



MAY 2024

State Innovations to Advance Respite Care

Policy Strategies Shared at the State-Federal Respite Summit

Introduction

Family caregivers are a [key component](#) to the sustainability of the long-term care system in the U.S., with their efforts reaching every state and cross-sector in society. Recognizing their importance, federal and state governments have made investments in supporting family caregivers — including the provision of respite care. [Respite care](#) — [one of the most desired caregiver services](#) — is a service typically delivered in the home or a facility-based setting that provides short-term relief for caregivers. Research trials have found that when older adults' caregivers receive supports that include respite, [caregiver outcomes improve, older adults' nursing home placement is delayed, and there is a decrease in hospital readmissions and emergency room expenditures](#). With caregivers increasingly asked to perform [more intense and complex care](#), respite care is integral to giving caregivers a much-needed break.



NATIONAL ACADEMY
FOR STATE HEALTH POLICY

In February 2024, the National Academy for State Health Policy (NASHP), as part of its Lifespan Respite Special Projects grant from the Administration for Community Living (ACL), hosted 16 state teams and federal officials from eight agencies in Washington, D.C., for a peer-to-peer learning exchange on innovative models, strategies, and policies to increase access to high-quality respite care services. To foster cross-agency collaboration, state team membership consisted of a Medicaid official with decision-making authority, a representative of the aging/disability agency, an ACL-funded Lifespan Respite grantee, or another individual of the state's choosing such as a respite or family caregiver coalition representative.

The states reflected a diverse geopolitical representation: Arizona, Colorado, Delaware, Georgia, Illinois, Massachusetts, Michigan, Montana, New Mexico, New York, North Dakota, Oklahoma, South Carolina, Washington, West Virginia, and Wisconsin. To align and assist with the implementation of the [2022 National Strategy to Support Family Caregivers](#), federal agency representatives joined state officials to discuss federal and state efforts to improve access to high-quality respite care throughout the lifespan. This dialogue allowed federal and state participants to learn from each other about what each is doing to advance respite care and family caregiving policy, as well as identify existing and potential synergies between these efforts.

With family caregivers providing [36 billion hours of unpaid care worth \\$600 billion](#), the gathering of both federal and state officials underpins how respite and family caregiving is a key issue among states and their federal counterparts. The state innovations highlighted in this brief reflect this dialogue to increase access to and improve the quality of respite services.

Awareness and Outreach

Awareness and outreach are the first steps to service access. Caregiver barriers to respite access include a [lack of self-identification as a caregiver](#), unawareness that the benefit is available, or misunderstanding of the benefits they can bring. State officials from Illinois, Massachusetts, and Arizona discussed promising practices for outreach to a range of populations:



Illinois SWOT (Strengths, Weaknesses, Opportunities, Threats) Analysis of Caregiver Resources.

The Illinois Department on Aging and 13 Area Agencies on Aging (AAAs) conducted a series of in-person and virtual [caregiver roundtables](#) to identify strengths, weaknesses, opportunities, and threats to caregiver resources. This strategy employed a [SWOT analysis](#) to allow the department to collect valuable information to help inform their future family caregiver policy decisions, including findings related to respite care.



Massachusetts's MassOptions Streamlining of Respite Service Access.

Through its ACL-funded [Lifespan Respite grant](#), one of the goals identified by the Massachusetts Lifespan Respite Project is to increase awareness by family caregivers on how to access respite services. This goal resulted in three deliverables: a [Respite Training for Care Coordinators \(MA CARE\)](#), a [caregiver respite video](#), and training to options counselors working with [MassOptions](#). MassOptions is a revised and updated referral pathway for callers to Massachusetts's No Wrong Door program. The MA CARE training aims to raise awareness of respite resources and seamlessly guide caregivers to respite options in their area, including asking guiding questions to triage access.



Arizona's Collaborative Partnerships for Diverse Outreach.

The [Arizona Caregiver Coalition](#)'s robust partnerships ensure that caregivers receive support through a variety of touchpoints in the service ecosystem. This collaboration includes AmeriCorps, universities/colleges, and the local AARP chapter. In addition to its work in coalition building, the coalition plans to conduct greater outreach efforts to LGBTQ+, American Indian, veteran, and deaf and hard-of-hearing communities, as well as law enforcement, fire departments, and local businesses. This outreach will result in caregiver summits specifically dedicated to diverse populations in collaboration with the Arizona Department of Health Services and health care providers. Lastly, with funding from ACL through its Lifespan Respite grant, the coalition develops and distributes [emergency respite workbooks](#) that include practical tools and information for family caregivers in emergency situations.

Respite Training Curriculum: Educating the Workforce

Equally integral to awareness and outreach is the capacity of a well-trained respite workforce. The [ARCH National Respite Network and Resource Center](#) and the [Respite Care Association of Wisconsin](#), in collaboration with NASHP, field-tested a free competency-based [online respite provider training curriculum](#) for entry-level respite providers in 10 pilot sites. This project was funded as a part of NASHP's Lifespan Respite Special Projects grant funded by ACL. The training curriculum incorporates the [respite care professional core competencies](#) — developed by an [expert workgroup](#) — along topics such as person and family-centered care, cultural competency, and self-care. The [initial evaluation](#) shows promising results of the training's effectiveness, with provider agencies most successful when they conducted targeted marketing of the training and had a provider registry to connect learners to respite jobs.



Wisconsin's Recruitment Strategy and Respite Care Provider Registry. To attract quality respite care providers and promote respite as an outcome and not just a service, the [Respite Care Association of Wisconsin](#) helped develop a recruitment campaign among the pilot sites that included building a talent pipeline with academic, cultural, and faith-based organizations. Additionally, Wisconsin's free robust [respite care registry](#), supported by state and ACL Lifespan Respite funds, includes [step-by-step instructions](#) to become a respite care provider and create an impactful profile.



South Carolina's Experience with Respite Training Curriculum Pilot. As one of the 10 pilot states, the [South Carolina Respite Coalition](#) was able to consolidate its training infrastructure into [one platform](#). From this pilot, South Carolina is currently adding a few modules to the respite training platform on how to become a household employer and build a respite plan.

Strengthening the Respite Workforce: Serving Diverse Populations

Another aspect to bolstering workforce infrastructure is meeting the needs of states' diverse populations. States are diverse and complex, which necessitates intentionally designed policies to adequately address the needs of the various populations they serve. Presenters from West Virginia, Montana, and New Mexico offered varying perspectives on specialized strategies for recruiting and supporting a respite care workforce to serve people from diverse cultures or with conditions that may affect services. Examples of such populations include adults with cognitive limitations (e.g., Alzheimer's disease and related dementias, children with serious emotional disorders, and Medicaid beneficiaries living in rural areas.



West Virginia's Partnership with Managed Care Organizations and Universities to Train the Workforce that Supports Children and Adults with Serious Emotional Disorders. West Virginia's Department of Human Services, through the Medicaid [1915\(c\) Children with Serious Emotional Disorders Waiver program](#), administers both in-home and out-of-home respite care for caregivers of children ages three to 21 with serious mental, behavioral, or emotional health conditions. The partnership between the West Virginia Department of Human Services, Bureau of Medical Services, and managed care organization partner Aetna includes a focus on workforce forecasting and provider network expansion. Most recently, West Virginia collaborated with West Virginia University to develop [a person-centered, trauma informed care training](#) both in-person and online for West Virginia home and community-based service (HCBS) direct service providers.



Montana's Healthcare for Healthcare Workers program provides funding to Medicaid-funded long-term care provider agencies to assist with the cost of [offering health insurance to personal care attendants and direct care employees](#). To be eligible for the support, employers must be providers of personal assistance services and/or private duty nursing services within the Community First Choice, State Plan, or Big Sky Waiver programs. Workers are eligible if they spend over 50 percent of their time delivering Medicaid services. This program is funded by Montana through both state plan allocations and federal matching funds.



New Mexico's New MexiCare Caregiver Health Model. New Mexico's Aging and Long-Term Services Department administers in 13 counties "[New MexiCare](#)," a financial assistance and training program for caregivers who assist friends or family members with physical or cognitive limitations. [Financed](#) through [state general funds](#), the goal of the program is two-fold: to allow older adults to live in HCBS while reducing nursing home placements and emergency department visits. If eligible, applicants can receive up to \$1,000 for up to 12 months to assist with paying caregivers who provide respite and other long-term care services. Caregivers enrolled in the program are required to complete 12 hours of online training per year.

Medicaid Payment Policy Improvements

Georgia, North Dakota, Colorado, and Washington presented on payment-related respite policies and provided examples of how states can better leverage Medicaid payment and program design to improve access and promote quality of respite services and family caregiver policies holistically. As [a major payer](#) of long-term services and supports (LTSS), these policy strategies can be implemented as small policy changes (e.g., waiver amendments and renewals) but can make a large impact and difference for beneficiaries and their caregivers.



Georgia's Structured Family Caregiving Service. Through a Medicaid [1915\(c\) waiver](#), Georgia administers a distinct, structured family caregiver service (SFC) that allows a live-in family member to be reimbursed for providing services to a beneficiary at home. [SFC services](#) typically consist of a service package that supports family caregivers to provide optimal care to a loved one. The package includes payment, individualized training, coaching, and respite care. One of the benefits of SFC services is that it allows individuals who do not receive [self-direction](#) to obtain in-home care by their desired caregiver. Georgia's SFC provider agencies assist the family caregiver with education and support, such as web-based assistance for documenting service notes that are shared between the caregiver and care coordinator.



North Dakota's Online Provider Networks and Rural Differential Rate to Incentivize Services.

North Dakota offers three online-based provider networks to recruit, retain, and support the direct care workforce. The first is a [Qualified Service Provider \(QSP\) Hub](#), a centralized source for QSP (direct support professional) information and training. Second, a [QSP Enrollment Portal](#) streamlines provider enrollment, which reduces administrative burden and provides quicker access to HCBS. Third, [through a partnership with ADvancing States and Altarum](#), North Dakota offers a customizable, web-based direct care provider registry that connects employers, employee candidates, and the state to address workforce needs. Moreover, given the [many frontier counties](#) within North Dakota, the Department of Human Services designed a flexible rate methodology to incentivize service provision. North Dakota's rate structure includes a higher rate for QSPs delivering HCBS in rural areas. The [rate structure](#) is implemented through a tiered approach based on an individual's round-trip mileage, with qualified QSPs willing to travel at least 21 miles round-trip.



Colorado Braids Funding Sources to Provide Respite Care to All Siblings in the Same Household, Including Those Who Do Not Qualify for Medicaid Waiver Services.

[New Adventures](#) is a pilot respite program in rural Southern Colorado that was initially supported by American Rescue Plan Act funding. The program braided funding options to support families with multiple children needing respite care services. Medicaid provides coverage for respite care for caregivers of children enrolled in several Medicaid waivers. For children in the same household who do not qualify for a Medicaid waiver, New Adventures accesses other funding sources, such as Colorado's ACL-funded Lifespan Respite grant. The cohesive approach allows for caregivers of all siblings to receive respite care, regardless if they qualify for a Medicaid waiver, which helps address service gaps in rural areas. Additionally, Colorado's Department of Health Care Policy and Financing implemented waiver system improvements to offer greater [respite delivery options](#) and flexibilities such as skilled respite and rate increases for Medicaid respite providers.



Washington's Use of an 1115 Medicaid Authority to Support Family Caregivers.

Washington uses a Section [1115 Medicaid Transformation Demonstration](#) to administer flexible family caregiver policies, including respite care. A key element is functional and financial presumptive eligibility for applicants, which allows individuals to receive LTSS, such as respite care, faster. It has now expanded into mainstream Medicaid LTSS [presumptive eligibility](#). Another key is a waiver of [Medicaid estate recovery](#). Additionally, [Tailored Supports for Older Adults \(TSOA\)](#) expands Medicaid funding to certain individuals who are at risk for spending down to become eligible for by providing person-centered LTSS to unpaid caregivers for these individuals. The TSOA service package may include caregiver assistance services, which offers both in-home and out-of-home respite for unpaid caregivers.

Cross-Agency Collaboration

Collaboration between state and local agencies, providers, and community-based organizations is essential to ensuring people across the lifespan have access to respite care. Different types of respite are provided and paid for by various state and community programs. States can best ensure access, understand resources, and identify gaps in coverage when they know how and what respite looks like across the state. Delaware, New York, and Oklahoma shared how they are implementing strategies such as cross-program coordination, partner collaboratives, landscape analysis, and Master Plans on Aging to accomplish cross-agency collaboration.



Delaware's Asset Mapping. The Delaware Division of Services for Aging and Adults with Physical Disabilities used a [National Center on Advancing Person-Centered Practices and Systems \(NCAPPS\)](#) Technical Assistance Grant to create [an asset map](#) of the state's aging and disability network, including respite services. The asset map illustrated existing engagement and partnerships, potential entities to build connections with, and opportunities for improvement. The state used the asset map to educate state agencies and providers and to plan a targeted and intentional path forward.



New York State's Master Plan for Aging. New York State is creating a [Master Plan for Aging](#) designed to ensure that all New Yorkers can live fulfilling lives and be in good health with freedom, dignity, and independence, regardless of age. The plan is based on 10 key pillars and is guided by the work of eight subcommittees and workgroups — with [two subcommittees](#) specifically devoted to formal and informal caregivers. The plan will guide state agencies, local governments, community groups, providers, and others in how to ensure aging adults and their caregivers have access to services such as respite care.



Oklahoma's Respite Collaborative. Through a strategic partnership, the Oklahoma Human Services Community Living, Aging and Protective Services, and Oklahoma Health Care Authority established a collaborative to enhance care coordination and respite service delivery to support Oklahoman caregivers across systems. This includes [respite vouchers](#) and comprehensive options counseling to help meet the diverse needs of caregivers. Additionally, Oklahoma has a respite referral online system comprised of eight statewide respite programs. If a caregiver does not qualify for a respite program, a secure online referral can be made to a different program. This system fosters data sharing across the state to identify service gaps, including those in rural communities. The University of Oklahoma Health Science Center's [Sooner SUCCESS](#) operates the respite referral online system with funding from ACL through a Lifespan Respite grant, which also includes the [Oklahoma Lifespan Respite Grant Voucher Program](#). Care coordination efforts are strengthened by the Oklahoma Caregivers Coalition and the OKCares website to share information with family caregivers and providers.

Looking Ahead

NASHP is proud to host [The RAISE Act Family Caregiver Implementation and Technical Assistance Center](#), a growing repository of resources for states to strengthen family caregiver policies. NASHP will soon reconvene the 16 states for individual technical assistance calls to discuss their progress and challenges with implementing respite policy priorities they identified at the summit. In fall 2024, NASHP will launch a new State Family Caregiving Learning Collaborative to provide technical assistance to states, including opportunities to convene as a group and learn from other states' approaches. NASHP also has recently created a family caregiving policy newsletter. To get news and updates on state family caregiving initiatives and resources, [sign up for our quarterly newsletter](#).

Contributing Authors

Kimberly Hodges, Ella Taggart, and Salom Teshale

Acknowledgements

The authors wish to thank the state teams and federal officials for their participation and knowledge sharing at the State-Federal Respite Summit. Federal agency representation included the Administration for Community Living, AmeriCorps Seniors, Centers for Medicare and Medicaid Services, Department of Labor, Health Resources and Services Administration, Indian Health Service, Substance Abuse and Mental Health Services Administration, and U.S. Department of Veteran Affairs. The authors also wish to thank Wendy Fox-Grage, Neva Kaye, and Hemi Tewarson from NASHP for their review of this brief.

This summit was supported by Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$942,520 with 75 percent funded by ACL/HHS and \$312,845 and 25 percent funded by non-government source(s). The contents are those of the authors and do not necessarily represent the official views of, nor are an endorsement, by ACL/HHS or the U.S. Government.

NASHP would also like to thank The John A. Hartford Foundation for providing the non-government matching funds for this project and the Ralph C. Wilson, Jr. Foundation for its support. In addition, NASHP thanks ARCH National Respite Network and Resource Center for its collaboration.



Visit nashp.org
for more information.

