite can be defined as a short break from caregiving, assistance with housekeeping tasks, receiving home-delivered meals, engaging the care recipient in a social activity (e.g., a video call, teaching a child who lives with a grandparent to ride a bike or play a video game). Respite can also be defined as supports, such as adult day programs, that create space in the caregiver’s day for a break or other initiatives focused on the needs of and self-care for the caregiver.

Respite can be delivered in so many ways: It can be provided by family members and friends (called informal respite) or through a more formal mechanism, such as community-based volunteers, paid caregivers (e.g., personal care professionals, hospice) or other entities that offer supports to provide a caregiver with a meaningful break.

## *Use of Respite*

Approximately 86 percent of caregivers of adults do not receive respite.<sup>7</sup> Reasons for this include lack of awareness, time or money to afford respite, scarcity of respite services or complex eligibility criteria. Community norms can also impact a caregiver accessing respite.<sup>8</sup> Non-White and/or Hispanic caregivers are less likely to use respite.<sup>9</sup> Understanding the role of filial responsibility in respite use is critical to introducing respite services to a caregiver. For example, in some communities, taking time for one’s own well-being may be viewed as compromising family responsibilities. Differences between caregivers and health care professionals have also been identified as a barrier to using respite care.

Caregivers often need encouragement from trusted individuals to realize that it is okay to ask for help. The Aging Network plays a critical role in helping caregivers identify their needs and connecting them to person-centered supports and resources.

## *Impact of Respite on Well-Being of Caregiver and Care Recipient*

Respite can help improve caregiver health, resilience, family relationships and delay or avoid facility-based placement.<sup>10</sup> It can be especially important for caregivers with limited incomes and those who are socially isolated with few social supports. Engaging the caregiver in respite can also reduce the likelihood of neglect, abuse and exploitation.<sup>11</sup>

## ***Action Steps for the Delivery and Support of Respite***

Strategies included in this Respite Action Guide recognize that the capacity and financial support available for respite services vary widely by state and tribal communities. The [ARCH National Respite Network and Resource Center](#) (ARCH) offers resources for respite providers, programs and caregivers, and it champions the use of quality, accessible respite care. Programs identified with an asterisk have been recognized by ARCH as an [Innovative and Exemplary Respite Service](#).

### **1. Explore resources to help caregivers find, plan and use respite.**

Helping caregivers understand options and develop a plan for how they will find and use services is key to maximizing the benefits of respite.

**Resource Name:** ARCH Resources for Caregivers

**Resource Description:** This resource provides insight on planning for respite, types of respite, locating and paying for respite, and how to choose a respite program or provider.

**Learn More:**

- [ARCH Resources for Caregivers](#)
- [Fact Sheets for Family Caregivers](#)

- [LifeCourse Tools for Respite](#)
- [The ABCs of Respite](#)

**Resource Name:** Emergency Respite Care/Plan Guide

**Resource Description:** This guide, developed by the Arizona Caregiver Coalition, provides essential steps to create an emergency respite care plan.

**Learn More:** [Arizona Caregiver Coalition Emergency Respite Plan Guide](#)

## 2. Explore innovative program examples and resources for informal respite strategies.

Introducing caregivers to informal respite opportunities can provide a critical lifeline to individuals who do not qualify for services or do not live in areas where formal respite services are available.

**Resource Name:** ATLAS CareMap

**Resource Description:** ATLAS CareMap helps caregivers identify relationships they may have with others who could provide respite or other support.

**Learn More:** [Atlas CareMap](#) and [How to use Atlas CareMap video](#).

**Resource Name:** Exhale–The Family Caregiver Initiative

**Resource Description:** Exhale provides funding for innovative collaborative projects to increase informal respite. The Exhale website describes successful projects in New York and Michigan.

**Learn More:** [Exhale – The Family Caregiver Initiative](#)

## 3. Explore innovative program examples and resources for formal respite strategies.

**Resource Name:** Adult Day Services

**Resource Description:** National Adult Day Services Association offers education and support and connections with adult day service (ADS) providers. In-depth support for a fee.

**Learn More:**

- The [NADSA website](#) includes a searchable [ADS program finder](#)
- [ARCH Adult Day Services and Respite](#)

**Resource Name:** Self-Directed Respite Voucher Guide and Readiness Assessment Tool

**Resource Description:** This tool aligns with [Applied Self-Direction](#) and includes case studies of respite voucher programs, tax and financial information and labor regulations.

**Learn More:** [Self-Directed Respite Voucher Guide and Readiness Assessment Tool](#)

**Resource Name:** Toolkit for Starting a Kin Caregiver Respite Program

**Resource Description:** This toolkit offers tips and no-cost resources for Area Agencies on Aging (AAAs) and Title VI Native American Aging Programs to develop new or expand respite programs or services for kin caregivers and their families.

**Learn More:** [Toolkit for Starting a Kin Caregiver Respite Program](#)

**Program Name:** The Center for Volunteer Caregiving (CVC), Cary, NC\*

**Program Description:** The CVC provides volunteer services, such as friendly visits, transportation to medical appointments and respite visits.

**Learn More:** [The Center for Volunteer Caregiving](#)

**Resource Name:** Respite and Faith Communities

**Resource Description:** Resources include a description of the benefits of faith community partnerships and innovative and exemplary faith-based respite models.

**Learn More:** Explore the following resources:

- [Fact Sheet: Respite and the Faith Community](#)
- [Volunteer and Faith-Based Respite Models](#)
- [Respite Breakroom: A How-to-Guide for Faith & Community Organizations](#)
- [Volunteer and Faith-Based Respite Learning Collaborative Meeting](#)

#### 4. Explore innovative program examples and resources on strategies to expand the respite workforce.

A well-trained workforce is essential to expanding access to respite.

**Resource Name:** National Respite Care Provider Training™ curriculum

**Resource Description:** This free competency-based online training curriculum is for respite care providers.

**Learn More:** [National Respite Care Provider Training and Replication Toolkit](#)

**Program Name:** Respite Squad Volunteers, Northwestern Vermont

**Program Description:** The “Respite Squad” comprised of trained volunteers spend three or more hours a week providing support to family caregivers. Training provides volunteers with strategies to communicate with families and understand dementia.

**Learn More:** [Age Well Volunteer Opportunities](#) (scroll down to Respite Volunteer Training)

**Resource Name:** Rhode Island CareBreaks-Nursing Student Respite Workforce Initiative\*

**Resource Description:** Five Rhode Island colleges and universities work in partnership with the Rhode Island Office of Healthy Aging to train and support nursing students as respite providers for children and adults with disabilities or medical needs.

**Learn More:**

- [Supporting Family Caregivers: Nursing Students as Respite Providers Toolkit and Video](#)
- [Student Respite Toolkit Flyer](#)

**Resource Name:** Respite Registries

**Resource Description:** These registries provide information on establishing or enhancing a respite-specific registry to link trained providers to family caregivers. These are examples of respite provider registries implemented by New Mexico Caregivers Coalition and Lifespan Respite Washington.

**Learn More:**

- [Building Respite Registries to Meet the Needs of Families](#)
- [New Mexico Respite Provider Registry](#)
- [Washington State Provider Registry](#)

#### 5. Explore awareness and outreach messaging and strategies to increase access to respite.

Communicating the value of respite to caregivers requires repetition and messages from trusted sources and employers.

**Resource Name:** Delaware awareness campaign” “You are important to your family. Be good to yourself. Enjoy your respite time.”

**Resource Description:** This one-page fact sheet addresses how to pursue and effectively use respite time.

**Learn More:** [Making the Most of Respite Flyer from Delaware Lifespan Respite](#)

**Resource Name:** Outreach and messaging strategies for Hispanic caregivers

**Resource Description:** This two-page fact sheet developed by the Texas Department of Aging and Disability Services, covers strategies for reaching out to Hispanic caregivers. There are also videos in Spanish for Hispanic caregivers developed by SC Respite Coalition.

**Learn More:**

- [Fact Sheet: How to Help Hispanic Caregivers](#)
- [Video: South Carolina Respite: Cuidador Familiar](#)
- [Video: Tomar un Descanso](#)

**Resource Name:** Respite for Agricultural Caregivers Brochure

**Resource Description:** This is a brochure developed by the Nebraska Lifespan Respite Network.

**Learn More:** [Respite for Agricultural Caregivers Brochure](#)

**Resource Name:** Employed Caregiver Survey

**Resource Description:** This webinar on the [Employed Caregiver Survey](#) is designed to engage employers to communicate with working caregivers.

**Learn More:** [Tools for Employer Engagement in Respite and Caregiving Support](#)

## 6. Explore innovative program examples and resources on strategies to tailor respite for underserved populations in respite.

The delivery of respite services tailored to the cultural values and characteristics of a population requires organizational capacity, engagement with the community and an understanding of available resources.

**Resource Name:** Supporting Native Elders in Their Communities Chartbook

**Resource Description:** Findings from the 2023 Title VI Native American Aging Program Survey indicate over half of the responding programs offer respite services, many in partnership with tribal and non-tribal entities, including AAA or Title III programs.

**Learn More:**

- [Title VI Native American Aging Program Surveys](#)
- [Supporting Native Elders in Their Communities: Title VI American Aging Programs and Services 2024](#)
- [Zuni Senior Center](#)

**Resource Name:** Culturally Aware Training for Respite Providers and Families in the Port Gamble S'Klallam Tribe, Washington

**Resource Description:** This pilot program was designed to educate tribal families about the benefits of using a trusted, familiar respite provider to give caregivers a break.

**Learn More:** [Port Gamble S'Klallam Tribe Child & Family Services: Elder Services](#)

**Resource Name:** Jewish Federations of North America (JFNA)

**Resource Description:** JFNA collaborates with organizations to provide respite care and caregiver support through a person-centered, trauma-informed care approach.

**Learn More:** [Jewish Federations of North America Center on Aging, Trauma, and Holocaust Survivor Care](#)

## 7. Explore strategies for systems change and sustainability.

Professionals in the Aging Network are “boots on the ground” advocates who can inform policymakers and funders about the importance of respite care.

**Resource Name:** Scaling Up: Caregiver-Directed Respite Care in New York State

**Resource Description:** This is an overview of the process and experiences of expanding respite voucher services through AAAs and National Family Caregiver Support Program.

**Learn More:** [Respite Voucher Learning Collaborative Meeting](#) webinar and supporting documents

## 8. Explore funding opportunities for respite.

Funding to develop, deliver and sustain respite services are available from federal and state public and private sources.

**Resource Name:** AmeriCorps Seniors: Senior Companions and Seniors RSVP

**Resource Description:** RSVP funding priorities include support for older adults, caregivers and kin families, including respite initiatives.

**Learn More:**

- [Meeting the National Strategy Goal of Growing the Respite Care Workforce through AmeriCorps Seniors](#)
- [AmeriCorps Seniors](#)

**Resource Name:** Center for Dementia Respite Innovation (CDRI)

**Resource Description:** CDRI funds respite care innovation projects across the country through grants to local respite care providers to enhance delivery of dementia care.

**Learn More:** [Center for Dementia Respite Innovation](#)

**Resource Name:** Community Care Corps

**Resource Description:** Community Care Corps fosters innovative local respite models in which volunteers provide nonmedical assistance to caregivers and older adults.

**Learn More:** [Empowering Communities Through Volunteer-Driven Care](#)

## Conclusion

Many caregivers identify respite as their most pressing need, and it can take many forms. The Aging Network is in a unique position to recognize caregivers, create opportunities for the delivery of respite services and capitalize on community partnerships to expand and sustain this essential service.

## Additional Resources

- [AARP Respite Services: A Critical Support for Family Caregivers](#)
- [ACL–National Family Caregiver Support Program](#)
- [ACL–National Strategy to Support Family Caregivers](#)
- ARCH Guides, Tools, and Presentations
  - [Tools for Sustainability: Financing Strategies for Lifespan Respite Programs and State Respite Coalitions](#)
  - [Approaches to State Policymaking and Diversified Funding Webinar](#)
- [Dementia Friendly America](#)
- [National Association for State Health Policy \(NASHP\)–Respite Care Resource Guide](#)
- [NASHP–State Innovations to Advance Respite Care: Policy Strategies Shared at the State-Federal Respite Summit](#)

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