

IN SUPPORT OF  
**CAREGIVERS**



**KEY ACCOMPLISHMENTS**  
OF LIFESPAN RESPITE PROGRAM GRANTEEES

*In acknowledgment  
and support of more  
than 50 million  
Americans providing  
care to loved ones.*



Author: Susan Janko Summers, PhD | Publication Design: Barbara J. Witt

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**KEY ACCOMPLISHMENTS**  
OF LIFESPAN RESPITE PROGRAM GRANTEES

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## **RESPITE**

*is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers.*

**THE TIMES IN OUR LIVES** when we care for others—celebrating births, or honoring those who are dying—are among our most significant and meaningful. No less meaningful are the times when caregiving is extended—when a beloved child is born with a disability or health condition that will not resolve; when a parent has dementia; when a husband or wife returns from military duty wounded and with a disability. While caregiving can be spiritually and emotionally fulfilling for many, these times can be physically and emotionally stressful, economically debilitating, and socially isolating for others.

**RESPITE IS PREVENTIVE AND SUPPORTIVE**, and may enhance quality of life and well-being for both family caregivers and care receivers. Respite may help families avoid or delay out-of-home placements for their loved one—placements that can exact emotional, psychological, social, and financial costs for families and society, and are particularly worrisome during the pandemic. Depending on the level of care families need or prefer, community-based and in-home respite services offer a variety of options—some at no cost to families.

### **SUPPORTIVE LEGISLATION**

In acknowledgement and support of the *more than 50 million Americans*<sup>1</sup> providing care to loved ones, the Lifespan Respite Care Program was enacted under Title XXIX of the Public Health Service Act (42 U.S.C. 201) in 2006 and reauthorized in January 2021.

The **LIFESPAN RESPITE CARE PROGRAM** supports states' efforts to create respite *systems*. These systems work to coordinate across agencies so that families have access to respite regardless of age, disability, or chronic condition.

The Lifespan Respite Care Program does not supplant other funding sources. Rather, it capitalizes and improves upon existing assets. Through local knowledge of the unique needs and resources in states, regions and communities, state Lifespan Respite Program grantees work with key partners to address the universal need of family caregivers to receive temporary relief from providing continuous care to loved ones for extended periods of time.

Through competitive grants, the Lifespan Respite Care Program supports individual state grantees to achieve

### **FIVE OBJECTIVES<sup>2</sup>:**

1. **Expand and enhance respite services in the states;**
2. **Improve coordination and dissemination of respite services;**
3. **Streamline access to programs;**
4. **Fill gaps in service where necessary; and**
5. **Improve the overall quality of respite services where available.**

*Among the myriad and pressing needs of families caring for loved ones with special needs, respite is often the most requested type of caregiver assistance.*

### **EIGHT KEY ACCOMPLISHMENTS**

In the descriptions of State Grantee accomplishments that follow, knowledge, commitment, ingenuity, and skillful stewardship and administration of resources are evident. Because a research base to guide grantees in making strong, durable, and responsive state systems is relatively scant, the accomplishments of these state grantees are essential to improve the quality of respite services and to increase confidence among caregivers using respite services. Through their work, state Lifespan Respite grantees provide evidence of the merit of the **Lifespan Respite Care Program**, and they inform our path forward.





## 1. MAKE LEADERSHIP COLLABORATIVE.

**IT'S COMPLICATED.** Respite funding sources are dispersed across categorical programs, creating barriers to funding and using services. And although respite is among the services most valued by caregivers, awareness of respite—even within agencies mandated to support respite—may be limited.

**MAKING IT SIMPLE** for families requires state planning and coordinating bodies—typically *State Lifespan Respite Coalitions* that include funders, consumers, policymakers, and providers. These partners work together to make sense of multiple categorical funding sources, programs and agencies so that caregivers don't have to. Leadership shared among partners makes Lifespan Respite systems more stable and sustainable when conditions—funding, priorities or personnel—change in a single program or agency. This collaboration is not only administrative. It is also a deeply human endeavor based on relationships, requiring inclusivity of members and active engagement in initiatives and activities important to stakeholders and valued by caregivers.

### IDAHO

The **Idaho** Caregiver Alliance, with more than 400 members, worked in partnership with the Idaho Commission on Aging to convene regional Respite Summits in order to identify service gaps, learn how respite services are working, and hear directly from caregivers. To capture the unique needs and resources of a given region and connect with state coalition leadership and priorities, coalition leaders traveled to rural areas to assess needs and plan cooperatively. Translating ideas into actions, the [Idaho Caregiver Alliance](#) [2] and Idaho Commission on Aging established a community respite workgroup and created mini-grants that supported seven regional programs serving families of children with disabilities, caregivers of cancer survivors, caregivers of adults, caregivers of children with significant medical needs, and caregivers of seniors.

### MASSACHUSETTS

**Massachusetts'** Lifespan Respite grantee, after a change in grant funding and leadership, convened a seven-member state leadership team and invited 20 key constituents to re-establish a vision and to identify three key commitments focused on providing and paying for quality respite services. The leadership team began by examining economic research on respite with an eye toward aligning what they learned with the state respite coalition's past work. They then partnered with Brandeis University to produce a fact sheet outlining costs and cost savings associated with respite services. They gathered training resources and developed core competencies and case studies to strengthen the state's provider workforce. These foundational planning activities—research and policy on cost efficient respite and growing a strong provider workforce—increase the likelihood that respite practices in Massachusetts will be both sound and sustainable.



## 1. MAKE LEADERSHIP COLLABORATIVE.

### NEW YORK

New York's State Office for the Aging, the [New York State Caregiving and Respite Coalition](#) [3], New York Connects No Wrong Door System (New York's ADRC/NWD), Monroe County Office for the Aging, and Lifespan of Greater Rochester Inc., as key partners, organized and convened a statewide Summit—with the New York State Caregiving and Respite Coalition leading the effort—in order to articulate their vision, and importantly, to map out strategies that would help assure that the focus on caregiving and respite across age and disability groups is sustained into the future. The two-day Lifespan Respite Sustainability Summit was attended by 108 participants representing various disciplines and areas of expertise in caregiving and respite. Summit participants worked together to develop a comprehensive sustainability plan that identified fiscal, infrastructure and human resources; activities and corresponding performance measures; ways to strengthen systems internally; and strategies to identify key champions and engender broad-based community support for New York's Lifespan Respite initiative going forward.

### SOUTH CAROLINA

The [South Carolina Respite Coalition](#) [4] began in the 1990s in partnership with more than 30 organizations, including Family Connection of South Carolina, Inc., the South Carolina Office on Aging, the Center for Disability Resources at the University of South Carolina School of Medicine, and the Institute for Families in Society at the University of South Carolina. The Coalition incorporated in 2001. In 2009, grounded in a long partnership with the South Carolina Lt. Governor's Office on Aging and Family Connection, the state received its first Lifespan Respite grant. As a part of the grant, in 2010, the state conducted a statewide needs assessment and environmental scan, and invited 40 key stakeholders—family caregivers, state agencies, respite providers, non-profit organizations, and university researchers—to address identified needs and develop a *State Lifespan Respite Plan*. In 2014, the partners convened 120 participants in a *Vision 2020* Lifespan Respite Summit to increase outreach and broaden stakeholder engagement, to reevaluate and update their state plan, and to build a more comprehensive and sustainable system of care. Among the significant outcomes from their sustained efforts to inform and educate South Carolinians about the importance of respite is a 2.4 million dollar recurring line item in the state budget for the South Carolina Department on Aging to support a statewide Lifespan Respite voucher program for caregivers. With Lifespan Respite grant support, South Carolina developed a coordinated Lifespan Respite system bridging multiple respite voucher



## 1. MAKE LEADERSHIP COLLABORATIVE.

### **SOUTH CAROLINA** (CONTINUED)

programs (the State Voucher Program, Alzheimer’s Disease, Family Caregiver Support and Lifespan Voucher Programs) to provide easy access to respite for caregivers. Guided by the State Plan, the Department on Aging and South Carolina Respite Coalition are broadening membership and working to fully engage key public stakeholders including Medicaid, the Department of Disabilities and Special Needs, Long-Term Care Taskforce, business leaders, health care providers, faith communities, and service organizations in order to build a more comprehensive, coordinated, and sustainable system of care.

*The diversity of categorical diagnoses and funding make connections with partner agencies, across programs, and with caregivers and providers, essential. Here are some of the people, programs, and organizations that state Lifespan Respite grantees have partnered with in order to make Lifespan Respite accessible, coordinated, responsive, relevant and accountable.*

**Aging and Disability Resource Centers**

**Area Agencies on Aging**

**Behavioral and Mental Health Organizations**

**Caregivers and Care Recipients**

**Centers for Independent Living**

**Child Maltreatment/Trauma and Prevention Organizations**

**Child and Adult Protective Services**

**Colleges and Universities, including University Centers for Excellence in Developmental Disabilities**

**Dementia Organizations**

**Developmental Disabilities and Condition-Specific Organizations**

**Early Learning/Early Intervention Programs**

**Employers**

**Ethnic and Minority Organizations**

**Faith-based Organizations**

**Health and Medical Providers**

**Hospice and Palliative Care Organizations**

**Managed Care Organizations**

**Medicaid Agencies**

**Peer-to-Peer and Family-to-Family Organizations**

**Public Health Programs**

**Tribal Organizations**

**Veterans Organizations**



## 2. MAKE RESPITE ACCESSIBLE THROUGH NO WRONG DOOR.

**FINDING RESPITE** becomes necessary when caregivers experience a life-altering event, or have just survived a crisis. A wife and mother returns home to her family after suffering a brain injury while serving in Afghanistan. An infant son has an incurable health condition causing him to deteriorate over the coming few years before he will die. A husband, in middle age, is diagnosed with Lewy Body Dementia. At a time of great need for information, support and services for loved ones, caregivers often feel raw, vulnerable, overwhelmed, and exhausted. Resources, tied to categorical funding, are too often fragmented, duplicative, and confusing.

**THE NO WRONG DOOR** initiative is a collaborative effort of the Administration for Community Living, the Centers for Medicare & Medicaid Services, and the Veterans Health Administration. Building upon the Aging and Disability Resource Centers, and working in partnership with Lifespan Respite grantees and other organizations, **No Wrong Door** helps to counter negative effects on care recipients and their families when support services are difficult to find, understand, or afford. **No Wrong Door** includes person-centered counseling and streamlined access to programs, and it provides for governance and administrative structures that support a strong, sustainable system. In the following examples, we see Lifespan Respite grantees partnering with agencies in their states that received ACL **No Wrong Door** funding. We see how states establish a single point of entry to respite services and supports, develop a universal process or application to assure respite services access and coordination, innovate according to local needs, and enhance data collection to assure accountability to caregivers and to funders.

### **ALABAMA**

**Alabama** Lifespan Respite (established in 2009 as the lead entity for Lifespan Respite coordination by Alabama's resolution HJR 170) and the Alabama Respite Coalition work cooperatively with the state's broader **No Wrong Door** system to ensure that Lifespan Respite is included in the Universal Intake Form screening door used by Aging and Disability Resource Center (ADRC) staff, and by the 13 state Areas Agencies on Aging (AAAs), creating seamless access to respite services for clients. With their permission, caregivers contacting these agencies are screened and referred to resources in their communities, and follow-up is provided to make sure caregiver needs are addressed. To make sure ADRC specialists are prepared for this role, [Alabama Lifespan Respite](#) [5] staff work collaboratively with Alabama Department of Senior Services to plan and provide training.



## 2. MAKE RESPITE ACCESSIBLE THROUGH **No Wrong Door**.

### NEVADA

**Nevada**, a geographically large state with a sparse and mostly rural and dispersed population, has worked strategically since 2005 to create and refine their **No Wrong Door** system. The Planning, Advocacy and Community Services Unit of the Aging and Disabilities Services Division partnered with five Aging and Disability Resource Centers to serve all of Nevada's 17 counties with: resource and service navigation; Veterans/home and community-based services partnerships; care transitions; and integrated caregiver supports. Initially, these services focused on training for resource centers; a website for respite; and vouchers. The first phase of Nevada's efforts resulted in a 60 percent increase in respite referrals. Phase one activities also resulted in a respite page integrated into the **No Wrong Door** portal, and an Information and Referral Module on the webpage that includes a Caregiver Self-Assessment, helping caregivers recognize risk for burnout, and connecting them with resources that support them in their caregiving role. Over time, Nevada has worked to align state policies to streamline access and align data collection, providing a more accurate picture of the status of caregivers and care recipients, and the extent to which their needs are being met.

### NEW YORK

**New York**, as part of its expanded NY Connects **No Wrong Door** system, offers the online [NY Connects](#) [6] Resource Directory, accessible to the public. The NY Connects Resource Directory includes contact information about long-term services and support programs and resources, including respite services for family caregivers. Current directory listings total more than 104,000 programs across all age and disability groups from New York's Aging Network and the New York Department of Health, Office for People with Developmental Disabilities, Office of Mental Health, and Office of Alcoholism and Substance Abuse Services, as well as a recent addition from Food Pantries of the Capital District that provides up-to-date Food Pantry listings. Respite resource listings identified through the work of the New York State Caregiving and Respite Coalition are also shared with the Aging Network so that they may be added to the Directory.



## 2. MAKE RESPITE ACCESSIBLE THROUGH NO WRONG DOOR.

### SOUTH CAROLINA

South Carolina's family-centered respite program, funded by state and federal Lifespan Respite dollars and private respite donations, awards up to \$1,500 per year, per caregiver. The program assists families with applications to minimize stress, educates them on respite, how to take a real break, how to build circles of support, and it helps caregivers find their best caregiving option—including individual private providers, in-home agencies, adult day centers, or summer camps. Building on the ACL/**No Wrong Door** model, South Carolina's voucher program coordinates closely with the Area Agency on Aging (Aging and Disability Resource Centers/Family Caregiver Support Program), the Department on Aging, South Carolina Respite Coalition and Family Connection of South Carolina, which is the state's [Family-to-Family Health Information Center](#) [7], to promote access, and with community programs to increase respite awareness. South Carolina's collaborative work is a noteworthy example of a state **No Wrong Door** approach that coordinates across the lifespan. Notably, South Carolina also includes a caregiver survey in the application that produces information helpful in guiding families, documenting respite use, and producing an annual *Faces of Respite* publication.

### VIRGINIA

Caregivers in Virginia use the **No Wrong Door** system to find information, referrals and resources that match their individual needs. The Virginia Department for Aging and Rehabilitative Services (the Lifespan Respite grantee) convened a group of stakeholders from aging, disability, and Alzheimer's communities, representatives of [Virginia Navigator](#) [8] and in consultation with Virginia's **No Wrong Door** director, conducted a year-long assessment of the **No Wrong Door** resource database. Data identifying caregiver resources and service gaps are used to assure that services match and meet caregiver and family needs and preferences. These data are also used to guide automated respite voucher referrals, to secure the exchange of data across system partners, and to capture outcome measures.



### 3. MAKE SERVICES AFFORDABLE.

**CAREGIVING PLACES HIGH COSTS** on caregivers. According to AARP, one in five caregivers experience increased financial strain as a result of caregiving.<sup>4</sup> More than one in ten caregivers in the “sandwich generation” provide intergenerational care to their children while also caring for their aging parents, compounding their financial burden.<sup>5</sup> And more than half of caregivers who work outside the home in addition to providing care for a family member need to take time off, reduce hours, or quit work to meet caregiving demands. In addition to compromising access to income in real time, for these caregivers, long-term prospects for building a career are diminished. Families caring for the 5.6 million children in our country with special health care needs provide nearly 36 billion dollars worth of care annually. Their associated foregone earnings total 17.6 billion dollars, or \$3,200 per child.<sup>6</sup> For the nearly 40 percent of full-time caregivers who don’t work outside their homes, and for the more than 60 percent who face the dual demands of work *and* caregiving<sup>7</sup>, research shows that caregivers may experience social, emotional, and health benefits from receiving as few as four hours of respite a week.<sup>8</sup>

**FINDING AFFORDABLE RESPITE** is challenging to families, despite its importance in mediating the negative effects of uninterrupted caregiving. To make respite affordable, to reach underserved populations, and to address service gaps, many Lifespan Respite grantees and partners create statewide voucher respite programs. Sometimes also known as respite stipend, reimbursement, or grant programs, put simply, vouchers allow caregivers to pay someone they trust to care for their loved one while they take a short, restorative break from caregiving duties.

#### ALABAMA

Alabama’s Lifespan Respite program issues vouchers to reimburse costs for direct and emergency respite, allowing caregivers to choose anyone they wish to provide care for their loved one. Data collected from Alabama’s respite surveys show that after receiving respite, a substantial percentage of caregivers report a decrease in feeling overwhelmed by daily routines.

*Respite services are vital for caregivers! I have been a nurse for about 40 years with many years in case management, but until someone experiences being a caregiver themselves, they cannot appreciate the value and need for respite services.*

*My dad was widowed and my only two siblings are deceased, therefore, I became THE caregiver. I was blessed to find a paid caregiver that helped some during the day, but 17 or more hours every day I stayed with him and was there every night for over nine months. I hope this program continues for the many other caregivers in need...*

– A 63 year-old caregiver



### 3. MAKE SERVICES AFFORDABLE.

#### ARIZONA

Arizona's Lifespan Respite grantee in collaboration with the [Arizona Caregiver Coalition](#) [9] offers respite support primarily through community adult day health centers to older adult populations. In order to reach and serve other underserved populations, the Lifespan Respite grantee engaged the Area Agencies on Aging and other community-based programs and created a program that uses voucher allocations targeting rural areas, reaching families without other respite resources, supporting developmental disability populations not eligible for services in adult day centers, and providing in-home alternatives to congregate care for families during the Covid-19 pandemic.

#### COLORADO

Colorado's Lifespan Respite Care program, in partnership with Easterseals Colorado and the Colorado Respite Coalition, successfully advocated for state general funds to support community grants and respite vouchers to reach families across the state, and across the lifespan. Strengthening and expanding respite services, vouchers pay for in-home, center-based and recreational respite, including Colorado's [Coming Up for Air](#) [10] family respite weekend.

#### IDAHO

Idaho's Lifespan Respite grantee worked strategically to build a consumer-directed voucher system, reaching underserved populations of all ages and especially those in rural communities with workforce shortages. Idaho's Commission on Aging partnered with one of six Area Agencies on Aging (Idaho's No Wrong Door agencies) to institute a pilot program. Its success has created statewide demand leading Idaho to establish the consumer-directed program in four more service areas. As part of the pilot, a manual—highly valued by caregivers—was developed to guide and support families in accessing affordable respite services, and to facilitate replication in new sites around the state.

#### MISSISSIPPI

Mississippi, one of the newest states to the national Lifespan Respite network, and guided by the Mississippi Department of Human Services, started out strong in developing partnerships with the Mississippi Family Caregiver Coalition, all ten state Area Agencies on Aging, and Mississippi Access to Care, the state's No Wrong Door entity. These partners introduced unserved families to the voucher respite program through social media blasts. Interested families complete a caregiver assessment with their application, providing data that helps to guide services and to demonstrate how respite services support Mississippi families.



### 3. MAKE SERVICES AFFORDABLE.

#### MONTANA

Montana's Lifespan Respite voucher program often received incomplete applications that delayed services to caregivers. In response, the [Montana Lifespan Respite Coalition](#) [11] began sending informational packets to referring agencies that explained the referral process and the importance of caregiver surveys (stressing prevention of out-of-home placements, promotion of caregiver health, and reduction of family stress), and offered information about the state's Lifespan Respite Coalition. As a result, referrals are increasing, a database of referral sources has been established, and referring agencies are 130 strong (and growing).

#### NEVADA

Nevada's Lifespan Respite grantee at the Department of Health and Human Services, Aging and Disability Services Division conducted a statewide voucher pilot project and accompanying evaluation that provides an outstanding example of leadership, innovation and accountability in making respite affordable and accessible to caregivers. In addition to funding respite vouchers, Nevada's *Respite Rx Voucher Program* provided self-directed, regularly and flexibly scheduled, person-centered respite services with the goal of removing barriers to respite and filling service gaps—especially in rural areas, and for caregivers of family members 18 to 59 years-of-age, an underserved group. Caregivers were supported in a person-centered planning process that focused on their unique preferences and circumstances, and the resources available in their communities. Caregivers were also supported in identifying how they would use their respite time—an approach that research has shown to yield benefits to caregivers. This focus on caregiver support—in addition to the family member they provide care for—is captured by the words of a caregiver participating in the *Respite Rx Voucher Program*:

*It was nice to have someone ask about me.  
I don't think anyone has ever asked before.*

#### NORTH CAROLINA

North Carolina's [Lifespan Respite Voucher Project](#) [12] increases voucher use by targeting populations without accessible respite services, and by making sure respite works for caregivers and care recipients through consumer-directed voucher services. When needed, the program's coordinator talks with caregivers about how to find respite providers, and she also calls caregivers to support them in using vouchers and problem solving any issues they may encounter. Supporting caregivers in planning how to use respite time—an approach research shows improves the



### 3. MAKE SERVICES AFFORDABLE.

#### **NORTH CAROLINA** (CONTINUED)

benefits of respite for caregivers—has resulted in 99 percent of caregivers expressing that their “time was well spent.” Caregivers reporting that they “got to go to my granddaughter’s graduation,” “got to go on vacation for the first time in four years,” and “went to the movies for the first time in 10 years” convey the simple, but essential, benefits caregivers experience from receiving guidance with respite.

#### **OKLAHOMA**

**Oklahoma’s** Lifespan Respite voucher program, supported by federal Lifespan Respite grant and state funds, helps assure that care recipients can remain in their homes and communities by enabling caregivers to take a temporary break while their loved one is provided in-home or center-based care. This person-centered voucher program allows family caregivers to hire respite providers from their own networks of social support. The [OKCares Caregiver Coalition](#) [13] partners work together to create a seamless way to make sure all eligible caregivers are connected with a funding stream in the state. For underserved care recipients not qualified for other state or federally funded respite programs, Oklahoma’s Lifespan Respite voucher program provides a lifeline to respite care.

#### **TENNESSEE**

**Tennessee’s** family-directed respite voucher program provides one-to-one family-centered guidance to help families identify resources for self-care and select appropriate programs, facilities, or persons to provide care, defraying some of the cost of respite to families. [Tennessee’s Respite Coalition](#) [14] also focuses on increasing use of vouchers through an easy to locate and navigate website offering a universal online application for respite services, and a caregiver survey to document caregiver outcomes as a result of having used respite services.

#### **VIRGINIA**

**Virginia’s** Lifespan Respite voucher program works to strengthen family systems and protect the health and well-being of both caregivers and care recipients through respite vouchers that reimburse caregiving costs. Prioritizing families with the greatest social and economic need, Virginia’s voucher program focuses on grandparent and relative caregivers of children under 18 years-of-age, persons with dementia, and persons ages 19 to 59 with severe disabilities. Virginia builds flexibility in their voucher respite program to support families in rural areas by permitting non-traditional respite resources, such as short-term stays in nursing facilities, summer camps for children with special needs, and travel reimbursement for extended family caregivers.



## 4. COLLECT AND USE DATA.

**HOW CAN WE HELP?** Once a society has established a collective commitment to the well-being of fellow citizens, it is important that the society recognizes and uses effective service approaches and models that fulfill that commitment. *How do we best support family caregivers providing long-term, daily support? How can state systems provide quality, accessible respite to citizens? What are the costs and benefits of providing respite care? Did systems change efforts accomplish what they set out to accomplish? Are we “getting it right” for those caregivers in need of respite?* These questions necessitate that state agencies and systems collect data that demonstrates the merit of their work supporting caregivers and families, the effectiveness, stability and sustainability of the respite system they design, and accountability for public dollars.

**IMPROVING PROGRAM QUALITY AND SUSTAINABILITY** are the foundation of data collection and use by state Lifespan Respite Program grantees. State grantees work across agencies and partners to reconcile differences in definitions and rules, to make the collection of common data elements possible, and to strengthen the system as a whole. Lifespan Respite grantees have created statewide, centralized data collection systems that make accountability and decision-making possible. And some conduct in-depth and nuanced studies of respite service accessibility, use, and benefits to general and underserved populations that inform quality improvement, safety, and accountability to caregivers.

### **ALABAMA**

Alabama’s Lifespan Respite grantee collects comprehensive data on respite use including first contacts, unduplicated counts on voucher and emergency services, caregiver outcomes, and caregiver stress and anxiety. These data have been used to develop a strategic plan focusing on sustainability. To assist in planning, with the assistance of faculty from the University of Alabama’s Center for Mental Health and Aging, data collected and used include cataloguing statewide caregiver surveys to determine service gaps. Databased documents developed by the Alabama Lifespan Respite Coalition include evaluation tools, and a [White Paper](#) [15] with an accompanying Comprehensive Strategic Plan. Alabama uses an in-house evaluator to develop data collection procedures, oversee collection and analysis, and help the grantee and partners document beneficial family outcomes.



## 4. COLLECT AND USE DATA.

### MASSACHUSETTS

Massachusetts' Lifespan Respite grantee is working with all state agencies that fund or provide respite services in the state in order to reconcile respite definitions tied to categorical funding rules, and to identify common data elements that will allow agencies to capture demographic, service and cost data across agencies and programs. These efforts should result not only in increased understanding by agencies of how and how much respite services are used by caregivers, but should also lead to increased access to respite services for families. In a laudable act of leadership, Massachusetts Lifespan Respite is simultaneously conducting an evaluation of the collaborative process to make sure it works, and will continue to work productively on behalf of Massachusetts' caregivers and their families.

### NEBRASKA

[Nebraska's Lifespan Respite Network](#) [16] sets a high standard for evaluation of respite services that is of great practical use to planners and providers. In partnership with University of Nebraska's Medical Center Munroe-Meyer Institute, Nebraska Lifespan Respite uses data from family caregiver and respite provider surveys to evaluate program activities and caregiver satisfaction as well as impacts of respite on family caregivers' physical and mental health. Importantly, these evaluation partners also examine network activities to identify factors affecting respite accessibility and use so that they can ensure that respite services meet their promise. In addition, Nebraska's [Data Dashboard](#) [17] provides centralized, on-line access to caregivers seeking and using respite. The Data Dashboard yields current and historical respite data for each of the six regions of the Nebraska Lifespan Respite Network through a secure computing environment.

*(Respite) has helped me out a great deal, especially this year. I had two deaths in my family just months apart—my daughter and my dad...It would have been impossible for me to deal with the stress and grief without a break from caregiving.*

— A 48 year-old caregiver



## 4. COLLECT AND USE DATA.

### NEW YORK

**New York's** Lifespan Respite grantee, in partnership with an independent evaluator from the University of Rochester Medical Center/Finger Lakes Geriatric Education Center, uses qualitative and quantitative methods to measure intended outcomes of the state's Lifespan Respite activities. The evaluation includes a number of approaches that help to assure quality improvement and program sustainability: systems level analysis of the Lifespan Respite sustainability planning and implementation processes; data analysis for mini-grants awarded by the New York State Caregiving and Respite Coalition, including respite volunteer training; analysis of post-training surveys of volunteers; and monitoring quality, fidelity, and safety of respite programs at mini-grant sites through a post-respite survey for caregiver recipients. For the current grant's voucher model, the evaluator will use pre- and post-intervention surveys to assess service impact. The New York State Office for the Aging provides NY Connects Resource Directory respite information for analysis of improved standardization of respite listings. Interim and final evaluation reports describe program implementation and outcome results. Additionally, the New York State Office for the Aging will work with the New York State Department of Labor and the evaluator to include feedback tools for analysis in the use of the *Caregiver Guide for Businesses* in order to determine whether stated outcomes have been achieved, to capture lessons learned from the activities undertaken, and to share findings with stakeholders.



## 4. COLLECT AND USE DATA.

### NEVADA

Nevada's Lifespan Respite grantee documents the value of their work by assessing the extent to which respite supports caregivers in meeting some of their greatest needs. While 98.2 percent of family caregivers rate the two to four hours of respite services they received each week as "good" or "excellent", when asked to identify stressors, caregivers tell a more complicated story. Caregivers identified: *arranging services; emotional and physical health strain; and the capacity to provide care* as stressors. After working to address these stressors and asking caregivers again, the Lifespan Respite grantee discovered that caregivers' capacity to provide care was strengthened after receiving respite, but arranging services and emotional and physical health strains persisted. By identifying specific stressors, Nevada's respite programs and services are working to refine Lifespan Respite services to better serve caregivers and their families.

### WASHINGTON

Washington's Lifespan Respite grantee collects data from all counties, including the number of initial caregiver contacts, referral sources, vouchers applied for and received, respite hours utilized per voucher, and demographic data of care recipients. Presenting these data in graphic form, along with data from special projects and initiatives to the more than 100 coalition partners at [Lifespan Respite Washington](#) [18] coalition meetings allows partners and stakeholders to gauge their work's effectiveness as it progresses, and to make adjustments as needed. Grounded in data, and essential to continuous quality improvement, Washington's Lifespan Respite grantee maintains a list of challenges they encounter along with a proposed solution for each challenge. To capture the worth of Lifespan Respite in human terms, Lifespan Respite Washington collects qualitative data providing insight about how caregivers value respite, and they develop case studies highlighting information about successes and challenges encountered by those providing and those using respite services. Qualitative data provides access to caregivers' experiences of respite, as illustrated in this quote:

*Thank you. I would probably be checking in to see a therapist if it weren't for you. I was so despondent this morning. I am still crying, but have hope because of you. Know that you made a difference.*



## 5. GROW A STRONG PROVIDER WORKFORCE.

**WHO WILL HELP?** Approximately 10,000 Americans will reach 65 years-of-age every day between now and 2030. In the next 30 years, the number of Americans over 65 will double, and the proportion of adults over 65 years-of-age in our country is expected to reach 22 percent by 2050. For those living long, healthy lives, old age may be a blessing. For those struggling with cognitive decline, mobility challenges, illness, and social isolation, less so. Other Americans—children with disabilities and complex or chronic health care conditions, Veterans suffering permanent injuries from battle, for example—and their caregivers will face these challenges not only during their last years of life, but throughout their lives. The workforce needed to care for, and help caregivers care for their loved ones is in short supply and frayed. It will become more so unless public policies and funding build a work force—paid and volunteer—to address caregiving needs.

**WHAT IS THE WAY FORWARD?** For care recipients needing relatively straightforward care, some respite care programs provide simple, elegant volunteer training models, easy to afford and replicate in other settings. For care recipients with complex mental and physical health and medical needs, some respite care programs provide a beacon for what societies are capable of providing through paid and highly trained care providers. These individual program models should be replicated across the country, and we must also strive to address the need for training respite care providers commensurate with the size of the challenge we face in the coming decades. State grantees and exemplary respite programs show us how we might accomplish this.

### ARKANSAS

Arkansas's Lifespan Respite grantee, in order to grow the state's caregiver workforce, partnered with the University of Arkansas for Medical Sciences Schmieding Caregiver Training Program to provide Continuing Education Unit (CEU) approved training sessions to Schmieding Certified Home Caregivers and registered nurses. One master trainer trained nine nurses and Certified Home Caregivers who in turn provided training to more than 100 healthcare professionals, respite care workers, healthcare students, caregivers, and volunteers across the state. Growing over the years based upon "lessons learned" through program evaluation, eight trainings were provided each grant year, reaching community- and faith-based respite programs throughout the state that recruited volunteers to their programs.



## 5. GROW A STRONG PROVIDER WORKFORCE.

### COLORADO

As part of the [CO Respite Care Task Force](#) [19], the Colorado Respite Coalition (CRC) developed respite care provider core competency training recommendations for Colorado respite care providers and employers. The recommendations consist of a series of training skill statements grouped into six core competency areas. Further, the three training tiers demonstrate the differing levels of training skills required to provide companionship, personal, and medical-level respite care. These recommendations were incorporated into a [Training Toolkit](#) [20] for respite providers and employers. [Colorado Respite Coalition](#) [21] also developed a [video](#) [22] on what it means to be a respite provider.

### NEW YORK

**New York's** Lifespan Respite grant partners, the New York State Office for the Aging, New York State Caregiving and Respite Coalition, NY Connects No Wrong Door System (New York's ADRC/NWD), Monroe County Office for the Aging, and Lifespan of Greater Rochester Inc.—and more than 1,000 stakeholders throughout the state, and community groups affiliated with Lifespan Respite—came together to develop a Lifespan Respite workforce initiative. Bringing partners together was the foundational first step of planning for the purposes of engaging stakeholders; building infrastructure; and planning for financial sustainability. These plans enabled the partners to expand the volunteer care provider workforce: implementing [REST](#) [23] Train-the-Trainer Courses to increase respite provider competence; providing volunteer training to grow the workforce; and funding “mini-grants” to underserved communities to establish drop-in respite sites and improve access to services. These activities are evaluated through training surveys that assess trainee satisfaction, confidence, and competence; caregiver surveys to assess the benefits of having used respite services; and process measures to establish accountability at mini-grant sites.



## 5. GROW A STRONG PROVIDER WORKFORCE.

### NORTH DAKOTA

**North Dakota's** Lifespan Respite grantee partnered with North Dakota's Workforce Development Task Force to conduct eight regional forums across this rural state with a goal of increasing the number of in-home care providers in communities and regions. After conducting the forums and receiving strong local media coverage on television and radio, and in print, other communities requested forums to help them identify workforce issues specific to their region and strategize ways to address these. To address information outreach needs to families, professionals and employers in this winter weather-challenged state, the grantee developed a stellar informational [video](#) [24].

### RHODE ISLAND

**Rhode Island's** Lifespan Respite grantee launched a student respite initiative in 2014 to further knowledge about respite among health care professionals and to strengthen the future quality and availability of respite services in Rhode Island and beyond. Known to families as [CareBreaks Volunteer Students Respite Initiative](#) [25] (recognized by ARCH in 2020 as an Innovative and Exemplary Service), the initiative began with two nursing programs at Rhode Island College and University of Rhode Island, and expanded to include respite in all five Rhode Island college schools of nursing. The New England Institute of Technology offers respite in their nursing school curriculum (with volunteer respite services discontinued during the pandemic). And Salve Regina University and the Community College of Rhode Island offer clinical experience and course credit to student nurses for their work with family caregivers of low and moderate income without access to subsidized respite care. Student nurses carry powerful, direct experiences of providing respite forward as they enter the work force, enabling them to share their expertise in future settings and with future colleagues.



## 5. GROW A STRONG PROVIDER WORKFORCE.

### TENNESSEE

Tennessee's Lifespan Respite grantee is establishing a standard training curriculum for volunteer respite providers across the state and creating a seamless system for family caregivers to access trained volunteer providers. Working in partnership with Tennessee Technical University, the Lifespan Respite grantee will institute technology-supported training, including a respite training video, to reach respite care providers across a rural state and help to ensure that families receive quality respite care.

### WISCONSIN

Wisconsin's Lifespan Respite Care Program, administered by the [Respite Care Association of Wisconsin](#) [26] through the Wisconsin Department of Health Services, in 2019 surveyed more than 500 family caregivers statewide to learn more about the shortage of available respite workers in the state. Identifying a lack of trained and supported respite workers, the Wisconsin Department of Human Services, Respite Care Association of Wisconsin, and other agencies began a collaboration to improve training opportunities and overcome barriers to respite use. In 2020, they were awarded funding to support "[caring network](#)" training [27] that includes ten, online courses that comprise the Respite Care Certificate Program, and that meet rigorous state training requirements. Upon demonstrated successful completion of the Certificate Program, learners may be added to the [Wisconsin Respite Care Registry](#) [28] housed on the Respite Care Association of Wisconsin website. The Registry makes respite services available at no cost to primary caregivers searching for respite care providers in their community. "Caring Network" training also serves as a stepping-stone to more advanced training for nursing assistants, personal care workers, supportive home care workers, and others, with the goal of strengthening the respite workforce throughout the state. Respite Care Association of Wisconsin partners with University of Wisconsin-Oshkosh Center for Community for Development, Engagement and Training to allow those who successfully complete Respite Care Association of Wisconsin's Respite Care Certificate Program to access their specialized online dementia trainings at no charge.



## 6. INNOVATE PROGRAMS AND PRACTICES.

**STRENGTHENING STATEWIDE COORDINATED SYSTEMS** across agencies and through the lifespan is a purpose of the Lifespan Respite Program. The importance of large, strategic systems change efforts are evidenced by No Wrong Door systems that improve accessibility to services, and by workforce development and statewide training initiatives that strengthen programs and systems by increasing the competence of respite providers.

**RESPITE SYSTEMS ARE ALSO STRENGTHENED** by evidence-based and informed day-to-day practices, local public/private partnerships, such as those with employers, health care providers, and faith communities, and by the work of small and quietly influential model programs innovated to reflect the unique culture and needs of local communities. These local programs are of great worth to those using them, and also of great worth in informing all of us about how to “get it right” for caregivers as we endeavor to plan, create policies and make responsible decisions about funding. These two approaches to strengthening statewide coordinated Lifespan Respite systems are abundant among grantees collaboratively planning and coordinating at the state level, and strategically supporting local programs and initiatives at the street level.

### **COLORADO**

**Colorado** Lifespan Respite Coalition, in partnership with Easterseals Colorado, developed a [Caregiver Friendly Workplace Toolkit](#) [29] to help employers create sustainable efforts to support caregivers in their employ in ways that also fit the particular demands and work culture of their businesses. In addition to providing information about the impacts of caregiving on workers and companies (60 percent of caregivers are also employed outside their homes), the *Caregiver Friendly Workplace Toolkit* offers practical strategies employers can use in the workplace to support caregivers so that they can remain productive in their jobs, maintain employment, and continue sharing their talents with colleagues and community.



## 6. INNOVATE PROGRAMS AND PRACTICES.

### IDAHO

Idaho's Caregiver Alliance, formed from the state's first Lifespan Respite Care grant, works through their [Family Caregiver Navigator](#) [30] online program to help caregivers throughout this rural state connect with resources that improve their quality of life, promote wellness, and help sustain caregivers over their years of caregiving for loved ones. Funded from the state's Medicaid Money Follows the Person Program, the *Family Caregiver Navigator* allows caregivers to explore available resources, and connects them telephonically with a Navigator who uses a research-based assessment to identify stress factors, and who works with caregivers to develop a care plan based on assessment results, the caregiver and family's priorities, and available state and community resources.

### NEBRASKA

Nebraska's Department of Health and Human Services, wanting to address respite needs for working family caregivers, partnered with the Nebraska Lifespan Respite Network, the Nebraska Caregiver Coalition, and evaluation partners at the University of Nebraska Medical Center, Munroe-Meyer Institute and Nebraska Medicine to conduct a survey of employers at University of Nebraska (one of the state's largest employers) and determine awareness of and support for respite among employers of caregivers. Although 87 percent of employers surveyed had a general understanding of respite, half had no knowledge of employee assistance available for caregivers in their employ, and the employers surveyed did not document information about respite resources requested or used. Informing employers about the benefits of respite to caregiver health—including decreases in fatigue, headaches, chest pain, sleep problems, and anxiety, for example—and about the effects of caregiving on caregiver employees—including absenteeism, reduced job retention, and reduced ability to focus on work, for example—helped shape a statewide Employer Engagement Initiative. Based on the pilot project, new hire orientations became a venue to distribute information about respite; a respite resources website for UNMC employees with referrals to larger state respite system was created; and outreach to inform managers, department heads and supervisors was implemented. Coordinators in six respite regions throughout Nebraska worked closely with employers in their regions to inform and support family caregivers, and to ensure inclusion of employers on regional respite coalitions, helping to ensure that changes would be long lasting.



## 6. INNOVATE PROGRAMS AND PRACTICES.

### SOUTH CAROLINA

The **South Carolina** Respite Coalition partnered with a local university to develop informational referral cards and posters to educate the medical community about respite, to offer guidance in assessing the need for respite among their patients and families, and in directing family caregivers to respite resources. The Respite Coalition worked closely with First Choice, South Carolina's largest Medicaid managed care organization, with ADT residential and medical services, and with the South Carolina Faith Community Nurses Association to reach medical providers, and included representatives from these healthcare organizations on regional respite councils to align goals and activities across coalitions and health care settings.

The **South Carolina** Respite Coalition and South Carolina Department on Aging worked to create the [Breakroom Project](#) [31] in 2019, a respite model that enabled five churches (with more faith- and community-based programs to come) across the state to create respite spaces, and engage trained volunteers to provide care and supports for care recipients with special needs, allowing their caregivers to worship within their faith communities. In addition to providing respite for caregivers, this model engages the care recipients in church activities, helping them to become part of their faith communities as well. A How-To Guide was developed to help others replicate this model.

*I just had to express my deep appreciation for the respite you offer. I had never known or felt worthy of such a thing, and I always thought others needed it worse than I did. It surely came at a very good time as I was sick for two weeks and had a lot of my own medical things to attend to. It was such a help to have someone come in and work with my husband (who has suffered multiple strokes), and work she did! I am much better now and thankful for that. I am up and going strong now at 83. Thanks again, and may God bless each of you who work with such a wonderful program.*

— An 83 year-old caregiver of her 90-year-old husband



## 6. INNOVATE PROGRAMS AND PRACTICES.

### WASHINGTON

**Washington's** *Tribal Kinship Navigator Program* helps kinship families—those grandparents or other family members caring for a child—to establish or maintain in culturally acceptable ways the self-sufficiency and long-term stability needed to keep their children out of foster care. Seven tribes in Washington State have *Tribal Kinship Navigator* programs that connect grandparents and other relatives raising tribal children with community resources, providing critical support to extended family caregivers who may be financially stretched. To help tribal children maintain strong connections to tribal culture and traditions, *Tribal Kinship Navigators* actively reach out and locate kinship care families, identifying those who need services and ensuring they receive them. *Tribal Kinship Navigators* also educate the greater community about families' needs, and endeavor to develop strong, collaborative, working relationships with groups and agencies that can help address those needs.

**Washington's** Lifespan Respite grantee has also formed partnerships with two tribal communities, using direct contracting with tribes, in order to create subject matter experts in the area of respite care and to increase knowledge of statewide respite service options tailored to the needs of diverse populations across the lifespan, with a focus on American Indian/Alaska Natives. At the outset of the pandemic, tribal staff had begun educating the community about respite services based on families' needs, while they also worked to build strong collaborative working relationships with groups and agencies that could help address those needs. Because Washington law doesn't allow paid in-home respite service provision without specific care provider training, the tribes have been working with respite trainers to create hybrid training that addresses service needs and meets state requirements. In the interim, the tribes are filling service gaps and addressing the need for distant services during the pandemic with expanded Tele-services and support.



## 7. DIVERSIFY RESOURCES.

**DESPITE FINITE RESOURCES**, the federal Lifespan Respite Program is laudatory in its goals of supporting state's efforts to expand and enhance respite services; improve coordination and dissemination of respite services; streamline access to programs through efforts such as **No Wrong Door**; fill service gaps in service where necessary; and improve the overall quality of respite services currently available through outreach, training, and data collection that supports quality improvement. In reality, grant funds available to realize the goals of the Lifespan Respite Program are limited and of relatively brief duration given the size of the task of creating a state respite system, and the reality of shifting priorities and continuing changes in state leadership that may compromise any or all of what has gone before.

**TO ADDRESS THESE CHALLENGES** several states provide models and guidance for leveraging federal and state funds, diversifying resources, and making apparent to state legislators, policymakers, and private funders the importance of respite to their state's citizens. Some grantees and partners have successfully encouraged state leaders to establish durable policies and programs, and create dedicated funding streams that ensure caregivers and families receive local, high quality, and sustainable respite services. Some states embed Lifespan Respite activities into ongoing long-term services and supports efforts, reconcile eligibility requirements or rules across agencies and programs, or align categorical funding from multiple agencies or funding streams. And some receive support from private foundations, establish public-private partnerships, or engage in successful fundraising efforts.

### ALABAMA

**Alabama** Lifespan Respite uses diverse community partner stakeholders to identify gaps and barriers to respite, provide education and public awareness about the need for and benefits of respite, develop new, or expand existing resources, and advocate at the grassroots level to educate federal, state and local legislators. Alabama Respite has successfully received community foundation grants to sustain these and other Lifespan Respite activities including partnering with home health and hospice agencies across the state. Alabama uses diverse sources of funding to support older adult caregivers and families of children with disabilities, to increase emergency respite services access, and to support caregiver mental health.

Leveraging additional state and federal funds has been key in Alabama's successful sustainability efforts. United Cerebral Palsy of Huntsville & Tennessee Valley, Inc. (UCP Huntsville), parent organization of Alabama Lifespan Respite, is a grantee of the Alabama Department of Child Abuse & Neglect Prevention: Children's Trust Fund, which funds their *HEARTS* consumer-directed respite, and supports programs for families



## 7. DIVERSIFY RESOURCES.

### ALABAMA (CONTINUED)

of children with disabilities in the six-county region they serve. The *HEARTS* program has been duplicated throughout the state at each UCP of Alabama affiliate. UCP Huntsville receives state funding for Alabama Lifespan Respite operating expenses from the Alabama Department of Rehabilitation Services, which serves as a cash-match for federal Lifespan Respite funding.

The Alabama Department of Mental Health contracts with Alabama Lifespan Respite to manage consumer-directed respite for caregivers of adults and children with intellectual disabilities. And all 13 Alabama Cares/Area Agencies on Aging throughout the state contract with Alabama Lifespan Respite to manage consumer-directed respite for older adult caregivers. Notably, Alabama Lifespan Respite's *Caregiver Wellness Initiative* is funded by community grants to increase emergency respite funds and provide statewide mental health counseling at no cost to caregivers.

### COLORADO

**Colorado** Lifespan Respite Coalition, through a sustained effort with Easterseals, worked to educate legislators about the importance of respite in supporting long-term family caregivers. The Colorado legislature responded by supporting respite with three sources of income. First, court judges were empowered to assess a surcharge in cases of crimes against at-risk persons, with monies collected going to support respite for caregivers of at-risk adults or children. Second, Colorado's legislature allocated \$350,000 annually of state general funds to respite as part of a "long bill", increasing the likelihood of continued funding. Third, as respite became more important to Coloradans, the governor and general assembly created a respite task force, appointing members who generated seven recommendations. In 2016, the legislature approved an allocation of \$900,000 to implement five of the seven task force recommendations by June 2020 including: commissioning a study of outcomes and return on investment; creating a comprehensive statewide training system for respite providers; expanding the state's existing respite website; developing centralized community outreach and education programs; and reviewing policies and recommending ways to streamline regulations.



## 7. DIVERSIFY RESOURCES.

### RHODE ISLAND

**Rhode Island** leverages grant funds with the Older Americans Act Title III-E National Family Caregiver Support Program and Rhode Island state funds designated for respite services to increase participation in the *CareBreaks* program. The *CareBreaks* program helps pay part of the respite care costs for those families of low to moderate income without access to any other program for subsidized respite care. The Rhode Island Department of Human Services, Office of Healthy Aging (formerly the Division of Elderly Affairs) also works to enhance group respite activities as an approach to manage increased costs and a shortage of homecare workers in the state.

### SOUTH CAROLINA

**South Carolina's** Lifespan Respite grant, housed within the state's Unit on Aging, a state cabinet agency, provides an example of how readiness to respond to opportunity can bring positive change. South Carolina's former Lt. Governor and head of the Office on Aging, who with his wife had been caregivers for his mother, brought the wisdom of personal experience to his work. After conducting a "Tour on Aging" around the state and hearing the critical needs for respite directly from caregivers, he worked with the state legislature to allocate one-time funding of \$2,999,999 specifically for respite. Appropriated to South Carolina's Department on Aging, South Carolinians now have \$2.4 million in recurring funding solely designated to direct service respite. As part of the coordinated Lifespan Respite system, state respite vouchers are disseminated to caregivers throughout the state by the ten Area Agencies on Aging/Family Caregiver Support Programs and the South Carolina Respite Coalition. Because of South Carolina's Lifespan Respite Program and the strong working partnership between the state's Department on Aging and State Respite Coalition, stakeholders recognized the importance of expanding eligibility and of making respite available to caregivers across the lifespan. The coordination of the South Carolina Lifespan Respite Program, between the state Department on Aging, Family Caregiver Support Network and the South Carolina Respite Coalition assures that caregivers providing unpaid care for a loved one with a significant disability, special need or chronic illness requiring substantial care may receive a short and temporary, but essential, break from caregiving.



## 7. DIVERSIFY RESOURCES.

### TENNESSEE

The **Tennessee** Respite Coalition receives funding from Tennessee Department of Mental Health and Substance Abuse Services to provide respite vouchers for families with children with serious emotional disturbance or Autism. The Coalition also runs a federally funded Senior Companion Program that uses older adult volunteers to provide respite services for caregivers of older adults.

### WASHINGTON

Lifespan Respite **Washington** collaborated with the state Department of Health, Children and Youth with Special Health Care Needs program to conduct an outreach pilot program to help caregivers of children access respite voucher programs through local health departments using Maternal Child Health funds. This pilot served as a model to expand respite vouchers to other special populations, including a current partnership with the state's Traumatic Brain Injury program.

### WISCONSIN

**Wisconsin's** state legislature, beginning in 1999 with enactment of a State Lifespan Respite Program, appropriated \$225,000 in general revenue funds each year to support community-based respite providers. The Respite Care Association of Wisconsin, demonstrating compliance with the funding purpose outlined in the state statute, has created the infrastructure needed to expand capacity of existing programs, create needed programs, increase availability of providers, and improve accessibility to caregivers. The Respite Care Association of Wisconsin oversees program implementation, including identifying and monitoring outcomes. To ensure quality and uniformity of services, they created a statewide respite reimbursement program. In July 2019, the Wisconsin legislature passed, and the Governor signed, a state budget including a critical funding increase. Combined with private foundation funding, and a new federal Lifespan Respite Care grant, Lifespan Respite in Wisconsin is in a strong position to meet their mission to *promote, support, and expand quality statewide respite care across the lifespan.*



## 8. EDUCATE AND ADVOCATE.

**ALTHOUGH RESPITE IS NOT A HOUSEHOLD WORD**, it is a household need. But even when the need for a break from caregiving is great, caregivers too often wait until a crisis occurs before seeking respite. Caregivers need information, time and support to understand, locate and navigate respite—especially when they first take on a caregiving role. With preventive respite, the risk of physical or emotional burnout among caregivers decreases, along with the risk of hospitalizations and institutionalizations among care recipients. Without preventive respite, families alone shoulder the economic, physical, and mental health burdens of uninterrupted and unsupported caregiving.

**REACHING CAREGIVERS EARLY AND EFFECTIVELY** is highly dependent upon public policies and practices. Lifespan Respite initiatives across the nation demonstrate how public policy and practice can effectively support caregivers. Public outreach, awareness campaigns and designated state legislative days are also effective approaches. All of these approaches—when supported by informed champions of respite who possess the power and insight to influence positive change—create statewide Lifespan Respite systems that are strong and durable in supporting our nation’s caregivers.

### ALABAMA

Alabama’s Department of Senior Services, and the Alabama Lifespan Respite Coalition, in partnership with Alabama Lifespan Respite, assessed caregivers’ needs, made recommendations for policy solutions, and incorporated these in a recently updated [White Paper](#) [32 ] designed to guide sound decision making on behalf of family caregivers. These partners keep Alabama’s Governor and Legislature informed and edified on key topics and issues—respite eligibility requirements, streamlining enrollment for multiple programs, improving respite accessibility, and diversifying funding to support the long-term success and stability of Alabama respite services.

### MONTANA

Montana’s Lifespan Respite Coalition, almost 100 members strong in a rural state, has worked strategically over the past decade to make sure policy and funding decisions are based on solid data conveying the actual status of respite services and needs. Beginning with an environmental scan of available respite funding and services, and identifying unmet needs, the Lifespan Respite Coalition continued their work by collaborating with AARP, the Alzheimer’s Disease and Related Dementia State Planning Workgroup, and the Money Follows the Person Program to add caregiver related questions to the Behavioral Risk Factor Surveillance System. Data from the system are shared with government administrators, policy makers and other stakeholders, ensuring that future funding requests are sound and supportable, and helping to assure that those most in need of respite services in Montana receive them.



## 8. EDUCATE AND ADVOCATE.

### OKLAHOMA

Oklahoma's Lifespan Respite grantee and OKCares, the Oklahoma Caregiver Coalition, offer brief informational and educational opportunities to employers and the business community throughout the state, and to anyone wishing to learn more about the meaning and benefits of respite, through Lunch and Learns. Upon request—and the Oklahoma Caregiving Coalition receives several requests every month—a team of three or four persons with expertise in a given area are matched with a group according to the topic they have requested—ranging from the meaning of respite and available respite options, to ways employers can support employees who are caregivers, to legal options associated for long term care, and more. More than 30 of the 130+ Oklahoma Caregiver Coalition partners generously share their expertise at no cost, helping to assure that OKCares fulfills the promise of the Lifespan Respite Care Program.

### STATE GRANT MESSAGING

State Lifespan Respite Program grantees across the nation use messaging to inform various audiences—caregivers, employers, the public, policy makers and legislators—about the importance and benefits of respite. Bureaucratic complexity, family vulnerability and hesitancy, geographic distance, and cultural differences all create barriers to understanding and using respite. To counter these, state grantees have created clear and simple messages to reach caregivers. State Respite Coalitions, such as the [Nevada Lifespan Respite Care Coalition](#) [33], play a key role in message dissemination. For example, Colorado's [Your care may be super, but you're only human](#) [34]; Montana's [It's OK to need it, it's OK to want it, and it's OK to get it](#) [35]; Nevada's [Respite Refuels Caregivers](#) [36]; and North Dakota's [Taking Care of You](#) [37] all support information about and access to life changing support through respite.

*As the caregiver for my daughter who is 54 and has special needs, and my husband who suffered a traumatic brain injury in a workplace accident, thank you for the respite you offer me. It is emotionally helpful to know someone cares and is trying to help me. I feel so alone in this journey at times, but you care and do what you can. Thank you!*

— A 76 year-old caregiver

## AFTERWORD: RESPITE'S RESPONSE TO COVID

**RESPITE SERVICES ARE RELIANT UPON ONE-TO-ONE RELATIONSHIPS** among care providers, care receivers, and families, occurring in-person, and in real time in order to give caregivers temporary relief from 24/7 caregiving. One might assume that when “stay-at-home” measures were prescribed at the beginning of the COVID-19 pandemic, respite services would cease—at a time when caregivers needed them more than ever. But based on qualitative data collected by [ARCH](#) [38] throughout the pandemic, and by a national survey conducted by [The BREAK Exchange](#) [39] at the University of Wisconsin School of Nursing, in partnership with ARCH, we know that many respite providers in the Lifespan Respite network rallied, carefully planned, and retooled to reopen or stay open safely. For many family caregivers, respite was the only service they received during the ongoing pandemic.

**IMMEDIATELY RECOGNIZING THE NEED** for services and supports during a time of increased caregiver stress and social isolation, respite grantees, partners and affiliated respite programs and services responded rapidly, creatively, flexibly and holistically according to caregivers’ and families’ needs. The BREAK Exchange study showed that as of April, 2020, 75 percent of respite programs surveyed had created new or alternative services, or had adapted existing services including: *regular check-ins* with formal and informal assessments to determine caregiver and family needs in a timely way; *resource referrals* to help caregivers and their families connect with a variety of community resources; *self-care guidance and support* to strengthen person-centered and personal-choice activities; *social emotional support* to support healthy coping and bolster social connections; and *practical support* to meet families’ basic needs for PPE, and food, pharmacy, and supplies deliveries. Some programs also helped families with needed technology—the primary lifeline between caregivers and others during the pandemic—by distributing tablets to caregivers and providing support in technology use.

## AFTERWORD: RESPITE'S RESPONSE TO COVID

Lifespan Respite grantees engaged in all of these activities and more. Because many state respite voucher programs are consumer-driven, most have continued to serve caregivers—through increased program flexibility to meet caregiver needs and with guidance to providers and families on how to do so safely. To support their efforts, early on in the pandemic, ARCH issued [National Voluntary Guidelines for Providing and Using Respite during the Pandemic](#) [40], including Decision Guides to inform respite program administrators' and families' decision-making about when and how to resume regular respite services. ARCH also published [case studies](#) [41] to help programs understand the practicalities of offering respite safely during the pandemic. Early on and throughout the pandemic ARCH scheduled regular Lifespan Respite network calls to encourage state-to-state, program-to-program, and peer-to-peer learning and support, and to support those caring for caregivers in Lifespan Respite programs across the country. Highlights of innovative activities undertaken by Lifespan Respite grantees to continue to support family caregivers during the pandemic follow.



## AFTERWORD: RESPITE'S RESPONSE TO COVID

### ALABAMA

**Alabama** Lifespan Respite, in order to increase targeted support to caregivers during the pandemic, offered Care Chats (one-on-one support hours available by phone or video conferencing) with their social worker staff, monthly support groups, and caregiver mental health education opportunities to help increase overall caregiver wellness. Alabama Lifespan Respite also introduced a [Caregiver Wellness Initiative](#) [42] that increases Emergency Respite reimbursement funds and designates funds specifically for mental health counseling to caregivers currently enrolled with any Alabama Lifespan Respite reimbursement (voucher) program. Because mental health services availability is challenging during the best of times, Alabama Lifespan Respite is also building a statewide list of licensed mental health providers who are familiar with caregiver and disability-related mental health issues. The intended impacts of the Caregiver Wellness Initiative include decreases in caregiver stress, anxiety, fatigue, and burnout after receiving Emergency Respite and/or mental health counseling, resulting in increases of overall caregiver wellness—physical, mental, and emotional—that can help reduce the possibility of abuse and neglect as the result of caregiver burnout, and help prevent premature out-of-home placement of care recipients.

### OKLAHOMA

**Oklahoma's** Lifespan Respite voucher program made practical changes to improve access to respite and support, and reduce health risks during the pandemic for caregivers, care recipients and families by increasing the dollar amount available for vouchers from \$300 to \$400; by allowing family members, 18 years and older who live in the home with the caregiver and care receiver, to be providers; and by lifting household income restrictions. Oklahoma's highly popular "On the Road Family Perspective Conference" was held virtually during the pandemic so that families could share, and providers could hear and understand, family experiences during these challenging days.

## AFTERWORD: RESPITE'S RESPONSE TO COVID

### TENNESSEE

Tennessee's Respite Coalition, in response to limitations in respite services imposed by COVID-19, created mini-grants to provide eligible caregivers unable to access traditional respite funding to purchase health and wellness "breaks" of their choosing—meal kits, magazine, movie channel or on-line class subscriptions, experiences, board games, tablets for accessing online support, home exercise equipment, and items for crafts and hobbies, among many examples. This person-centered, in-demand initiative encourages caregiver applicants to be creative with what would give them the most effective break and to tailor their requests accordingly. Those caregivers receiving mini-grants remained eligible to receive traditional respite vouchers from the coalition to secure in-home respite services from a provider in their trusted networks. The Tennessee Respite Coalition provided caregivers with self-care packages including adult coloring books, bubble bath, books, journals, and other wellness-related items. The Tennessee Respite Coalition also provided computer tablets when needed so caregivers could access online support groups and other respite support services.

### WASHINGTON

Washington's key respite partners, PAVE (Partnerships for Action, Voices for Empowerment) and the state's Aging and Long Term Support Administration offer support to caregivers through vouchers and mini-grants. The pandemic—and "stay at home" orders—came to Washington State early in 2020. The respite voucher program continued services throughout the pandemic by creating flexible options for families using vouchers, and by securing ongoing and future respite funding, including funding for technology from ACL, and from the Christopher and Dana Reeve Foundation. Washington's respite voucher program proactively contacted families and focused on what individual families were encountering in order to provide person- and situation-centered services—made possible through coordinated and shared resources with partners such as the Family to Family Health Information Center; Parent Training and Information/PTI Center; and Parent to Parent. Families were given extended time to use their respite funds, and they received sustained personal support in determining when and how to find and use respite services safely.

### WISCONSIN

Wisconsin's Respite Care Association worked from the start of the pandemic to assess caregiver and provider comfort levels for providing in-home services through its Caregiver Respite Grant and Respite Care Registry. The Respite Care Registry—which connects care providers with primary caregivers — stayed open during the pandemic and focused on finding reliable and credible resources, answering questions from families and providers during uncertain times, providing guidance in selecting and using respite services, and allaying caregiver concerns about receiving respite services through the registry. The Respite Care Association of Wisconsin continued to offer self-directed caregiver respite grants to help pay for respite provided by someone the caregiver deemed safe to include in their home. And as a tangible demonstration of care, and one that received an overwhelming positive response from caregivers, the Respite Care Association of Wisconsin distributed Care for the Caregiver kits that included stress balls, playing cards, tea, chocolate, cozy socks, hand lotion and Respite Care Association of Wisconsin water bottles. Respite Care Association of Wisconsin was among the first to offer resources and support to providers, family caregivers and those who support them through online training, [Finding Your New Normal during COVID-19, Resources, Tips and Tricks](#). [43]

## THE PATH FORWARD FOR OUR NATION'S CAREGIVERS

**MENTAL HEALTH CHALLENGES AMONG CAREGIVERS ARE NOT NEW.** But the burden the COVID-19 pandemic has placed upon caregivers makes us, collectively, more aware of what protracted, unsupported caregiving means. Daily accounts in print, and on radio and television, make visible the experiences of everyday Americans trying to balance work, childcare and care for adult family members—while many also struggle with economic impacts from the pandemic, and social isolation resulting from public policy recommendations to shelter in place in order to reduce the spread of a deadly virus. According to a study by the Centers for Disease Control and Prevention, mid-way through 2020:

U.S. adults reported considerably elevated adverse mental health conditions associated with COVID-19. Younger adults, racial/ethnic minorities, essential workers, and *unpaid adult caregivers* reported having experienced disproportionately worse mental health outcomes, increased substance use, and elevated suicidal ideation.<sup>9</sup>

**THE CHALLENGES OF THESE TIMES ARE REAL TO ALL OF US.** But these are times of learning as well as times of challenge. Perhaps our society will carry forward the insights that have come from experiencing our own individual personal hardships. Enduring protracted social isolation is unhealthy physically and mentally. It is difficult to take care of one's own health and well-being when one is solely responsible for the care of others. Taking care of others *and* meeting the demands of work is impossible on some days. Caregiving without practical and social supports can break a person.

**LET US REMEMBER OUR HARD-EARNED LESSONS AND APPLY THEM IN WAYS THAT HELP GOING FORWARD.** Providing respite is a straightforward way to support caregivers who will continue caring for loved ones long after the pandemic has receded. Respite is a service highly valued and frequently requested by caregivers. The work of the state Lifespan Respite grantees and their partners described in this report shows us how respite can be provided effectively and efficiently, in ways that are culturally relevant and that can reach underserved populations, and with attention to quality assurance and improvement so that we are certain that we are “getting it right” for caregivers and families. Knowing what we can do to support caregivers, and knowing how much caregivers need that support, will we as a society do what needs to be done to support all caregivers going forward? As we begin to return to lives of relative ease and freedom, will we remember those who cannot?

## RESOURCE LINKS

- [1] Compendium of State Lifespan Respite Grant Activities  
[https://archrespite.org/images/Lifespan\\_Grant\\_State\\_Summaries/State\\_Matrices\\_Compendium.pdf](https://archrespite.org/images/Lifespan_Grant_State_Summaries/State_Matrices_Compendium.pdf)
- [2] Idaho Caregiver Alliance  
<https://idahocaregiveralliance.com/>
- [3] New York State Caregiving and Respite Coalition  
<http://www.nyscr.org/>
- [4] South Carolina Respite Coalition  
<https://www.screstitecoalition.org/>
- [5] Alabama Lifespan Respite  
<https://alabamarespite.org/>
- [6] New York - NY Connects  
<https://www.nyconnects.ny.gov/>
- [7] Family-to-Family Health Information Center  
<https://familyvoices.org/lfpp/f2fs/>
- [8] Virginia Navigator  
<https://virginiannavigator.org/>
- [9] Arizona Caregiver Coalition  
<https://azcaregiver.org>
- [10] Colorado *Coming Up for Air*  
<https://www.coloradorespitecoalition.org/our-programs/coming-up-for-air.php>
- [11] Montana Lifespan Respite Coalition  
<https://dphhs.mt.gov/respite>
- [12] North Carolina Lifespan Respite Voucher Project  
<https://www.highcountryaging.org/services/lifespan-respite-project>
- [13] Oklahoma *OKCares Oklahoma Caregiver Coalition*  
<https://okcares.org/>
- [14] Tennessee Respite Coalition  
<https://tnrespite.org/>
- [15] Alabama White Paper  
<https://alabamarespite.org/whitepaper/>
- [16] Nebraska Lifespan Respite Network  
<https://respite.ne.gov/>
- [17] Nebraska Data Dashboard  
[https://nrns.ne.gov/respite/data/dashboard\\_index.php](https://nrns.ne.gov/respite/data/dashboard_index.php)
- [18] Lifespan Respite Washington  
<https://www.lifespanrespitewa.org/>
- [19] Colorado Respite Care Task Force  
<https://coloradorespitecoalition.org/our-programs/respite-care-task-force.php>
- [20] Colorado Training Toolkit  
[https://issuu.com/eastersealscolorado/docs/respite\\_toolkit\\_final](https://issuu.com/eastersealscolorado/docs/respite_toolkit_final)
- [21] Colorado Respite Coalition  
<https://coloradorespitecoalition.org/>
- [22] Colorado respite provider video  
[https://www.youtube.com/watch?v=a63\\_ULZbWFk](https://www.youtube.com/watch?v=a63_ULZbWFk)

## RESOURCE LINKS (CONTINUED)

- [23] New York's *Train-the-Trainer* Courses  
<https://aging.ny.gov/news/new-york-state-recognized-nationally-caregiving-training>
- [24] North Dakota Video: *Taking Care of You*  
<https://carechoice.nd.assistguide.net/home>
- [25] Rhode Island *CareBreaks* Volunteer Students Respite Initiative  
<https://www.youtube.com/watch?v=cJfC1laKMxU>
- [26] Respite Care Association of Wisconsin  
<https://respitecarewi.org/>
- [27] Wisconsin Caring Network Training  
<https://respitecarewi.org/training-courses/respice-care-certificate-program/>
- [28] Wisconsin Respite Care Registry  
<https://respitecarewi.org/registry/>
- [29] Colorado *Caregiver Friendly Workplace Toolkit*  
<https://www.coloradospitecoalition.org/resource-finder/education/view.php?Caregiving-Friendly-Workplace-Toolkit-103>
- [30] Idaho Family Caregiver Navigator  
<https://caregivernavigator.org/>
- [31] South Carolina Breakroom Project  
<https://www.scspspicecoalition.org/programs-services/breakrooms/>
- [32] Alabama White Paper  
<https://alabamaspice.org/whitepaper/>
- [33] Nevada Lifespan Respite Coalition  
<https://nvcaregivingrelief.org>
- [34] Colorado video: *Your care may be super, but you're only human*  
<https://www.youtube.com/watch?v=fpUKVdV0w2w>
- [35] Montana video: *It's OK to need it, it's OK to want it, and it's OK to get it*  
<https://www.youtube.com/watch?v=w3pSnsJONA0>
- [36] Nevada video: *Respite Refuels Caregivers*  
<https://youtu.be/UDTylUqIU>
- [37] North Dakota video: *Taking Care of You*  
<https://carechoice.nd.assistguide.net/home>
- [38] ARCH National Respite Network and Resource Center  
<https://archrespice.org/covid-19-respice-resources>
- [39] National Survey (University of Wisconsin Madison): The BREAK Exchange  
<https://breakexchange.wisc.edu>
- [40] ARCH Voluntary Guidelines for Respite Care Agencies, Providers, Family Caregivers, and Respite Care Recipients: Providing and Receiving Respite Safely during the COVID-19 Pandemic  
<https://archrespice.org/national-respice-guidelines-for-covid-19#Guidelines>
- [41] ARCH Case Studies: Providing and Restarting Respite Safely during the Pandemic  
<https://archrespice.org/national-respice-guidelines-for-covid-19#Cases>
- [42] Alabama Caregiver Wellness Initiative  
<https://alabamaspice.org/caregiver-wellness-initiative/>
- [43] Wisconsin - *Finding Your New Normal during COVID-19, Resources, Tips and Tricks*  
<https://wisconsin-respicecarewi.talentlms.com/catalog/info/id:143>

## ENDNOTES

- <sup>1</sup> National Alliance for Caregiving and AARP Public Policy Institute (2020). *Caregiving in the U.S. 2020*. Washington, DC: Authors.  
<https://www.caregiving.org/caregiving-in-the-us-2020/>
- <sup>2</sup> U.S. Department of Health and Human Services. Administration for Community Living. *Lifespan Respite Care Program*.  
<https://acl.gov/programs/support-caregivers/lifespan-respite-care-program>
- <sup>3</sup> U.S. Department of Health and Human Services. Administration for Community Living. *Aging and Disability Resource Centers Program/No Wrong Door System*.  
<https://acl.gov/programs/connecting-people-services/aging-and-disability-resource-centers-programno-wrong-door>
- <sup>4</sup> National Alliance for Caregiving and AARP Public Policy Institute (2020). *Caregiving in the U.S. 2020*. Washington, DC: Authors.  
<https://www.caregiving.org/caregiving-in-the-us-2020/>
- <sup>5</sup> Livingston, G (2018). *More than one-in-ten U.S. parents are also caring for an adult*. Washington, DC: Pew Research Center.  
<https://www.pewresearch.org/fact-tank/2018/11/29/more-than-one-in-ten-u-s-parents-are-also-caring-for-an-adult/#:~:text=About%20three%2Din%2Dten%20U.S.,for%20an%20adult%20as%20well.&text=The%20amount%20of%20time%20parents,decades%20in%20the%20United%20States.>
- <sup>6</sup> Romley, J.A., Shah, A.K., Chung, P.J., Elliott, M.N., Vestal, K.D., & Schuster, M.A. (2017). Family-Provided Health Care for Children with Special Health Care Needs. *Pediatrics*, 139(1).  
<https://pediatrics.aappublications.org/content/pediatrics/139/1/e20161287.full.pdf>
- <sup>7</sup> Feinberg, L.F. & Skufca, L. (December 2020). *Managing a Paid Job and Family Caregiving is a Growing Reality*. AARP Public Policy Institute.  
<https://www.aarp.org/ppi/info-2020/managing-a-paid-job-and-family-caregiving.html>
- <sup>8</sup> Avison, C., Brock, D., Campione, J., Hasell, S., Rabinovich, B., Ritter, R., Severynse, J., & Yang, D.-H. (2018). *Final Report prepared for the U.S. Administration for Community Living: Outcome Evaluation of the National Family Caregiver Support Program*. Washington, D.C.: Westat.  
[https://acl.gov/sites/default/files/programs/2018-12/Caregiver\\_Outcome\\_Evaluation\\_Final\\_Report.pdf](https://acl.gov/sites/default/files/programs/2018-12/Caregiver_Outcome_Evaluation_Final_Report.pdf)
- <sup>9</sup> Czeisler, M.E., Lane, R.I., Petrosky, E., et al. (2020). Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic—United States, June 24–30, 2020. *Morbidity and Mortality Weekly Report*, 69: 1049–1057.  
<https://www.cdc.gov/mmwr/volumes/69/wr/mm6932a1.htm>



**IN HONOR OF  
OUR NATION'S  
CAREGIVERS**

