



The
John A. Hartford
Foundation

Respite Care Resource Guide

Respite care is a service typically delivered in the home or a community, faith, or facility-based setting that provides short-term relief for caregivers. It is one of the most desired services by caregivers who report that they need a break.

The Challenge

Despite the demand for this service, many family caregivers do not receive it. Challenges include a lack of trust of unknown providers to provide care, especially in homes; difficulty in finding and paying for quality providers; and rigid program policies that limit the types of respite providers (e.g., those that do not allow for family, friends, and known providers to provide respite).

A Historic Opportunity

The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG) developed a [National Strategy to Support Family Caregivers](#) that is now ready for implementation. Released to Congress in September 2022, this comprehensive strategy identifies actions for the federal government to take and lays out actions for states, communities, health care systems, long-term support and service providers, researchers, employers, philanthropic organizations, and many others to support family caregivers. Respite care is a key component of this strategy.

State Action Guide

The ARCH National Respite Network and Resource Center created a Learning Collaborative of state administrators and their partners. In partnership with the National Academy for State Health Policy (NASHP), the Learning Collaborative created this roadmap for states that want to implement the respite actions identified in the National Strategy. The roadmap can support states interested in building or expanding respite care for family caregivers by offering the following policy strategies and promising practices.

Public Outreach and Awareness

To increase outreach about respite care to family caregivers, who often do not self-identify as caregivers, do not know where to turn for information, or feel “guilty” about needing a break from caregiving, states can:

- Develop culturally appropriate toolkits and resource guides that include the value of respite care
- Partner with community and faith-based organizations to identify family caregivers and organize individuals to assist with respite care
- Educate caregivers about how and where to access respite care



To find respite care near you, go to the [Respite Care Locator](#).

State Examples: Public Awareness Initiatives

- **Montana's** Department of Public Health and Human Services created a video to reduce stigma for receiving help (“[It’s OK to Need It, It’s OK to Want It, and It’s OK to Get It](#)”).
- **Nevada's** Lifespan Respite Coalition produced a video to help caregivers self-identify, find services, and promote the benefits of receiving respite care (“[Respite Refuels Caregivers](#)”).
- **New York's** Office for the Aging developed a video to help individuals self-identify as caregivers that included available resources (“[Caregiver’s Guide: What Is Caregiving & How to Get Help](#)”).
- **Washington's** State Health Care Authority and Aging and Long-Term Support Administration are piloting a culturally aware training and education program for respite providers and family caregivers with the S’Klallam Tribe.

Engagement of Family Caregivers in Health Care Services and Systems

To ensure person- and family-centered care, where providers listen to and engage family caregivers, states can:

- Use evidence-based assessments to evaluate family caregivers' own needs
- Work with health care professionals to educate family caregivers about respite care
- Help caregivers connect with respite care through online resources

State Examples: Assessments

- **Idaho** Caregiver Alliance uses an evidence-based caregiver assessment, within the [Family Caregiver Navigator](#) system.
- **Nevada** Lifespan Respite Care Program incorporated a caregiver intake form, [Respite Rx Caregiver Assessment](#), to identify caregiver needs and make appropriate service referrals.
- The **South Carolina** Respite Coalition collaborated with a physician to produce a video that promotes promote the benefits of respite care ("[A Physician's Perspective on Using Respite to Prevent Caregiver Stress Syndrome](#)").

Services and Supports for Family Caregivers

To help caregivers obtain respite services that enable them to provide care in the home, states can use the following strategies.

Fund Respite Care

- [Medicaid home and community-based services \(HCBS\) waivers](#), via federal-state funds, that allow individuals who meet an institutional level of care (e.g., nursing home) to receive optional services, including respite, in their home and community.
- The [National Family Caregiver Support Program](#) – which allocates Older Americans Act federal funding to all states and territories – provides services to caregivers of older adults, older relatives raising children, caregivers of people with Alzheimer's disease and related dementias, and older relatives of adults with disabilities. Services include counseling, respite, supplemental services, access assistance, and information services.

- The [Lifespan Respite Care Program](#) is a federal grant program to states to build or enhance coordinated systems of community-based respite care, provide respite services, train and recruit respite care workers and volunteers, provide information to caregivers about available respite and support services, and assist them in gaining access to services. Learn more about the [grantee activities and key accomplishments](#) based on the work of the [38 states and Washington, DC](#), that have received this federal grant funding since the program started in 2009.
- [State funding](#) for caregiver support programs such as HCBS, respite care via general revenue, appropriated funds, or alternative state-based revenue sources such as “dedicated revenues” (e.g., tobacco taxes, lottery revenues, etc.).

Increase the Range of Options for Both In-Home and Out-of-Home Respite Services

- [Vouchers](#) are a payment mechanism, either through stipends or grants, for family caregivers to access respite. Vouchers document that respite services have been bought or respite services have been rendered and authorizes payment accordingly.
- [Self-directed programs](#) allow the participants decision-making and/or budget authority over certain services such as respite care, including who provides the services (i.e., a family member or friend) and how services are provided.



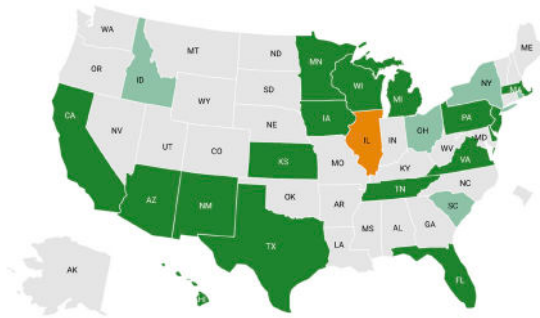
States That Use Lifespan Respite or State-Funded Respite Vouchers for Family Caregivers Caring for Anyone of Any Age

Source: [ARCH National Respite Network and Resource Center](#)

- [Culturally specific programs](#) integrate cultural and linguistic competence within respite care for more equitable service access.
- [Volunteer](#) and [faith-based](#) respite when available and appropriate to help provide respite services, curtail costs, and improve affordability for families.

Additional Options

- Engage [State Respite Coalitions](#), which often focus on public education and training, as well as administering respite vouchers.
- Contract with Medicaid managed care plans to cover and prioritize respite as a regular part of the service package.



Respite Care and Adult Day Services in Medicaid Managed Long-Term Services and Supports

[INTERACTIVE MAP](#)

- **Kansas** and **Texas** expanded coverage and eligibility of respite services as a [value-added benefit](#) under their Medicaid managed care contracts.
- **Florida, Iowa, Michigan, and Texas** use Medicaid contractual language to give managed care organizations the flexibility to increase respite care service limits to exceed those found in the states' Medicaid waivers.

State Examples: Respite Care

- **Multiple states** (AL, AZ, MD, ND, NE, NV, NY, SC, WI), through the Lifespan Respite Care Program, provide emergency respite vouchers and guidance for providing emergency respite.
- **South Carolina**, through the Lifespan Respite Care Program, created a [“Breakroom”](#) respite model using faith and community-based volunteers.
- **Iowa**, through the consumer choices (self-directed) option within its Medicaid 1915(c) HCBS waivers, allows [unused respite dollars](#) in an individual's monthly budget to go into savings for future respite purposes.

The Respite Care Workforce

To ensure that **trusted respite care** is available to family caregivers, who often struggle to find qualified aides to provide care, states can:

- Build professional training tracks and career pathways in the direct care workforce, particularly initiatives to encourage retention of trained workers so that family caregivers have greater access to assistance and respite care

- Increase the number of trained direct care workers and volunteers who can provide respite by:
 - Prioritizing a workforce reform agenda to inform legislation and policy
 - Coordinating workforce policy and resources across various sectors (e.g., state agencies, community college systems, etc.)
 - Improving training requirements (e.g., incorporating core competencies)
- Expand self-direction options to supplement the lack of agency-hired respite providers with family or friends of service recipients

Respite Training Curriculum

The ARCH National Respite Network and Resource Center and the Respite Care Association of Wisconsin, in collaboration with NASHP, developed a **competency-based respite provider training curriculum** administered in 10 pilot states. This culminated in the release of **a free respite training curriculum** for entry-level respite care professionals that incorporates the **Respite Care Professional Core Competencies**.

Financial and Workplace Security

To help working caregivers who are juggling employment with caregiving responsibilities, states can:

- Identify working caregivers and connect them to services
- Create resource guides for employers to assist caregivers

State Examples: Working Caregivers

- The **Nebraska** Lifespan Respite Network developed a working caregiver survey to identify caregiver needs ([Working Caregiver Survey](#)).
- The **Wisconsin** Family and Caregiver Support Alliance created an employed caregiver survey in collaboration with the University of Wisconsin-Madison ([Employed Caregiver Survey](#)).
- **New York's** Office for the Aging launched a [Working Caregiver initiative](#), including a [Resource Guide for Businesses](#), to identify working caregivers and connect them to support services.

Data, Research, and Evidence-Based Practices

To promote data and research on respite care, which is needed to inform policies and evidence-based practices, states can:

- Expand evidence-based research on respite
- Collect family caregiver data and outcomes from respite care — for example, through family caregiver assessments and plans of care
- Compile state inventories of respite care

State Examples: Data, Research, and Evidence-Based Practices

- **Connecticut** uses the [Care of Older Persons in their Environment \(COPE\)](#) evidence-based support model to incorporate supports such as respite for caregivers of those with Alzheimer’s disease and related dementias.
- **Nebraska** created a [respite data dashboard](#) that includes lifespan respite data across multiple populations, including older adults, people with disabilities, and children.
- **North Dakota** contracted with North Dakota State University to develop a [state family caregiver support inventory](#) to identify resources, barriers, and best practices.

Acknowledgments

This action guide was made possible by a grant from [The John A. Hartford Foundation](#) in collaboration with the [U.S. Administration for Community Living](#).